

The CAREGIVER

*A Bridge to Understanding
Your Options*

Newsletter of the Duke Family Support Program

Volume 32, Issue 1

Spring 2013

WHAT IS THE DUKE FAMILY SUPPORT PROGRAM?

And What Happened to the Bryan Alzheimer's Conference?

The Duke Family Support Program (DFSP) is a first responder service, funded by the NC Division of Aging, for NC families and professionals caring for someone with a memory disorder. The DFSP publishes this *Caregiver* newsletter, dedicated to family caregiver support. The Program offers free for all North Carolina residents:

- Help with care decisions, evaluating home and day services, residential care and family coping strategies.
- Personalized tips on caring for people with memory disorders.
- Research updates and options for participation in Alzheimer's studies.
- Help selecting support groups, education programs, online help or books.
- An info packet on Alzheimer's and *The Caregiver* newsletter twice a year.
- Additional resources on the DFSP website www.dukefamilysupport.org

It's simple and convenient. No red tape forms or eligibility information required.

The Program established the first support group in NC for families of adults with memory disorders in 1979. That original group led to the formation of support groups of the Alzheimer's Association or Alzheimer's NC, now in almost all 100 counties. The DFSP currently facilitates four support groups for individuals with a diagnosis and their families.

Lisa Gwyther, Program Director, directs education for the Bryan Alzheimer's Disease Research Center (ADRC) at Duke. For twenty five years, Lisa led the Bryan ADRC Conference at Duke. The last annual conference was in 2011. Cheryl Copeland, ADRC conference coordinator and DFSP coordinator left Duke last month with our gratitude for her five years of service.

We remain committed to helping you find education options, whether you seek continuing education credits or answers to your questions about family care. Heads up: Upcoming education events of interest:

- Dementia Care @ AAIC July 17, 2013 Boston, MA. The first care-focused event at the Alzheimer's Association International Conference. www.alz.org/aaic/care/overview.asp
- Triangle Caregivers Conference, June 18, 2013 Raleigh, NC and June 25, 2013 Durham, NC www.trianglegiverconference.com
- "Depression in the Senior Adult" August 15, 2013, Durham, NC Senior Health Support of the Triangle www.shstriangle.com Free two-hour programs open to older adults in the Triangle.

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Duke Family Support Program

Lisa Gwyther, MSW, LCSW
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Joseph and Kathleen
Bryan Alzheimer's Disease
Research Center (ADRC)

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and Human Development

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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

Duke Family Support Program

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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
 Email: info@alz.org

Blondes vs. Brunettes Raleigh Game Day: June 1, 2013

Walk to End Alzheimer's Eastern, NC

- Fayetteville: September 7, 2013
- Durham: September 21, 2013
- Johnston County: September 28, 2013
- Wilmington: November 16, 2013

See their website for a list of Alzheimer's Association support groups in Eastern NC.

**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
 Email: infonc@alz.org

Miles for Memories 5k - Greensboro, NC: May 11, 2013

Walk to End Alzheimer's Western NC

- Lake Junaluska, Gastonia and High Point: September 14, 2013
- Winston-Salem, Pinehurst, Kannapolis and Asheville: September 21, 2013
- Charlotte and Burlington: September 28, 2013
- Hickory, Mooresville and Mt. Airy: October 5, 2013
- Greensboro: October 12, 2013
- Asheboro: October 19, 2013

Caregiver Education Conference

- Hickory: June 20, 2013

See their website for a list of Alzheimer's Association support groups in Western NC.

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
 Email: info@alznc.org

25th Annual Stand By Me Golf Tournament:
 June 24, 2013

Alzheimer's NC Walks

- Craven County: May 18, 2013
- Fayetteville: May 19, 2013
- Mount Airy/Surry County: May 19, 2013
- Martin County: June 8, 2013
- Chatham County: September 14, 2013
- Triangle Walk: October 5, 2013
- Washington: October 12, 2013
- Greenville: November 2, 2013
- Wilmington: November 9, 2013

Alzheimer's NC Caregiver Conferences

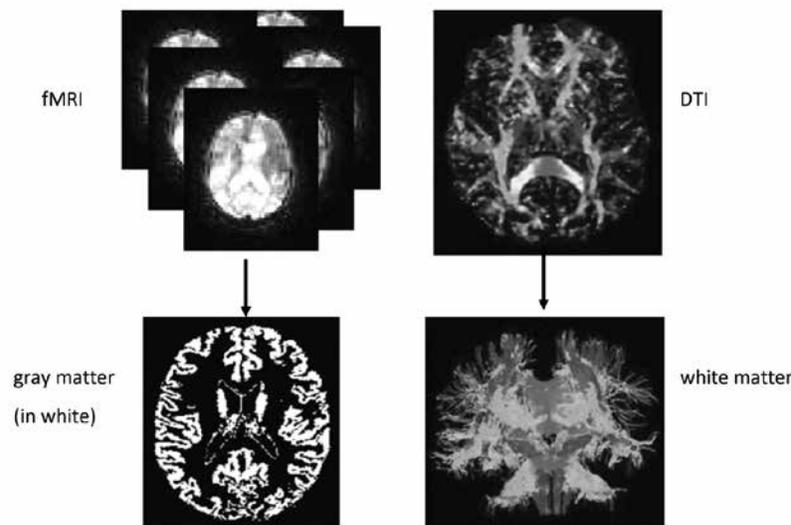
- Sanford: May 21, 2013
- Raleigh: June 18, 2013
- Durham: June 25, 2013
- Goldsboro: August 2, 2013
- Henderson: September 19, 2013
- Lumberton: November 21, 2013

See their website for support groups in North Carolina.

The multi-disciplinary training DVD, ***Accepting the Challenge***, is available for sale. The DVD is sold through Health Professions Press www.healthpropress.com; and family caregivers can purchase it at a reduced rate or borrow the DVD from the Alzheimer's NC lending library.

USING BRAIN IMAGING TO DETECT EARLY ALZHEIMER'S DISEASE

By Guy G. Potter, PhD and Kathleen A. Welsh-Bohmer, PhD
The Bryan Alzheimer's Disease Research Center at Duke



“The challenge of diagnosing AD early is that the behavioral symptoms are similar to benign changes in memory that occur with aging”

We may be on the verge of exciting advances in the treatment of AD. There are currently a number of promising AD treatments under study that focus on disease modification by altering A β deposition, tau aggregation, and other key targets in disease development. Yet, previously promising approaches tested in patients with mild to moderate AD dementia have been disappointing. For instance, recent immunotherapy trials directed toward A β have failed to demonstrate any effect on the primary clinical endpoints, despite evidence of action on the actual disease targets. In addition, studies with γ -secretase inhibitors, intended to reduce A β production, were halted for lack of clinical improvement at safe doses, and for evidence of clinical worsening in treated subjects compared to controls. Although work continues on these strategies, there is recognition of a need to shift toward developing treatments that impact multiple disease pathways affected in AD. In order to treat multiple pathways of disease, it is important to study these pathways with complementary approaches, and to identify individuals as early in the disease course as possible, so that disease effects can be stopped before irreversible damage can

occur. These possibilities may be realized with the help of brain magnetic resonance imaging (MRI), which has the capability to visualize the health of multiple types of brain tissue, and in many cases detect changes well before any clinical signs are present. This article will summarize some of the work we have been doing with MRI to realize the goal of identifying individuals with early AD-related brain changes.

Detection of Early Symptoms of Alzheimer's Disease with Brain Imaging

The challenge of diagnosing AD early is that the behavioral symptoms are similar to benign changes in memory that occur with aging. We look to biomarkers to provide some objective evidence of early disease. However, these approaches are not clean-cut either. Brain imaging can show atrophy in AD, but early in the disease when only memory weaknesses are emerging (the so-called Mild Cognitive Impairment stage, MCI), the brain changes can be quite subtle and difficult to detect. Previous attempts to identify differences in brain structure or function in MCI have not demonstrated high enough reliability to effectively discriminate MCI

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BRAIN IMAGING *(continued from page 3)*

cases that go on to progress to dementia from those cases that are due to other disorders. A challenge is to find patterns in the brain that are more telling of early AD than of other disorders such as stroke or depression.

One important tool for seeing patterns in the brain is MRI. MRI uses a magnetic field and radio waves to make pictures of structures inside the body, including the brain. MRI can be used to take pictures of different types of brain tissue, but can also be used to measure changes in brain activity over time, which is referred to as functional MRI (fMRI). fMRI can provide information about how activity is coordinated across different regions the brain. A special MRI technique called diffusion-tensor imaging (DTI) is used to visualize the connections between brain areas by mapping the health of the nerve pathways. Many previous studies have used either fMRI or DTI in attempts to classify MCI and early AD, often without finding sufficiently high sensitivity and specificity; however, few studies have combined these approaches to find a distinctive brain pattern for MCI or early AD. In the current study, our collaboration combined functional (fMRI) and structural (DTI) information about the brain to try to improve the ability to identify individuals with MCI separate from those with normal cognitive function. Our rationale was that fMRI and DTI provide essential complementary information about the brain that can enhance our ability to see unique patterns of early AD, and with high reliability in detecting true cases and differentiating these from normal aging and other medical conditions.

Individuals in this study were normal controls and patients with MCI recruited through the Memory Disorders Clinic, which is part of the Joseph and Kathleen Bryan Alzheimer's Disease Research Center (ADRC) at Duke University. Each individual had a brain MRI scan at the Duke-UNC Brain Imaging and Analysis Center (BIAC). Our colleagues at the UNC Image Display, Enhancement, and Analysis (IDEA) Laboratory analyzed the brain imaging data using Support Vector Machines, which are special and advanced models for recognizing patterns in large amounts of data, such as the combination of DTI and fMRI brain imaging.

Using this multimodality approach, we achieved 96.3% accuracy in classifying MCI and normal cognition. This compared to 88.89% accuracy with DTI alone, and only 70.37% accuracy with fMRI alone. Importantly, the combined approach had high sensitivity

(100%) as well as high specificity (94.12%), meaning the approach classified all individuals with MCI correctly, with very few instances of falsely classifying an individual with normal cognition as having MCI. The brain regions with the highest ability to discriminate MCI from normal cognition were regions in the frontal and temporal lobes that have previously been shown to play a potential role in early AD

Implications for Diagnosis and Treatment

This study demonstrates quite convincingly that a combination of structural and functional brain imaging approaches yields a very high ability to classify individuals with clinically diagnosed MCI. This is an important first step to building classification approaches that detect AD at an even earlier stage. The results also allow a more reliable method for identifying specific individuals who would benefit from early therapeutic interventions, while avoiding misdiagnosis or over-treatment of individuals who are less likely to develop AD. The results also highlighted that different types of brain structures are sensitive to early AD, which supports current opinion that AD emerges from the progression of subtle changes throughout the brain, rather than from a single area or a single type of brain tissue.

The research is a very positive advance toward earlier detection of AD and a good example of scientists from two universities in our area working together toward a common goal of preventing AD. Working together we can advance discovery, prevention, and treatment of Alzheimer's disease.

This article was based on a research publication titled, "Identification of MCI individuals using structural and functional connectivity networks (2012). *Neuroimage* 59(3):2045-2056. The participating authors were: Chong-Yaw Wee a, Pew-Thian Yap a, Daoqiang Zhang a, Kevin Denny b, Jeffrey N. Browndyke c,d,e Guy G. Potter d, Kathleen A. Welsh-Bohmer c,d,f, Lihong Wang b, Dinggang Shen a. The images in the current article are adapted from images appearing in the source article.

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TRAVELERS

By Margaret Toman

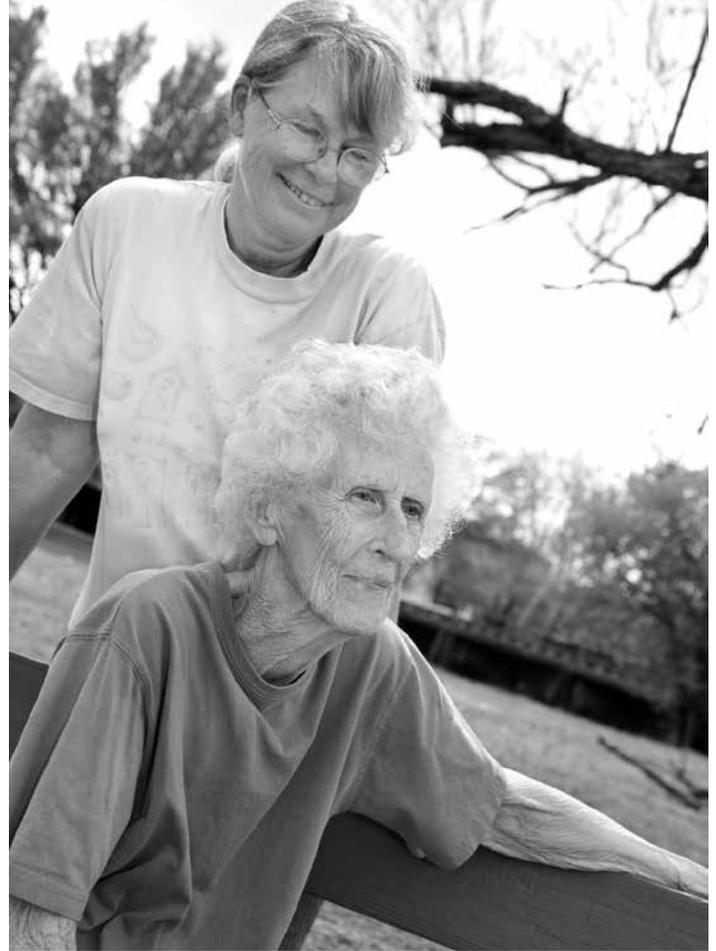
The gaping hole in my mother's right hip is florid and swollen around the rim, black on the inside – a caldera on her pale skin that erupted suddenly in a stream of pus and blood at adult daycare late on a Thursday afternoon, horrifying the staff. When I learn this upon picking her up at the end of the day, I am as shaken as they. There were no signs or symptoms. “We are not licensed to handle this,” the Director tells me. “She can not come back to this center with this wound.” I drive my mother to the hospital in panic barely held at bay.

At the hospital there is no accommodation for her nearly 99 years of age. We sit in the waiting room for hours with other ill supplicants, all of us beneficiaries and victims of modern healthcare, until we are taken to a curtained emergency room where my mother receives medical tests, I answer questions and sign papers, and hours creep by when nothing happens.

While she sleeps on a stretcher, I anguish. For 12 years I have provided my mother the most attentive, proactive, knowledgeable, loving care that I possibly can. That this enemy has been stalking her invisibly from within is an injustice I can hardly bear.

A physician steps into the room around midnight. He is direct and kind. “You have been taking very good care of your mother. This is not your fault. This is an E-Coli infection that originated in the prosthesis in her hip, has been festering in there for some time and has grown outward. Bugs tend to cluster around prostheses,” he explains. “This is not systemic and it is not contagious but it is serious. She will need to be admitted for a few days and you may have some difficult choices to make but this infection will not be the cause of her demise.” I breathe again for the first time in hours -- but briefly. I am keenly aware that the combination of Alzheimer's disease and hospitalization can produce swift downward spirals.

For the next six days I plant myself at my mother's bedside. She is receiving high doses of intravenous medications and is barely responsive. I try anyway. I talk and sing softly to her, brush her hair, wash her



face, put on her lipstick and earrings, dust her with fragrant bath powder, sit quietly and hold her hand. When she sleeps, I bury myself in challenging crossword puzzles. One day I bring in a CD player and fill her room with the smooth crooning of Frank Sinatra. “Who's that singing?” a young nurse asks me. “He's really good! Wasn't he on American Idol?” Another day I vigorously protest the scrubbing of hard nubby washcloths on my mother's fragile skin and I am told that disposable wipes have been banned from hospital use by the City of Raleigh because they were clogging city drains. I vow to send each city official a hard nubby washcloth with my personal instructions for use.

Mid-week the telephone at my mother's bedside rings. It is a physician presenting options. “First,” he says “the only way to cure this infection is with a total hip replacement followed by 6 months of intravenous antibiotics. Second, we can place her on an oral dose of antibiotics twice a day for 6 weeks and a maintenance dose daily thereafter for the rest of her life to try to keep the infection at bay. Third, we could place her under hospice care which would provide immediate skilled nursing but of course, she could no longer attend adult daycare. I suggest option three,” he says. I select option two.

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TRAVELERS *(continued from page 5)*

She is discharged on Thursday afternoon exactly one week after she was admitted. At home I let her sleep uninterrupted by pokes and pricks for the first time in days. I can't sleep. Away from the pressures of the hospital I think more critically about my decision. I'm not sure exactly where we are on this journey but I know I can't fend off the approaching horizon forever. The reality is that my mother will be 99 years old next month, she has advanced Alzheimer's disease and she is clearly declining. Years of financial, emotional and physical stress have exhausted me. Hospice would have meant immediate medical assistance, free incontinence and other supplies, and a host of other services. It also would have meant confinement for both my mother and me – the end of many positive aspects in our lives. Was my decision wise?

What I know better than anyone else is my mother's core resilience -- steel wool even in dementia. I have protected her fiercely from being minimized, ignored, neglected, dismissed or discarded by our culture's peculiar attitude toward the elderly. Now we are entering a stage where I must protect her from my own desire to keep her forever. I must let her go with all my love. Someday soon, alone eyeball to eyeball

with the universe, I will blink first through an ocean of tears long held at bay.

At the moment I write this she is recovering fairly well, I am providing the best quality of life for her that I can with meager resources, and the day center welcomed her back last Monday provided the wound does not drain. Daily, I ensure that it doesn't.

The Sunday after her release from the hospital, I take my mother for a long walk in her wheelchair on the greenway that connects Timber Drive and Lake Benson Park. We rest on a bench overlooking a broad green meadow fringed by trees under a perfect blue sky. People and dogs greet us as they pass. She can no longer respond but the sun is warm on her skin, she hears birdsong, feels wind and my touch on her shoulder. On days like this we used to walk miles together along fence lines, through woods or down gritty city streets. In one way or another we have traveled together for over 67 years.

Why stop now?

Margaret Toman is the sole caregiver for her 99-year-old mother. She is also a writer, public speaker, caregiver advocate and community volunteer. Margaret and her mother live in Garner, NC.

LIMIT UNWANTED CALLS & EMAILS

Some phone calls and emails are important, some can be annoying and others are just plain illegal. For households with a family member with dementia, unwanted calls can be especially troubling and yes, dangerous.

Learn how to reduce the number of unwanted messages you get by phone and online at this Federal Trade Commission's website: <http://www.consumer.ftc.gov/topics/limiting-unwanted-calls-emails>.

- **Privacy Choices for Your Personal Financial Information:** Federal law gives you the right to stop some sharing of your personal financial information.
- **Stopping Unsolicited Mail, Phone Calls, and Email:** Here's how to limit the number of unsolicited mailings, calls, and emails you get.
- **Robocalls:** Telemarketing sales calls with recorded messages are illegal unless you have given the company written permission to call you.
- **Cell Phones and The Do Not Call Registry:** How to put your cell phone number on the National Do Not Call Registry.
- **National Do Not Call Registry:** Detailed answers to frequently asked questions about the National Do Not Call Registry.
- **Stopping Unwanted Sales Calls:** Putting a number on the National Do Not Call registry will result in fewer telemarketing calls to that number. Here's how to do it.
- **Telemarketing Scams:** Phone scammers trick thousands of people. Here's how to protect yourself.
- **The Telemarketing Sales Rule:** Learn about your rights when it comes to telemarketing calls, including those that are pre-recorded.
- **Spam:** Here's how you can reduce unwanted commercial emails.
- **Text Message Spam:** Text message spam is to your cell phone what email spam is to your personal computer.
- **The "Nigerian" Email Scam:** Strangers who offer "big rewards" to help them move money out of a foreign country are lying.

HOSPITALIZATION HAPPENS

A Guide to Emergency Room Visits for Individuals with Memory Loss

From the National Institute on Aging

My mother went to the emergency room as a smart, pleasant 78-year-old woman with a fall. After 24 hours in the emergency room, she was screaming, delusional and no one listened to me. They didn't understand this was not the mother I brought in.

- A daughter/nurse

Here, you will find: steps you can take now to make hospital visits less traumatic; tips on making your relative or care partner more comfortable once you arrive at the hospital; and suggestions on how to work with hospital staff and doctors.

Share this information with family and friends, keep this information in a convenient location, and begin preparing now for what will happen in the future.

Hospital Emergencies: What To Do Now

Planning ahead is key to making an unexpected or planned trip to the hospital easier for you and your care partner. Here is what you should do now:

- Think about and discuss hospitalization before it happens and as the disease and associated memory loss progress.
- Hospitalization is a choice. Talk about when hospice may be a better and more appropriate alternative.
- Register your relative for a MedicAlert® + Alzheimer's Association Safe Return® bracelet through your local Alzheimer's Association chapter. People who are lost may be taken to an emergency room. This bracelet will speed up the process of reconnecting you with your care partner. Learn more about safety-related programs such as Project Lifesaver International (www.projectlifesaver.org).
- Know who you can depend on. You need a family member or trusted friend to stay with your care partner when he or she is admitted to the emergency room or hospital. Arrange to have at least two dependable family members, neighbors, or friends you can call on to go with you or meet you at the hospital at a moment's notice so that one person can take care of the paperwork and the other can stay with your care partner.

Pack an Emergency Bag

Personal Information Sheet

Create a document that includes the following information about your care partner:

- Preferred name and language (some people may revert to native languages in late-stage Alzheimer's disease)
- Contact information for doctors, key family members, clergy and helpful friends (also program into cell phone, if applicable)
- Illness or medical conditions
- All current medicines and dosage instructions; update whenever there is a change
- Any medicines that have ever caused a bad reaction
- Any allergies to medicines or foods; special diets
- Need for glasses, dentures or hearing aids
- Degree of impairment and amount of assistance needed for activities
- Family information, living situation, major life events
- Work, leisure and spiritual history
- Daily schedule and patterns, self-care preferences
- Favorite foods, music, and things your care partner likes to touch and see
- Behaviors of concern; how your relative communicates needs and expresses emotions

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HOSPITALIZATION *(continued from page 7)*

Mom fell, hit her head, and after the nurse practitioner at the Memory Care Unit stitched her up, I got a call saying they wanted to take her to the ER for a head scan. I asked what they might find. A: A fractured skull. I asked: and then what would they do? A: sew it up - I asked: in other words, open up her head to do so? A: well, yes. At that point I told them not to take her. When she was of sound mind, she made it clear that she wasn't going to undergo surgery at 92 years old. And now she is 95! Follow up: She's got a bruise, is reasonably comfortable, and is asking why people are making such a fuss.

- A daughter

Paperwork

Include copies of important documents such as:

- Insurance cards (include policy numbers and pre-authorization phone numbers)
- Medicaid and/or Medicare cards
- Durable Power of Attorney, Health Care Power of Attorney, Living Will and/or an original DNR (do not resuscitate) order

Supplies for the Care Partner

- A change of clothing, toiletries and personal medications
- Extra adult briefs (e.g., Depends), if usually worn. These may not be available in the emergency room if needed
- Moist hand wipes such as Wet Ones; plastic bags for soiled clothing and/or adult briefs
- Reassuring or comforting objects
- An iPod, MP3 or CD player; earphones or speakers

Supplies for the Caregiver

- A change of clothing, toiletries and personal medications
- Pain medicine such as Advil, Tylenol or aspirin. A trip to the emergency room may take longer than you think. Stress can lead to a headache or other symptoms.
- A pad of paper and pen to write down information and directions given to you by hospital staff. Keep a log of your care partner's symptoms and problems. You may be asked the same questions by many people. Show them what you have written instead of repeating your answers.
- A sealed snack such as a pack of crackers and a bottle of water or juice for you and your care partner. You may have to wait for quite a while.
- A small amount of cash.

- A note on the outside of the emergency bag to remind you to take your cell phone and charger with you. By taking these steps in advance, you can reduce the stress and confusion that often accompany a hospital visit, particularly if the visit is an unplanned trip to the emergency room.

At the Emergency Room

A trip to the emergency room may fatigue or even frighten your care partner. There are some important things to remember:

- Be patient. It could be a long wait if the reason for your visit is not life-threatening.
- Recognize that results from lab tests take time.
- Offer physical and emotional comfort and verbal reassurance to your relative. Stay calm and positive. How you are feeling will get absorbed by others.
- Realize that just because you do not see staff at work does not mean they are not working.
- Be aware that emergency room staff often have limited training in Alzheimer's disease and related dementias, so try to help them better understand your care partner.
- Encourage hospital staff to see your relative as an individual and not just another patient with dementia who is confused and disoriented from the disease.
- Do not assume your care partner will be admitted to the hospital.

Do not leave the emergency room to go home without a follow-up plan. If you are sent home, make sure you have all instructions for follow-up care.

The complete brochure is available at <http://www.nia.nih.gov/alzheimers/publication/hospitalization-happens>.



HOSPITALIZATION HAPPENS

How to Reduce Complications in Hospitalized Elderly

By Juliessa Pavon, MD, Duke Medicine Fellow in Geriatrics

Admission to the hospital is not a trivial event for patients with Alzheimer's or another dementia. The change from a familiar to an unfamiliar setting can be very stressful. Stress can also come from the risk of developing complications, and the risk of not being able to return home after discharge. By planning ahead and working together with a team of experienced physicians, nurses, social workers, dieticians, and therapists, the risks of a hospital stay can be reduced for both the patient and the caregiver. Below are common recommendations to help reduce complications for patients with Alzheimer's or another dementia during a hospital stay.

Complications of Hospitalization and Recommendations to Prevent Them

Patients and caregivers should be familiar with these recommendations and also with why they are recommended.

Delirium

Delirium is a sudden onset of mental confusion which fluctuates in intensity. The patient typically experiences a lack of awareness, attention, and decreased re-

sponsiveness to the environment. In severe forms, the patient may experience hallucinations or delusions. The presence of delirium is incredibly distressing for both patients and caregivers. Causes including medication, poor nutrition and a strange environment may contribute to the onset or worsening of delirium.

Medications – Medication changes and errors can be a source of delirium. Be sure to bring to the hospital a current list of medications your relative is taking. Monitor which medications the patient is receiving during a hospital stay. Medications such as pain medications, sedatives, antidepressants, steroids, antibiotics, among others, can cause delirium, and thus should be monitored closely.

Eyes and Ears – A distortion of sensory input can worsen delirium. Be sure to bring eyeglasses, hearing aids, or alternatives such as amplifiers or magnifiers to help him/her see and hear appropriately during the hospital stay. Bring in a large calendar and/or digital clock to assist with orientation to time and place while in the hospital.

Bowels and Bladder – Retention of stool and urine can

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HOSPITALIZATION *(continued from page 9)*

cause great discomfort and worsen the agitation that often accompanies delirium. Pay attention to whether your loved one is maintaining bowel and bladder habits and report changes to the care team.

Sleep/Wake Cycle – A disruptive sleep cycle can significantly alter a person's thinking and response to the environment. Try to ensure that your relative is sleeping during the night and awake during the day. The care team can make changes such as reducing the number of vital sign checks during the middle of the night, and rearranging blood draws for late mornings instead of early mornings. Turn off the television at bedtime, or at least be sure it does not stay on through the night. Keep the window shades open during the daytime. Try to maintain activity during the day as discussed below.

Physical Activity – Promoting self-care and getting the person moving are keys to reducing the risk of delirium in the hospital. The team will first ensure that the environment is safe. Bed handrails, grab bars, raised toilet seats, and non-slippery socks should be readily available. The hospital team will encourage the patient to spend some time in a chair rather than in the bed, to eat meals out of bed, and to go for supervised short walks down the hallway. For patients with advanced dementia who are very agitated, some hospitals may provide fidgeting devices, such as activity aprons, which have zippers, pockets, strings and other materials. This may help to divert minds and hands from pulling at dangerous items such as IVs, drains or tubing.

Nutrition – Illness can contribute to a lack of appetite. However, it is important to ensure adequate caloric intake during a hospital stay. Poor electrolyte balance, dehydration, and weight loss can worsen delirium. The nursing staff can help monitor caloric intake. Lack of assistance during meals can be a modifiable cause of poor nutrition in the hospital. If your loved one cannot open containers or eat on his/her own, make sure the family or care team arranges for assistance during meals. The care team may also recommend bringing in a patient's favorite food to supplement hospital meals. If nutrition is of concern, the team may recom-

mend a nutrition and/or speech therapy (swallowing) consult to develop an appropriate meal plan.

Care Attendants - If a patient with delirium is felt to be a risk to themselves or to others, the hospital care team may request a care attendant (also referred to as aides, sitters or companions) to be in the room with the patient to ensure safety. Care attendants can be a very valuable resource. They can help to monitor patient activity while the family is away, and can help promote and carry out the recommendations on sleep cycles, activity, and nutrition noted above.

Environment – An unfamiliar environment can worsen the severity of delirium. The hospital team will often recommend that families bring in familiar items from home, such as a favorite blanket, pillow, robe, or picture. Music, puzzles, or favorite books can also be comforting in the hospital. A safe environment is especially important for someone with delirium. The hospital team will do its best to avoid the use of restraints or sedative medications. To avoid falls from the bed, the bed may be positioned lower. The care team will also make efforts to hide any tubes, drains, or IVs that a patient with dementia may be tempted to pull. Items such as IVs and Foley catheters should be removed as soon as medically feasible. For safety, the care team will also be reviewing medications to ensure the indications and the dosages are appropriate.

Pressure Ulcers

Immobility, prolonged bed rest, incontinence and poor nutrition are all contributors to pressure ulcers (commonly called bed sores). Dementia prevents someone from responding typically to discomfort and pain that may occur from being in a seated or prone position for prolonged periods. For the prevention of pressure ulcers, the care team will often recommend frequent turning in bed every two to four hours. They will also suggest the use of special supportive mattresses. Attention to hygiene and nutrition is important because good skin care and balanced nutrition aids healing and prevents skin breakdown and weight loss. For healing pressure ulcers, the hospital team may involve the assistance of wound care nurses.

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HOSPITALIZATION

(continued from page 10)

Weight Loss

In addition to the contributing illness, the change in environment is largely responsible for weight loss in hospitalized patients with Alzheimer's or another dementia. An unfamiliar environment combined with unfamiliar food can limit appetite. Even worse, it is disruptive not to have the company of a usual meal partner in the hospital. Immobility in hospitalized patients is also a contributor to poor appetite. Immobility leads to decreased metabolic activity and thus decreased hunger. The nurses, physicians, and dieticians will work together to monitor food intake. Recommendations will often include liberalization of the diet to include comfort foods, assistance at meals, increased physical activity, and evaluation by speech therapists for appropriate and safe food consistencies. Creating a familiar dining environment, whether by bringing familiar foods or a familiar meal partner, is also recommended.

Decreased Mobility

Decreased mobility can lead to diminished ability to care for oneself and often prevents discharge home. Immobility in the hospital is preventable. The hospital care team may recommend daily physical activity such as supervised walking in the hallways, eating meals out of bed, walking to the bathroom, or spending time in the chair. The activities should be specific and routine. To be most effective, the routine should be established at the start of a hospital admission. Aim for physical activity twice a day. Post the activities in the room to set up reminders for the patient, family and for the hospital staff. The health care team may ask for the assistance of physical therapists and occupational therapists to ensure the patient is safe for activity and to provide the appropriate assistive equipment, such as canes and walkers. Caregivers play an essential role in coaching and providing positive feedback that motivates a loved one to increase activity during the hospital stay.

The Bottom Line

When a relative with dementia becomes hospitalized, the family caregiver must be an important member of the hospital care team. Family members or their surrogates are in the best position to watch for signs of complications and to advocate for the suggested measures to prevent or buffer these problems.

FAMILY CAREGIVERS ARE HEALTH CARE TEAM MEMBERS, TOO

From "Next Step in Care: Hospital Admission"

Here are some ways you can help

- Help make sure that your family member gets the treatments needed. You can do this by checking with the nurse going off duty and asking what needs to happen during the next shift. This includes medications, tests and procedures. You can make sure the nurse coming on duty next has the same information.
- Ask questions about your family member's medical condition, treatment, and follow-up plan of care. It is a good idea to write questions as you think of them. This way, you will be prepared when meeting with the doctor, nurse, or other health care professional.
- Keep track of all instructions and plans for discharge. A good way is to write this information in a notebook and keep it by the bedside.
- Tell the doctor or nurse if you do not understand something or want to learn more about a certain topic.
- Let the doctor or nurse know if you do not feel ready to care for your family member after discharge.
- Use good communication skills. This means listening carefully, speaking clearly, and using a friendly tone.
- Ask to speak with the doctor, nurse, social worker, or patient representative if feel there are communication problems with the staff or you or your family member are not being treated fairly.

For the complete Family Caregiver Guide to Hospital Admission, see <http://www.nextstepincare.org/uploads/File/Guides/Hospital/Admission/HospitalAdmissions.pdf>.

HOSPITALIZATION HAPPENS

A Guide to Anxiety in Hospitalized Individuals with Memory Loss

From the National Institute on Aging

When I saw how he was in the hospital, I knew I couldn't take care of him at home any longer. - A wife

Editor's Note: People with dementia may become very upset or anxious when they are hospitalized. In addition to the suggestions in Pavon's article (page 10), here are some tips specifically aimed at reducing anxiety or agitation in patients with memory loss.

If Anxiety or Agitation Occurs

Try some of the following:

Remove personal clothes from sight.

Post reminders or cues if this comforts your care partner.

Turn off the television, telephone ringer and intercom. Minimize background noise to prevent overstimulation.

Talk in a calm voice and offer reassurance. Repeat answers to questions when needed.

Provide a comforting touch or distract your care partner with offers of snacks and beverages.

Consider "unexpressed pain" (i.e., furrowed brow, clenched teeth or fists, kicking). Assume your relative has pain if the condition or procedure is normally associated with pain. Ask for pain evaluation and treatment every four hours without your care partner having to ask for it—especially if he or she has labored breathing, loud moaning, crying or grimacing, or if you are unable to console or distract your care partner.

Listen to soothing music or try comforting rituals such as reading, praying, singing or reminiscing.

Slow down; try not to rush your care partner.

Avoid talking about subjects or events that may upset your care partner.

Working with Hospital Staff

Remember that not everyone in the hospital knows the same basic facts about memory loss and Alzheimer's disease or related dementias. You may need to help teach hospital staff what approach works best with your care partner, what distresses or upsets him or her, and ways to reduce this distress.

You can help the staff by providing them with a personal information sheet that includes your care partner's normal routine, how he or she prefers to be ad-

dressed (e.g., Miss Minnie, Dr. James, Jane, Mr. Miller, etc.), personal habits, likes and dislikes, possible behaviors (what might trigger them and how best to respond), and nonverbal signs of pain or discomfort.

Help staff understand what your care partner's "baseline" is (prior level of functioning) to help differentiate between dementia and acute confusion or delirium.

You should:

Make the personal information sheet easy to read with headings and short, simple statements. Place a copy with the chart in the hospital room and at the nurse's station.

With the hospital staff, decide who will do what for your care partner. For example, you may want to be the one who provides assistance with bathing, eating or using the bathroom.

Inform the staff about any hearing difficulties and/or other communication problems your relative may experience and offer ideas for what works best in those instances.

Make sure your care partner is safe. Tell the staff about any previous issues with wandering, getting lost, falls, suspiciousness and/or delusional behavior.

Do not assume the staff knows your care partner's needs. Inform them in a polite, calm manner.

Ask questions when you do not understand certain hospital procedures and tests or when you have any concerns. Do not be afraid to be an advocate for your relative.

Plan early for discharge. Ask the hospital discharge planner about eligibility for home health services, equipment or other long-term care options. Prepare for an increased level of caregiving.

Realize that hospital staff are providing care for many people. Practice the art of patience.

What is possible and reasonable are two different things...Which would your care partner want?

The complete brochure is available at <http://www.nia.nih.gov/alzheimers/publication/hospitalization-happens>.

HOSPITALIZATION HAPPENS

Questions to Ask at the Hospital before Discharge

By Leslie Kernisan, M.D., *Caring.com* senior medical editor and Paula Spencer Scott, *Caring.com* senior editor

Make sure you've covered these points with a doctor and/or discharge planner before a loved one comes home from the hospital.

When hospital doctors decide your loved one is ready to plan for discharge from the hospital to home, a hospital discharge planner will review what the patient needs and will help arrange for post-hospitalization care. The medical staff caring for your loved one will also have a final conversation on the day of departure to go over discharge instructions.

Don't let the patient have these meetings solo; he or she will almost surely be too stressed from the hospitalization to remember everything or provide the full picture of caregiving needs at home.

As a caregiver, you can help ensure a safe, successful transition by being sure the following questions have been answered to your satisfaction. Depending on the hospital, most answers may be provided by the discharge planner; or you may need to ask the attending doctor as well (especially questions about illness, symptoms to watch for, and follow-up care).

About your loved one's illness

- What is the diagnosis at discharge? Could we review why my loved one was hospitalized, and could you summarize the status of his or her medical condition(s)?
- What should we expect regarding recovery?
- What should we look out for in terms of possible setbacks, and whom should we call in the event of problems?
- What follow-up appointments are needed with the patient's primary physician or others?
- Is any follow-up medical testing needed? What kind, where should it be done, and when?
- Does the hospital have the name and contact information for the patient's primary care physician, so that a discharge summary can be sent soon?

About getting your loved one home

- What day will my loved one be discharged, and at approximately what time?
- How will my loved one be transferred home (taxi, car, ambulance, etc.) and who should escort him or her?

- If my loved one can't move independently from the vehicle into the home, how do you suggest the transition into the house be made, and who will help?

About the physical set up at home

- What do you need to know from me about where my loved one will be living? (You may be asked about caregivers, home setup, and other questions that get at whether you're ready to bring a loved one home from the hospital).
- ***Can you arrange a home assessment to help me decide what kind of accommodations around the house would most help my loved one?***

About equipment and supplies

- What kind of equipment and supplies are being prescribed for my loved one?
 - Hospital bed?
 - Walker?
 - Wheelchair?
 - Shower chair?
 - Bedside commode?
 - Incontinence supplies (such as adult diapers, bed pads)?
 - Colostomy supplies?
 - IV equipment?
 - Respiratory equipment?
 - Wound care supplies?
 - Other supplies (rubber gloves, antiseptic wipes, skin lotion)?
 - Anything else you can think of? Be sure to mention it.
- Why is this equipment needed?
 - How do I use this equipment? Can I have a demonstration, if needed?
 - Where is the equipment coming from? Supplied by providers? From a home health agency? Must I rent (and if so, from where do you suggest)?
 - How do I reorder supplies?
 - Whom do I call in case of problems with supplies?

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HOSPITALIZATION *(continued from page 13)*

About healthcare services

- What kinds of healthcare and support services are being prescribed?
 - Physical therapy?
 - Occupational therapy?
 - Skilled nursing care (for help with wound care, monitoring)?
 - Home health aide (for help with mobility, personal care)?
 - Speech therapy?
 - Talk therapy?
- Where will the services take place: In the home or outside it? If outside it, how will your loved one get there?
- How often are services needed, and for how long?
- How will these services be paid for?
- What is the name(s) and contact information for the agency(ies) supplying these services?

About care

- What kind of supervision will my loved one need? (Plan for who will be with your loved one post-discharge, since an older adult who is recovering from a hospital stay should not be left alone, especially for the first week or two.)
- Can you help me prepare for aspects of personal care I'm not comfortable with (e.g. toileting, bathing) before we leave the hospital? What do I need to know? Can you arrange for a visiting nurse to educate me at home?
- Does the patient have any special dietary needs or restrictions? Can you help me prepare for them?

About medications

- Were any medications discontinued while the patient was in the hospital? If so, why? Should they be restarted?
- Do any of my loved one's current medications

raise the risk of falling or of increased mental confusion?

- ***Do any medications require special storage? Do any of them have special instructions regarding how they should be taken? (Make sure you have a complete plan for dispensing meds before you leave the hospital.)***
- Will my loved one's primary care physician be sent an updated list of medications? (Note: If the primary care doctor gets a discharge summary, it usually includes medications. The trouble is that often the primary care doctor doesn't get a discharge summary, so it's well worth asking again.)

About caregiving support at home

- What if I need more help with in-home care? Can you recommend providers?
- What if I need more help with meals? Can you recommend meal services?
- Can you recommend a support group for caregivers, or someone else I can talk to about my worries and concerns managing the demands of caregiving?
- I'm also worried about _____. (Don't hesitate to raise any other concerns you have about bringing your loved one home from the hospital, including legal issues, financial concerns, family disagreements, end-of-life planning, wandering, aggression, or other behavioral concerns.)

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SPECIAL REPORT ON LONG-DISTANCE CAREGIVING

The 2013 *Alzheimer's Disease Facts and Figures* includes a "Special Report on Long-Distance Caregivers." It describes the characteristics of long-distance caregivers, their needs, the barriers they encounter, how the caregiving situation affects them and efforts that have been made to alleviate the caregiving burden they experience. These issues have received little attention but are the source of increasing concern. http://www.alz.org/downloads/facts_figures_2013.pdf (See p. 15 personal perspective of a long-distance caregiver)

MAKING ALZHEIMER'S MOMS HAPPY WITH JUST A ONE-MINUTE CALL A DAY

By Marguerite Manteau-Rao

This story is for the 2.3 million long-distance caregivers who have a loved one with Alzheimer's.

Being a long-distance caregiver is hard, especially when a loved one's mind can no longer dwell on the memory of prior times together, or the anticipation of a future visit. One can easily feel helpless and overcome with grief, and guilt, and frustration.

I would like to share one small thing I have discovered with my mother that's made a huge difference in how I feel about living so far from her.

My mother resides 5,000 miles away -- and she is in the late stage of Alzheimer's. My contacts with her are mostly in the form of short, daily phone calls. At first, I wondered, what's the point? A few minutes can't possibly make a difference. And then, one day, I had to go on a long vacation without easy access to the phone. I did not call my mother for three weeks. When I returned, I learned from my brother that my mother had been out of sorts during my absence. After a few days of resuming my calls, her agitation subsided, and she was back to her normal self. Since then, I have observed the same phenomenon over and over again. My daily calls pay off big in my mother's heart.

More (time at once) is not necessarily more. Rather, it is the frequency, predictability, and quality of the connection that matter most:

Make that daily call

Better to have daily contact, even if very short and on the phone, than to spend a whole day with your loved one and then not have any interaction for three months. I have found that establishing a connection usually carries over the whole day. By the next day, the effect has dissipated, and it is time to recharge the person's heart with some more reassurance and love.

Call at the same time

People with Alzheimer's have a keen internal clock, and routine is extremely important. That routine includes your daily long-distance call. The more consistent you can be in terms of the timing of your call, the better. I time my calls at 8:30 every morning, just in time to catch my mother before dinner in France where she lives.

Be fully present when you call

The words almost do not matter, but your authentic presence does. Before making the call, free your mind from all "your stuff" and fill up your heart with loving kindness, readying yourself to be with your loved one. I visualize my mother's face and I smile before I pick up the phone. Sit down while you talk, and be all to your conversation, nothing else. Treat each call as a brand new call, no matter how repetitive it may seem from one day to the next.

Pack your talk with emotional goodies

Touch upon your loved one's emotional needs all at once. Stick to safe topics that don't test memory and preserve self-esteem. "What is the weather like where you are?" "How is your health?" "How are you feeling?" Keep the conversation simple. Bring in good news. I usually talk about my daughter and how well she is doing in college. End with an affirmation of your love and a reassurance that you will reconnect the next day. "I love you lots, mom." When she reciprocates, tell her how good it makes you feel to hear those words from her.

Don't get hung up on reality

I have learned to let my imagination run wild, and say anything that leaves a positive impression in my mother's heart. She will not remember the exact content, but she will remember the emotion. That I love her, and care for her, and am a constant in her life. That there are still things for her to look forward to. That she can still treat me to lunch, even though it's been years... "When are you coming?" I have my response ready, "I am coming next week." "How long will you be staying?" she always asks. And each time, I answer, "One week". That brings her so much happiness.

Such a small thing, and it means so much to her! I can do this, every day.

Marguerite Manteau-Rao is a licensed clinical social worker and Co-Founder of Presence Care Project, <http://www.presencecareproject.com/> This article originally appeared in the Huffington Post.

Online Help



AD = Alzheimer's disease *New staff favorites in this issue

Aging

<http://www.americangeriatrics.org/files/documents/Five Things Physicians and Patients Should Question.pdf> American Geriatrics Society recommendations on five tests and procedures physicians and patients should question.

<http://agerrtc.washington.edu/sites/agerrtc/files/files/Aging Sleep.pdf> Fact sheet on sleep and aging with a disability.

*<http://www.npr.org/blogs/health/2012/04/19/150953395/staying-active-fends-off-alzheimers-even-in-people-over-80> Great story of Rocking Grannies with solid research evidence to back it up.

*<http://www.nytimes.com/2012/10/10/booming/10story-booming.html?ref=booming&r=0> A *New York Times* "Booming" column about a childless woman wondering who will care for her when she's older.

*<http://www.over65.thehastingscenter.org/> The "Over 65" blog about health care and security by prominent writers about important ethics topics.

<http://www.booksaloud.org/> A free audio library for blind, visually impaired, learning disabled or physically disabled individuals who are unable to read conventional print, hold a book or turn pages.

Alzheimer's Disease and Related Disorders

*<http://memory.ucsf.edu/education/diseases> Comprehensive, detailed, understandable fact sheets on disorders that cause dementia include causes, signs and symptoms, diagnosis, disease progression, management and treatment.

<http://www.alzheimersreadingroom.com/2013/01/how-to-use-alzheimers-reading-room.html> Learn how to access information from the Alzheimer's Reading Room Knowledge Base.

<http://www.govhealthit.com/news/alzheimers-connection-project-wins-hhs-innovation-award> Innovative resource developed by two major federal agencies working together – NIA (NIH) and the Administration on Aging (now ACL).

<http://www.hospicefoundation.org/uploads/hic fs alz.pdf> Easy-to-read fact sheet on Alzheimer's disease and hospice.

<http://www.nia.nih.gov/alzheimers/publication/helping-children-understand-alzheimers-disease> How to give children understandable information about AD.

www.nia.nih.gov/alzheimers/topics/caregiving Tips and resources for caregivers of people with AD.

*<http://www.nia.nih.gov/sites/default/files/Alzheimers Caregiving Tips Helping Family and Friends Understand Alzheimers Disease.pdf> Guidelines to help visitors understand AD and to communicate well with someone with AD.

<http://nyti.ms/UDS6vc> *New York Times* column on Lewy Body Dementia, "A Form of Dementia that is Often Misdiagnosed."

<http://www.rwjf.org/en/about-rwjf/program-areas/quality-equality/care-about-your-care/patient-resources.html> Hospitalization and transitional care resources for families.

<http://www.sweetreaders.org/> An intergenerational program to teach kids skills to raise funds and awareness for AD, develop an understanding of scientific research, and help scientists end AD.

Caregiving

http://www.alz.org/downloads/facts_figures_2013.pdf The 2013 *Alzheimer's Disease Facts and Figures* includes a Special Report on Long-Distance Caregivers.

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Online Help *(continued from page 16)*



<http://caregiving.adcouncil.org/index.asp?page=221> Video, featuring AARP family caregiver and expert, about moving parents in with daughter when one parent has Alzheimer's.

<http://www.guidinglightsn.org/dementia-training.php> Guiding Lights Dementia Training "Do You Know Who I Am?" Online and free to family caregivers.

<http://www.legacystories.org/> Record talking photos directly from one's home computer to share with future generations.

<http://www.seniorhelpers.com/SeniorGems> Complimentary Senior Gems™ DVD, featuring Teepa Snow, about dementia, including coping strategies, techniques for behavioral challenges and communication tips.

singathome.org Free music website for seniors and caregivers. Includes tips for using music in caregiving.

Planning, Insurance & Long Term Care

*<https://www.prepareforyourcare.org/> The PREPARE website is designed to help families prepare for medical decision-making.

<http://theconversationproject.org/> The Conversation Project, co-founded by Ellen Goodman, is dedicated to helping people talk about their wishes for end-of-life care.

http://caregiver.com/articles/print/financial_abuse_spot_it.htm Crucial information about financial exploitation and abuse of older adults.

*http://www.jointcommission.org/assets/1/18/Palliative_brochure.pdf What one needs to know about serious illness and palliative care from the Joint Commission. Video and Spanish available.

*<http://www.nextavenue.org/article/2013-02/how-find-financial-adviser-whos-right-you> Critical questions to ask a potential financial advisor.

http://nextstepincare.org/Provider_Home/Home_Care_Complete "Home Care: A Family Caregiver's Guide," describes the types of home care services and agencies, and outlines the referral process. Download free in English, Spanish, Chinese, and Russian.

*http://nextstepincare.org/Provider_Home/Home_Health_Aides/ "Working with Home Health Aides," offers advice about working effectively with a home care aide. Download free in English, Spanish, Chinese, and Russian.

Products & Technology

<http://www.asksara.org.uk/> Online guide to enable people with dementia to maintain independence through the use of assistive technologies and devices.

*<http://www.forbes.com/pictures/ejmm45klk/high-tech-help-for-grandma-grandpa/> Ten high-tech gadgets to help older adults continue to live independently.

www.hearthealthmobile.com Free downloadable app recommended by federal sources that may be useful for those interested in AD prevention through heart health.

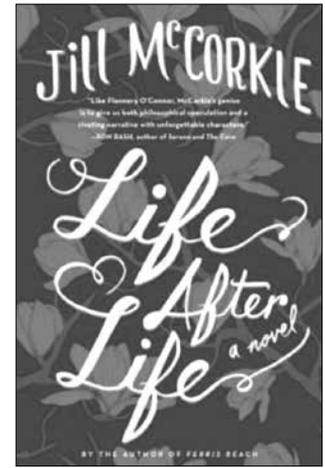
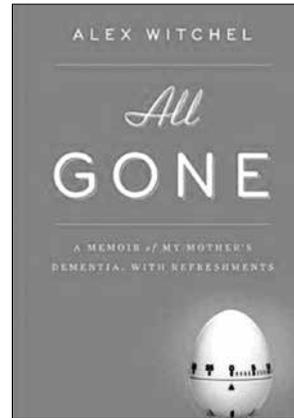
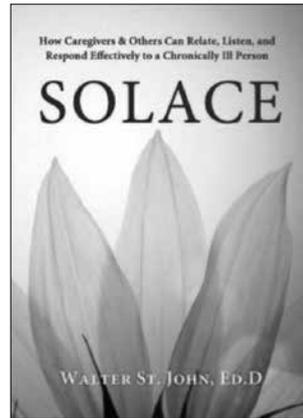
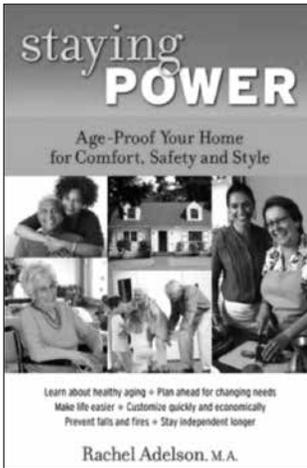
www.memoryappsfordementia.org Introduce older adults with dementia to new touchscreen iPad technology.

*<http://musicandmemory.org> Non-profit that programs donated iPods to play personalized playlists for nursing home residents.

Research Participation Options

<https://adrc.mc.duke.edu/> Within range of Duke? Join the Bryan Alzheimer's Disease Center Alzheimer's Disease Prevention Registry.

<http://newoldage.blogs.nytimes.com/2012/11/20/signing-up-to-help-fight-alzheimers/> Different ways to register to help accelerate the pace of Alzheimer's research.



Have You Heard About?

Adelson, Rachel 2013. *Staying Power: Age-Proof Your Home for Comfort, Safety and Style.* Adelson's guide shows aging adults how to make their homes safer, more comfortable and livable. Written in a clear, conversational style by an award-winning science writer and baby boomer herself, the book's instructions are easy to follow.

Bercaw, Nancy Stearns, 2013. *Brain in a Jar: A Daughter's Journey through Her Father's Memory.* The author recounts life with her father who became a neurologist in response to seeing his own father die with Alzheimer's, and then gets the disease himself. Bercaw's memoir also describes her own struggle to find emotional stability while watching her father's decline.

Bohannon, Judith, 2012. *Sleep Tight.* Based on Bohannon's own experiences caring for her husband, this novel accurately depicts the difficult emotions and relationships associated with being an Alzheimer's disease caregiver.

Goldstein, Stephen, 2012. *When My Mother No Longer Knew My Name: A Son's "Course" in "Rational" Caregiving.* Written anecdotally, this book offers advice for difficult situations caregivers face in the Alzheimer's progression. Each chapter details how Goldstein traversed his new caregiver responsibilities.

Marley, Marie, 2011. *Come Back Early Today: A Memoir of Love, Alzheimer's and Joy.* A memoir detailing the 30-year love story between Marley and her soul mate Ed, who develops Alzheimer's during their relationship. Marley also offers suggestions for common problems Alzheimer's caregivers face.

McCorkle, Jill, 2013. *Life After Life: A Novel.* Award-winning NC author explores time and memory in a southern retirement center and its Memory Unit. This

novel is enriched by the author's personal experience.

Prescott, Judy, 2011. *Searching for Cecy: Reflections on Alzheimer's.* Prescott's poems are about her mother's Alzheimer's progression and her own path to finding peace with the disease. Each poem is accompanied by artwork from members of the Prescott family.

Scarff, Susan Kiser and Zultner, Ann Kiser, 2012. *Dementia: The Journey Ahead.* Sisters Zultner and Scarff offer advice to help prevent caregiver burnout, based on Scarff's experience caring for her husband with dementia. The book also covers practical information about common concerns such as managing finances and home safety.

St. John, Walter, 2011. *Solace: How Caregivers & Others Can Relate, Listen, and Respond Effectively to a Chronically Ill Person.* Written for both health care professionals and family caregivers, this handbook offers tips on communicating effectively with people who have chronic illnesses.

Westheimer, Ruth, 2012. *Dr. Ruth's Guide for the Alzheimer's Caregiver: How to Care for Your Loved One Without Getting Overwhelmed...and Without Doing It All Yourself.* The book offers effective coping strategies for both the practical problems and emotional stresses of Alzheimer's care. Dr. Ruth gives advice on balancing caring for a dependent adult and maintaining a healthy mental and physical lifestyle for the caregiver.

Witchel, Alex, 2012. *All Gone: A Memoir of My Mother's Dementia.* In this warm memoir, a New York Times staff writer describes her experience coping with her mother's progressing dementia. Witchel retreated to the kitchen, and found solace in cooking comfort foods from her childhood.