

*A Bridge to Understanding
Your Options*

The CAREGIVER

Newsletter of the Duke Family Support Program

Volume 34, Issue 1

Spring 2015

DUKE FAMILY SUPPORT PROGRAM: 35-YEARS OF CONNECTING PEOPLE

By Lisa Gwyther, MSW, LCSW

“From Murphy to Manteo” challenged Dr. George Maddox, the late director of the Duke Center for Aging (CFA), in 1979. The Duke Hospital Auxiliary, NC Foundations and committed families like the Culbreths of Raeford, Louise Martin of Davidson, the Marks of Wilmington and Rebecca Hundley of Thomasville seeded Dr. Maddox’s challenge to mobilize communities of support throughout NC for families caring for members with Alzheimer’s and related diseases. We partnered with Winston-Salem professionals like Jan Sawyer and powerfully articulate writers like Myrna Doernberg (see page 18). *The Caregiver* newsletter connected families through stories and tips like those from Emily Albera of Bath, NC (see page 5) when long-distance calls were expensive and there was no email or internet.

The NC Division of Aging (NC DAAS) – with champions like Mary Bethel and Marian Sigmon – helped NC become one of the first states to invest in a gateway, first-responder service for families and professionals. NC DAAS has helped fund the Duke Family Support Program since 1984. By the late 1980s, Duke’s Bryan Alzheimer’s Disease Research Center offered signature annual conferences for families and professionals, starting each meeting from the perspective of the person with the diagnosis and family. Tommy Thompson of the Red Clay Ramblers opened one conference, and Liz Priestley and her mother presented at another (see page 13). Edna Ballard, the program’s social worker for 27 years, creatively worked with families on uniquely southern stories to engage hard-to-reach groups.

Today, with sustained leadership from Duke CFA director Dr. Harvey J. Cohen, there are new partners like Duke’s Nasher Art Museum (see page 12), novel initiatives building community among individuals with early-stage memory disorders, innovative local authors like Maggi Grace (see page 15) and new social work staff. Now, after 35 years, a new era marks the end of mailing paper copies of *The Caregiver* newsletter. NC state funding for printing and mailing *The Caregiver* stops with this issue. We are committed to reaching our loyal readers. **See the back cover, and let us know how to keep you in our loop.**

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Duke Family Support Program
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View this newsletter online at
www.dukefamilysupport.org

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National Alzheimer's Association

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

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

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

2015 Community Education

- Pittsboro, Effective Communication Strategies: May 28
- Pittsboro, Understanding and Responding to Dementia-Related Behaviors: June 11

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

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

2015 Events

- Charlotte, Blondes vs. Brunettes Flag Football, May 30

Alzheimer's North Carolina, Inc.

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

2015 Caregiver Education Conferences

(see website for details)

- Raleigh, Triangle Caregivers Conference: June 16, 8 am – 3:30 pm
- Durham, Triangle Caregivers Conference: June 25, 8 am – 3:30 pm

2015 Walk (see website for updates and other events)

- Forsyth Co. Springfest; Johnston Co.; Onslow Co.; Edgecombe Co. Walks: May 30
- Guilford County Walk: June 6
- Martin County Walk: June 13
- Surry County Walk: June 20

ALZHEIMER'S MEDICAL ADVISOR – SEEKING FAMILY CAREGIVERS TO TEST NEW WEBSITE

Are you sometimes uncertain or anxious about what to do when your family member with dementia develops a new symptom – such as pain, agitation, or coughing? If so, you may be eligible to use and test a new online resource to help deal with these issues. It was designed by doctors, nurses, and social workers from UNC and Duke, and is not yet available to the public.

You're eligible if you live with a person with dementia or visit them at their home at least once a week. Caregivers who participate will be given a password and access to the website for six months, and will receive \$100 for their time and feedback.

If you're interested in participating or to obtain more information, please contact Julia Thorp: Email: Julia_Thorp@unc.edu
 Phone: (866) 687-9342 (toll free) or (919) 966-7173.

*All study procedures have been approved by the Office of Human Research Ethics
 at the University of North Carolina at Chapel Hill.*

NOVEL APPROACHES IN DEVELOPING TREATMENTS FOR ALZHEIMER'S DISEASE

By Brenda L. Plassman, Ph.D. & Kathleen A. Welsh-Bohmer, Ph.D.

Bryan Alzheimer's Disease Research Center, Duke University

The search for effective treatments for Alzheimer's disease has suffered a number of disappointing setbacks in recent years when medications that initially looked promising later failed in larger clinical trials. Armed with improved knowledge of disease mechanisms, researchers are investigating novel treatment approaches aimed at key disease targets. Here we summarize a few therapies that have drawn a lot of public attention recently because of their novelty and promise.

Researchers in Canada and Australia are experimenting with ultrasound to remove amyloid from the brains of mice that have a genetic defect that causes Alzheimer's disease. Amyloid is one of the main pathologies found in the brain of individuals with Alzheimer's disease. So this is a new therapeutic approach for an old target, amyloid. The research team first injected tiny gas bubbles in the blood which traveled to the brain and temporarily caused small openings in the gate to the brain, called the blood brain barrier. An ultrasound beam was then directed at the brain. This resulted in both a decrease of amyloid in the brains of the mice and improvement in memory.

Another study showing promise uses an experimental cancer drug (Saracatinib: AZD053) to treat Alzheimer's disease in mice. This is a novel approach to address a yet unanswered question – how does amyloid damage the neurons? The team at Yale found that specific forms of amyloid, called oligomers, attack the neuron by attaching to specific proteins on the cell surface. By preventing the oligomer from attaching to the neuron, they have shown in mice that they can prevent the toxic effect of amyloid on the neurons. The animals also showed improved memory and there was less amyloid in their brains (Annals of

Neurology, Kaufman 2015 published online).

And in breaking news from Duke, Dr. Carol Colton's laboratory is taking an entirely new look at fundamental mechanisms responsible for the neuronal cell death in Alzheimer's disease. Instead of focusing on the plaques and the tangles, Dr. Colton's team is examining the microenvironment to the neurons, the microglial cells which provide support and are important in brain immune function. In work reported in the April issue of the Journal of Neuroscience, the research team reported that cells which are normally involved in protecting the brain begin to abnormally consume an essential nutrient for neuronal health, arginine. By blocking this process with a small molecule drug, the team was able to prevent the characteristic brain plaques and memory problems in genetic mice engineered to develop Alzheimer's disease.

These promising results in mouse models of Alzheimer's disease are suggesting important new targets for human therapies in this highly complex chronic disease. However, despite the exciting positive findings of disease modification in mice, caution is warranted. Alzheimer's disease in mice is less complex than it is in humans. It is quite a leap, taking results in mice and applying them to conclusions about human disease. Nonetheless, the results are promising enough that these various lines of investigation are expanding to evaluate the safety and effectiveness of these treatment approaches in other types of animals and in initial studies in humans.

In the interim, other studies are underway in human trials using new medications on old targets like beta amyloid, the pathological hallmark of Alzheimer's disease. A pharmaceutical company, Biogen, Inc., recently reported preliminary findings on a new

Armed with improved knowledge of disease mechanisms, researchers are investigating novel treatment approaches aimed at key disease targets.

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TREATMENTS *(continued from page 3)*

monoclonal antibody medication called aducanumab. This medication targets amyloid in the brain, but unlike a number of other amyloid-reducing medications that were tested in individuals with more advanced Alzheimer's disease, this new medication was tested in a small number of individuals with very mild symptoms of Alzheimer's disease. Individuals on higher doses of the new medication showed less decline during the study period on measures of cognition and everyday function compared to individuals on lower doses of the medication or placebo. Once Biogen publishes the complete study results, we will have a better understanding of how aducanumab compares to other amyloid-reducing medications.

These are just a few of the ongoing and recent studies aimed at Alzheimer's disease, but they demonstrate the novel and diverse efforts to prevent and treat this devastating disease.

These exciting findings add optimism to a field that has seen its share of disappointments. We are hopeful that one day soon these trials will bear fruit and we will have effective therapies for Alzheimer's disease.

With so many different drugs under development, we hope to have therapies that will treat Alzheimer's disease effectively at all stages of the disorder – from beginning to end.

Healthy seniors: help us shed light on Alzheimer's disease.

Despite progress being made in our understanding of Alzheimer's disease (AD), there's still a lot we don't know. Currently, there is no cure for Alzheimer's...and no way to delay its symptoms.

The TOMMORROW study seeks to learn more about the early phase of Alzheimer's—a phase referred to as mild cognitive impairment due to Alzheimer's disease (or MCI due to AD).

This important clinical research study is now seeking healthy senior participants between the ages of 65 and 83.

to learn more:

 CALL 919-668-0988 OR

 VISIT 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.



DukeMedicine

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TOMMORROW
Today's journey. Tomorrow's discoveries.

TENDING MISS EMILY

Taking the Car Away

By Emily Albera

When a woman has lived alone without husband or child for twenty-five years, her car is her independence. How do you tell a person with Alzheimer's disease that she can no longer drive? It isn't easy!

Making the decision to take the car away is most difficult. Three incidents helped me realize that I, the daughter, had to make this decision. First, after my mother-in-law claimed that Mother drove the wrong way down a one-way street, I realized that Mother's driving frightened her passengers. Second, one day I secretly followed Mom on a Friday afternoon (the worst time of the day and week) into Food Lion. Again, in the parking lot, a one-way lane was a two-laner to her. Leaving the grocery store, she had to turn left against major traffic to get home. I was terrified watching her make the turn. The third decision maker: a friend told me her grandmother had had eight accidents, not killing anyone YET. Mother killing herself was one thing. Her accidentally killing someone else would be MY responsibility. Thus, the car had to go.

The process: first, when it was time to renew her license, I called DMV and asked them not to grant a new license. Faking her vision as poor (she actually passed), they required approval from her eye doctor to continue her license. Next, I called her eye specialist and asked him not to pass her vision and not to sign the DMV document. We did that. Finally, my mother had no driver's license.

Now, how do you deal with the anger, the realization that after eighty years, one's vehicle and independence are gone? The car sat under the carport

for months. We hid the keys, but reminding this lady with Alzheimer's that she couldn't drive, reminding her that the officer and doctor took her license away was another challenge. I wrote the sequence of events down for her—to save me energy. It didn't work. She didn't believe me nor the doctor nor my stupid piece of paper.

Finally, a solution: many years prior, Mother adopted a young priest, "Rev. Bob," who was assigned to her church. In the late 60's, when my sister died, the young minister helped my mother through the emotional pain. Even after moving away, Rev. Bob would visit or call Mother throughout the years. My husband helped me create the "car lie." During one of Bob's visits, Mother had loaned him her car (that part is true). The car broke (not true); "That's why it is still under the carport, and we are waiting for a part to come from Japan." She accepted the story—anything Rev. Bob did was okay. We had to tell the story

many times, but this fib relieved her anger that we were taking her car away from her. She no longer had done something wrong not to deserve the car. Mother had helped a friend, and cars break sometimes.

Sometimes one must tell a small lie to make a loved one happy. Mother was happier. So was I.

Emily Albera is retired educator who cared for her mother for many years. She has written a series of stories, "Tending Miss Emily," about caring for her mother. Mrs. Albera lives in Bath, NC; and she, her 90-year-old mother and her mother's faithful helper, Liz, presented at a Bryan Alzheimer's Conference years ago.



FINDING THE BRIGHTER SIDE OF CAREGIVING

By Chloe J. Smith

I found the brighter side of caregiving when I learned how to communicate with my mother through engaging all five senses of sight, smell, taste, touch and hearing. My mother was a church musician so she still loves music and loves to play the piano. So what if she misses a few notes, there are still times when a recognizable tune comes through and we smile. She also is amused by the touch, taste, and smell of various foods. We make a game out of it and I show her something pretty, colorful and pleasant to the eyes and she smiles. In times like these, I can see that we have connected in that brighter side of caregiving by the look on her face and that heartwarming grin.

There are also times when I look into her eyes that I can see how lost she is for words. Yet, even at times like these, I can read her thoughts because I know my mother and words aren't always needed to convey our inner most feelings. Sometimes we laugh, and other times we cry as our feelings convey unspoken thoughts of scattered memories from other times and people long ago. I realize also that part of my mission in life now is centered in those things that keep us connected on the brighter side of caregiving. That's when we both

are most comfortable and I can see it in the smile on her face. When I see that heartwarming grin it reminds me of the best of times we've shared together and I believe it does the same for her.



It was 2001 when I received the dreaded telephone call that my mother was in the hospital and the family needed to make some lifestyle changing decisions about her care. It was difficult asking for help from family and friends and trusting that everyone would do what was needed so we kept things simple and documented everything daily on calendars and Post-it Notes. We also organized a time sharing schedule and "held" people accountable.

Finding the brighter side of caregiving helped me maintain order in my own life and connect with my mother and family in ways I never thought I could. Moreover, it helped me become the support and strength my family needed during this difficult time.

Ms. Smith's mother, Julia, passed away last September. The family gives many thanks to their physicians, Duke's Joseph & Kathleen Bryan Alzheimer's Disease Research Center, Raleigh Rehabilitation, Life International of RTP, Story Corps Brooklyn, NY and families and friends.

HE STAYS IN TOUCH WITH THE WORLD

By Carol Wise, Duke Family Support Program

Edwin Armstrong spent most of his life working hard, traveling and enjoying his friends and family. Edwin's diagnosis of Alzheimer's disease in 2012 hasn't changed his commitment to friends and social activities, thanks to his devoted daughter, Lee. Moving closer to her parents as they grew older, Lee sees to it that her father makes his weekly appointments to doctors, concerts, lunch with friends, and monthly museum visits to the Nasher Museum of Art (see story on page 12) through the Duke Family Support Program. In fact, one such visit introduced the father-daughter fans of classical music to a performance by a local classical Spanish guitarist, Ed Stephenson, who inspired Lee to host a special birthday performance for her father, with 30 of his closest friends. Said one longtime friend when toasting Edwin that night, "He stays connected with the world!" This is the essence of Lee and Edwin's relationship – connecting with other people.

Now retired, but when Edwin was an active Rotarian, he visited many Rotary clubs around the world, including remote clubs in Nepal and one on a tiny island in the Indian Ocean. He and his friends launched a local ROMEO group more than 30 years ago with 20 members. They still meet weekly for lunch with five other original members and several new members. ROMEO clubs (Retired Old Men Eating Out) have been expanding in the US over the last decade, according to AARP. Lee knows that social connections help physical and emotional health and wellbeing for people with memory disorders, and for their care partners. They often attend lectures at Edwin's alma mater, NC State, as well as at UNC, Elon, and Duke.

As a family, the Armstrongs travelled all over the world. One family trip to Kenya and Egypt is a favorite memory. Photographs in Edwin's home depict exotic landscapes, classic sailboats and smiling faces. Lee recalls fondly, "Dad always took such great care of us.

He was the ultimate protector and still is! At 85 he still comes around and opens the car door for you -- quite the gentleman. Some things don't change!" Lee



lives a few blocks from her father, and enjoys cooking dinner for him, saying how much she loves to cook. Edwin responds, "and I love to eat!" When Edwin was widowed in 2008, it became clear to Lee that she had relocated at the right time. "It was a hard time then, but we made it through, with a lot of support." So,

when her father was diagnosed a few years later, Lee reached out right away to the Duke Family Support Program, and joined their eight-week Early-Stage Alzheimer's Education and Support Group for people with a newly diagnosed memory disorder and their care partners. "Oh it was wonderful!" she said. "There, we could relax and it was such a comfort to be able to share ideas with others in the same situation."

With new friends, more knowledge about Alzheimer's, caregiving, and a robust early-stage community in the Triangle, Lee has more resources than ever. "We've taken steps to care for Dad as we go along – he has business cards with both our names and phone numbers, and I've ordered a Road ID bracelet for him. They were made for long distance road bikers, but it is terrific for people with memory disorders, too." At a recent "Look and Lunch" program at the Nasher Art Museum, Edwin and Lee spent time with several other participants touring a modern art exhibit, which included works by Andy Warhol. Asked what he thought of the art, Edwin said, "Oh, my family and I like art very much. Maybe a different style, but this is good, too. And you?" he inquired, "What do you like?" Ever the gentleman.

Carol Wise is an intern at the Duke Family Support Program and will be graduating with a Master's in Social Work in May from the UNC School of Social Work.

THE ABCs OF LONG-TERM CARE

By Bobbi G. Matchar, MSW, MHA
Social Worker, Duke Family Support Program

The alphabet soup of long-term care can be confusing even to those of us in the field. ALF? SNF? CCRC? Understanding this sometimes-baffling vocabulary is critical, as 70% of people turning 65 can expect to use some type of long-term care during their lifetime.¹ Learn about long-term care options now – don't wait for a crisis.

What are Long-Term Services and Supports (LTSS)? LTSS, the new official term for “long-term care,” includes a variety of services and supports intended to assist with health or personal care needs. Most LTSS are not medical, but involve assistance with basic self-care tasks known as activities of daily living or ADLs. These include eating, bathing, dressing, toileting, and transferring in and out of beds, chairs and cars. LTSS services can be home-based, community-based or facility-based.

Most US adults 65 and older live independently in their own homes. Numerous studies, including AARP's *Home and Community Preferences of the 45+ Population* survey found 75% of older adults want to “age in place,” meaning they wish to remain in their own homes as long as possible.² Home- and community-based LTSS address this preference.

LTSS are expensive. Wondering how people pay for LTSS? That too is complicated! Medicare, Medicaid, private long-term care insurance, and Veterans Affairs (VA) may help pay for the costs of LTSS services under some circumstances for qualifying conditions when individuals meet eligibility. Families are often stunned that Medicare does not pay for most LTSS. Many families deplete their financial resources paying for LTSS.

Home-Based Services

North Carolinians are increasingly expected to turn to relatives, friends, neighbors and our faith communities to provide unpaid help at home for aging relatives. Such caregivers are referred to as **unpaid caregivers**. While frequently called “informal caregivers,” many feel that is a disrespectful term, implying that families are not as involved as they really

are, so we prefer the term “unpaid.” Unpaid caregivers provide most home-based services.

If you are an unpaid caregiver, keep your list of support network names and phone numbers handy for an emergency, and always have chores in mind when a family member or friend says, “let me know if I can do anything to help.”

When family or friends are not available, are burned out or are not capable of providing the needed care at home, families may hire help independently or through a licensed agency for in-home care. There are pros and cons to each choice. Families frequently cite lower costs as a reason they prefer to hire caregivers privately.

Home-based care falls in two categories: **non-medical home care** and **medical home care**. Non-medical care includes **companion and homemaker** services and **personal care** services. Such services are available anywhere from a few hours a week to 24 hours a day. Companion care varies and there is no one-size-fits-all service. It may include simply keeping someone company, engaging them in games or crafts, going on walks or outings, giving medication reminders and doing meal preparation. Homemaker services involve light housekeeping, laundry, grocery shopping and errands and transportation assistance. Companion and homemaker services do not involve any “hands on” care. Personal care is very much “hands on” and connected to ADLs, such as assistance with eating, bathing, dressing, toileting (including incontinence care) walking and transferring.

Home health care, also called medical home care or skilled home care, includes nursing services, rehabilitation services and/or social work services. Rehabilitative services refer to physical therapy (PT), occupational therapy (OT) and speech language pathology (SLP). Home health care requires a physician's orders, and the number and length of visits are limited.

Medicare does not pay for non-medical home care, but Medicaid may. Both Medicare and Medicaid will cover home health care for homebound individuals

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¹NIH Senior Health <http://nihseniorhealth.gov/longtermcare/whatislongtermcare/01.html>

²Oberlink, Mia. “Community Innovations for Aging in Place (CIAIP) Final Report.” CIAIP. Administration on Aging, Apr. 2014

THE ABCs *(continued from page 8)*

when ordered by a physician, provided by a qualifying agency and when the care recipient meets certain eligibility criteria. Medicaid CAP/Choice does permit a family member to be a paid caregiver, but eligibility is limited and waiting lists are long.

Community-Based Services

Adult day programs provide supervision, structured social activities, nutrition and sometimes health care in a community group setting for people who cannot stay home alone but do not necessarily require residential care. These programs also provide respite (a break) for family caregivers. In North Carolina we have three types of adult day programs certified by the state: **adult day care** (the “social” model), **adult day health** (“health” model) or programs can be certified as both (“combination” social/health model). The main difference is that the health model and the combination model are required to have a nurse on staff.

PACE (Program of All-Inclusive Care for the Elderly), allows people 55 and older who qualify for nursing home care and meet certain other criteria, to remain at home by providing one-stop health care and a variety of other services. PACE has sometimes been described as “a nursing home without walls.” North Carolina currently has 11 PACE sites serving over 700 people, with another one scheduled to open in Asheville this year.

Medicare does not cover adult day programs. Medicaid pays for adult day programs under certain circumstances. (Most PACE Participants are eligible for both Medicare and Medicaid – often referred to as “dual eligibles.”)

Facility-Based Services

Assisted living refers to group residences for older (or disabled) adults who require some supervision and help with personal care needs, but who do not need ongoing skilled nursing care. Assisted living facilities (ALF) can house as few as 2 residents or as many as 100 or more. Formerly termed “domiciliary homes” or sometimes called “rest homes,” in North Carolina the larger facilities are now officially named **adult care homes** and the smaller ones, licensed for two to six residents, are **family care homes**. ALFs provide 24-hour supervision and personal care assistance with activities such as bathing, hygiene, grooming, dressing and toileting, and trained staff dispense medication.

Residents live in private or semi-private rooms, and may share bathrooms. Meals are usually shared in large dining rooms in adult care facilities and around a small dining room table in family care homes. Other services include personal housekeeping and laundry, social activities, exercise programs, worship services and transportation. Specific amenities, staff and policies vary among communities; some ALFs have on-site beauty salons, some have full-time activities coordinators and some facilities allow pets. Family care homes are generally in traditional houses in residential neighborhoods, providing a less institutional setting some families prefer.

Special care units (SCU), also known as Alzheimer’s units, dementia units or memory care communities are designed for residents with Alzheimer’s disease or other related memory disorders. In North Carolina, SCUs can be free standing, or a distinct floor, unit or wing within an ALF, skilled nursing home or continuing care community. SCUs require higher staff-to-resident ratios and are often secured with keypad entry and exit. Residents with dementia may or may not have an opportunity to be integrated with those without dementia. Like ALFs, the state regulates SCUs, but features and services vary. Most SCUs have secured outdoor courtyards, some offer music therapy, brain stimulating games, and many have specially designed architectural features.

Medicare does not cover ALF. North Carolina’s State-County Special Assistance (SA) program helps financially eligible individuals pay for adult care (including SCU) and family care homes, but facilities may not accept public assistance or allocate few beds for SA.

Skilled nursing facilities (SNF), also called nursing homes, provide round-the-clock nursing care, and high levels of medical and personal care. Residents are either chronically ill or needing short-term rehabilitation after a hospitalization. Some SNFs have SCUs.

Medicare may pay for up to 100 days of care in a SNF if admission follows a qualifying hospital stay and there is a documented need for skilled care. More commonly, Medicare only covers a very short stay for rehabilitation. Many SNFs accept Medicaid for ongoing care, but financial eligibility must be proven, and finding an available Medicaid bed in North Carolina can be challenging.

THE ABCs *(continued from page 9)*

Continuing Care Retirement Communities (CCRC) provide a continuum of care, usually including independent living, assisted living and skilled nursing care within one community. CCRCs typically require substantial entrance fees, charge high monthly fees and operate under contracts to care for people for life. (Contracts may be reviewed by an attorney.) As a rule, residents must enter while they are healthy and active and can live independently. CCRC housing options usually include apartments, town houses and cottages, as well as an ALF and SNF. The grounds will have one or more dining rooms/restaurants, a fitness center and activity areas. Other amenities often found at CCRCs are libraries, primary care clinics, walking trails, dog parks and guest accommodations.

Neither Medicare nor Medicaid pays for living in a

CCRC, but some have Medicare-certified SNFs.

This article does not include every form of LTSS, but focuses on the more common types of LTSS to which families caring for someone with Alzheimer's or another memory disorder most frequently turn. One of the best ways to learn more about LTSS options in your community is through word of mouth. Ask friends, neighbors or health care providers for recommendations. Or attend a caregiver support group for the double bonus of first-hand consumer information AND support from others facing similar challenges.

Still confused about LTSS for someone with dementia? Check out the resources on the next page, call the Duke Family Support Program at 919-660-7510 or look at our website www.dukefamilysupport.org.

TO LEARN MORE ABOUT LTSS

Adult Day Care and Adult Day Health Programs - A county-by-county list of certified adult day programs in North Carolina. <http://www.ncdhhs.gov/aging/adcadh.pdf>

Assisted Living Comparison Experts - A directory of all assisted living residences in North Carolina compiled by a non-profit, UNC-based group. <http://alce.unc.edu>

Continuing Care Retirement Communities 2014 Reference Guide - A consumer guide to NC CCRCs assembled by the NC Department of Insurance. http://www.ncdoi.com/SE/Documents/CCRC/CCRC_Guide_2014.pdf

Duke Family Support Program - No-charge consultations for family or professional caregivers of individuals with dementia for evaluating long-term care options, referral to community resources and connecting families to Alzheimer's support groups. www.dukefamilysupport.org

Eldercare Locator - A service of the Administration on Aging, part of the U.S. Department of Health and Human Services, that connects older Americans and their caregivers with information on senior services. www.eldercare.gov

Family Caregiver Alliance (FCA) - FCA focuses on caregiver services, policy and research, and their website offers valuable information about LTSS options and planning. <https://caregiver.org>

Friends of Residents in Long-Term Care (FORTLC) - FORLTC is a nonprofit organization providing advocacy and education on the entire continuum of long-term care issues in North Carolina. <http://www.forltc.org>

Genworth 2015 Cost of Care Survey North Carolina - State-specific data on in-home and facility-based long-term care services. https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/cost-of-care/118928NC_040115_gnw.pdf

Home Health Compare - A government website with details about skilled nursing care, physical therapy, occupational therapy, speech therapy, medical social services and home health aide services. <http://www.medicare.gov/homehealthcompare/search.html>

Meals on Wheels America - Meals on Wheels bring a nutritious meal, a friendly visitor and a safety check to homebound seniors. Find the Meals on Wheels program closest to you or a family member. <http://www.mealsonwheelsamerica.org/signup/find-programs>

Medicare.gov - Go to this official government website to learn about how and when Medicare covers long-term care costs. <http://www.medicare.gov/coverage/long-term-care.html>

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National Consumer Voice for Quality Long-Term Care - The Consumer Voice represents consumers at the national level for quality long-term care, services and supports. The Consumer Voice website offers families knowledge and tools to advocate for quality care for themselves and their relatives. <http://theconsumervoic.org>

NC Division of Aging and Adult Services (DAAS) - DAAS works to promote independence and enhance the dignity of North Carolina's older adults, persons with disabilities and their families. <http://www.ncdhhs.gov/aging/>

NC Division of Health Service Regulation (DHSR) - Listings of NC licensed facilities by the type of service they provide their clients. These listings may be updated at different times. <http://www.ncdhhs.gov/dhsr/reports.htm>

NC Long-Term Care Ombudsman Program - Ombudsmen advocate for nursing home and adult care residents and investigate complaints. <http://www.ncdhhs.gov/aging/ombud.htm>

NC PACE Association - Program of All-Inclusive Care for the Elderly is for nursing-home eligible seniors. <http://ncpace.org>

Nursing Home Compare - A government website with information about Medicare and Medicaid-certified nursing homes. <http://www.medicare.gov/nursinghomecompare/search.html>

Resources for Seniors - Resources for Seniors serves senior and disabled adults in Wake County, by providing home- and community-based services and information. See their "Long-Term Care Facility Checklist." <http://www.resourcesforseniors.com/pdf/lcchecklist.pdf>

Your Guide to Choosing a Nursing Home or Other Long Term Care - How to find and compare nursing homes and other long-term care options, how to pay for nursing home care, your rights as a nursing home resident and alternatives to nursing home care. <http://www.medicare.gov/Pubs/pdf/02174.pdf>

How Much Will You Pay in NC?

Service	Minimum	Median	Maximum
Homemaker Services <i>"Hands-off" care such as cooking, cleaning.</i> (Hourly)	\$9	\$18	\$25
Home Health Aide Services <i>Personal care, not medical care (such as PT, OT or speech).</i> (Hourly)	\$9	\$18	\$25
Adult Day Health Care (Daily)	\$21	\$51	\$125
Assisted Living Facilities (Monthly/One Bedroom - Single Occupancy)	\$1,000	\$3,000	\$7,143
Nursing Home (Daily/Semi-Private Room)	\$102	\$206	\$316
Nursing Home (Daily/Private Room)	\$108	\$225	\$630

The above information is from the Genworth 2015 "Cost of Care Survey NC"

https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/cost-of-care/118928NC_040115_gnw.pdf

CCRCs – A Different Kind of Math

According to the NC Department of Insurance "Continuing Care Retirement Communities 2014 Reference Guide," Entrance fees for North Carolina CCRCs range from a few thousand dollars to over one million dollars. However, a typical entrance fee would range anywhere from \$60,000 to \$325,000. Entrance fee refund plans vary. Monthly fees listed in the Guide range from \$664 - \$5,104 and actual fees may be different. http://www.ncdoi.com/SE/Documents/CCRC/CCRC_Guide_2014.pdf

PEOPLE LIKE ME

New Duke Nasher Museum of Art Partnership Gives Tours to Families Facing Early-Stage Alzheimer's

By April Dudash

Couples crowded around a silver painting and stared at floating ovals and faint, stitch-like lines.

The name of the painting at the Nasher Museum of Art hadn't been revealed yet to the afternoon group, leaving the artwork up to interpretation. The piece looks like a little pond filled with water plants, someone mused aloud. Or an embroidered, cheerful silverscape, added another.

"We do have some real question marks," said Jessica Ruhle, the Nasher's associate curator of education and the tour leader that day. "It's a real narrative, and we can piece together our own stories for it."

In the group gazing upon "Cloud Garden" by Pinaree Sanpitak were care partners and their family members diagnosed with early-stage Alzheimer's disease. Every month, familiar and new faces gather together for lunch in the Nasher Museum Café and a guided tour of the exhibits. The program, known as "Reflections: The Nasher Museum Alzheimer's Project," has tour participants study the sculptures and paintings and share their personal interpretations of the pieces.

This Nasher tour started in 2014 when the museum partnered with the Duke Family Support Program, which provides information, care tips and support groups for families facing Alzheimer's and other memory disorders. The Museum of Modern Art in New York has organized a similar tour program since 2007 for people with dementia, and the Nasher wanted to create its own version.

"The tour involves just such a wonderful group of people and relationships," said Bobbi Matchar, a clinical social worker with the Duke Family Support Program. "It feels like family in a way."

The men and women participating in these Nasher

tours are navigating memory loss and sometimes may take longer to search for the right words when speaking. They may be experiencing a loss of independence from Alzheimer's, such as having to give up driving. Currently, the tours are only open to participants in support groups (see sidebar), but as part of "Reflections," plans

are underway to expand tours and offer them to people with mid- and late-stage Alzheimer's disease beginning this summer.

Every time there's a tour, which is scheduled once a month, there's a standout moment, organizers say. Every visit incorporates live music or a hands-on art activity, and one time, a participant began playing drums with a visiting Spanish guitarist.

For Gail Sloane, this Nasher experience provides her husband, Bill, with the chance to be around "people like me." Bill was diagnosed in Burlington about three years ago with dementia.

"It's just one of the highlights of my husband's month," Gail said. "He asks just about every day, 'Are we going to the Nasher today?' When he goes there, he feels very comfortable talking to the other people with a very similar diagnosis."

The tour group has visited the Nasher's recent Miró and Rauschenberg exhibitions. The Archibald Motley jazz age exhibition brought back memories for tour participants of big heels, big bands and smoking indoors. In the museum, the tour group has listened to guitarists and vocalists and created their own art.

But more than that, families find a group of friends, where they can talk about alternative housing or medication options, where a misplaced word in a sentence doesn't faze anyone. The tours bring together people going through the same problems, the Sloanes said.

"When you get finished with it, it's like you're



Gail and Bill Sloane during a recent tour at the Nasher Museum of Art

continued on page 13

PEOPLE *(continued from page 12)*

renewed and regenerated,” Bill said. “With this Alzheimer’s thing, you could really get down, but what happens with our group is we know that all of us know that we’re having problems, but we’re supporting each other.”

April Dudash is a writer for “Working@ Duke”. This article originally appeared in “Duke TODAY” under a different title.

See Sidebar to the right.

Here’s a link to a recent video clip from WNCN news in Raleigh about “Reflections:” <http://www.wncn.com/story/28756206/nasher-museum-helps-alzheimers-patients-caregivers-live-in-the-moment>



Liz Priestly of Chapel Hill, NC, took veiled photographs of her mother during her late mother’s journey with Alzheimer’s. Her “Alzheimer’s Series” was displayed at the Horace Williams House in Chapel Hill 15 years ago. Liz and her mother presented some of the photographs and spoke together on a panel at a Bryan Alzheimer’s Disease Research Conference at Duke many years ago. This mother and daughter created their own early public awareness effort to describe and de-stigmatize the veiled experience of living with Alzheimer’s. Joseph Bathanti, NC poet laureate from 2012-2014, wrote a poem titled “Madonna” about the Alzheimer’s Series which he read at a display of “The Alzheimer’s Series” in Winston Salem, NC. We appreciate Liz for sharing this photograph and updated story with us.

JOIN A SUPPORT GROUP

If you or a loved one is navigating the symptoms of dementia, contact the Duke Family Support Program for resources and information about upcoming support groups. Visit the website www.dukefamilysupport.org or call (919) 660-7510.

The 8-week “Early-Stage Alzheimer’s Education and Support Group” (ESG) is offered twice a year and provides educational, emotional and social support for people with early-stage Alzheimer’s and their family care partners.

The Nasher Museum of Art “Reflections” tours are only open to ESG graduates and participants of the Cary and Ruth Henderson Bryan ADRC Patient/Caregiver Support Group. The guided tours include visits to the current Nasher exhibits followed by a hands-on art activity or live music. Contact the Duke Family Support Program for more information.

AFFIRMATION

By Peggy Cohn

When I sit with a group of incredible friends
Who share their extraordinary pain without ends,
I find the blessed grace of forgiveness
Among people who know oh so well how life mends.

All the worries and wishes and anger and pain
That a life of care giving has in its domains
All the sorrow and hopefulness filling each day
Where our hearts hide their weariness and sing mem’ries praise,
We laugh, we remember, we share and we weep.
We let ourselves tell all the secrets so deep.
We have dirty little secrets of fear and lost bowels,
We fear all together the last steps not avowed.

But time after time as we visit and talk
We know that we are not alone on this walk.
Someone else knows our heart ache our desperate rage
Someone else has read with us through every hard page.

We treasure the affirmation of such friends
We know their understanding doesn’t have ends
The positive flow of good humor and caring
Makes our lives so much better
The pain worth the bearing.

Peggy Cohn is a retired private geriatric care manager who lives in Chapel Hill. Dr. Cohn cared for her husband Sid, who had dementia for many years, and wrote this poem while attending a caregiver support group.

HERE IF YOU NEED ME

By Carol Henderson

I had lunch the other day with a friend (I'll call her Jane; she's a private person). Now in her upper 70s, Jane lived in my neighborhood when we arrived in 1989. A few years ago she moved to a retirement community across town.

We have enjoyed each other's company since the day my family moved in. Jane spotted my two young daughters chasing each other out in our front yard, barefoot and tousle-haired, wearing their blue sleeveless nighties in the middle of the afternoon.

"I thought I was seeing fairies," she still says. She also said that day: "I tend to keep to myself. I won't bother you. But I'm always here if you need me."

Jane and I became soul friends. I often dropped by her place for afternoon tea and a chat on her screened porch. Her quiet house was a balm after the chaos at mine. The mother of a grown daughter, she was an independent, professional woman who relished living alone. Before I knew her, the solitary life scared me.

We shared favorite books, gardens, and art, and took care of each other's houses and pets when one of us was away. We get together for holiday meals – no frills, the focus is on friendship not the food. Hers was always the emergency number my children memorized, the contact person outside the family listed on all their forms, even in college, and beyond.

So when she asked me recently if I would share the duties of being her Health Care Power of Attorney with her daughter (who lives out of state), I said, "Of course." It made perfect sense: Jane stood by me during the decline and deaths of both of my parents. I was the reference she put down for her frail, aging mother when we moved her to a nursing home. We have never shied away from difficult subjects: illness, financial fears, our spiritual yearnings, or the death of my infant son, and her first husband.

Jane's independence is anchored in simple realism. She has little patience for those who can't face facts.

At a book reading she and I attended last winter, an older friend complained to us about her retirement

community: the early meals, being surrounded by old people, the feeling that she was living in some sort of prison.

"She's rebelling," Jane said later. "Waste of time. She hasn't accepted the phase of life she has entered."

I admire the grace and candor with which Jane has chosen to age. She expresses again and again her gratitude at being able to live in a facility that offers care and yet, for now, leaves her alone.

Jane's daughter, in town for a visit, was also at lunch the other day. The three of us discussed various health-care scenarios and how we would respond. We talked about the recent disappearance of a man from his retirement community; the police found him three days later in the nearby woods.

"We should all wear identity chips that track us, 24/7," Jane said. "When somebody comes up with one, I'll be the first to sign up."

Jane's Health Care Power of Attorney makes this and other preferences clear and official.

Over a shared dessert, Jane said, "You'll know when I shouldn't have any more food and water, even if I'm out of it and don't."

Her daughter and I nodded.

"You'll work well together," she said and smiled.

After lunch, I asked what they were doing for the afternoon. Both women shrugged. "We'll just hold hands and see where the day takes us," her daughter said.

"It's wonderful," Jane added. "We never make plans when we're together."

But plenty of plans are in place, just in case.

Carol Henderson is a Chapel Hill-based author and teacher who offers writing workshops all over the country. She is currently working with Heartland Hospice to train staff to integrate restorative writing into the hospice environment; and she also offers restorative writing workshops for caregivers. Visit her website: www.carolhenderson.com

SIXTH SENSE CARING: STORIES OF CREATIVE ELDERCARE

By Maggi Ann Grace with Vicki Johnson

There are all kinds of statistics about the “average” caregivers – their age and gender, and the number of hours a week they give to their caregiving role. I would bet that few of them would describe themselves as creative. But the more challenging a situation, the more creative caregivers can and do become. The creativity of a caregiver is often the key to making difficult circumstances not only bearable, but also more meaningful and pleasurable, to their loved ones who are coping with fear and loss of function.

And the caregiver’s role is constantly changing, especially with the progression of diseases such as Alzheimer’s and other dementias. What works today will not necessarily work tomorrow. Often the best solutions are rooted in the five senses: Sight, Sound, Smell, Taste and Touch.

Caregivers also have a keen sixth sense: the intuition required to imagine just the right thing that might help at just the right moment.

Whoever thought of taking a squishy ball to a doctor’s visit to cut through the anxiety and repetitive questions while you wait? I never knew what comfort can be found by dumping a load of warm clean clothes on the sofa or table and asking for help folding them. How much extra effort does it take to turn on a favorite song on a CD while you are eating or feeding someone? If you’re watching Lawrence Welk, you could even participate by accompanying the music with a homemade percussion instrument. One server in my parents’ dining room used to stand near my mother with his basket of fresh hot yeast rolls, just to let her smell them (even though she was trying to resist eating them). We have sought out musical performances (even jam sessions) so my father could hear certain musical instruments, since we learned of his favorites. Who knew he enjoyed the sound of a pan flute?

With the eye of designer Vicki Johnson, I have

begun the dialogue with caregivers everywhere. This first collection of ideas is an organic one. It is focused on creative ways to provide stimulating activities, ways to make difficult chores easier and safer, and simple ideas to make day-to-day living at home as vibrant and pleasant as possible when efficiency can no longer

play a major role. We begin offering activities that stem from Sight, Sound, Taste, Smell and Touch. We have also included sections on Sensory Outings, Activities of Daily Living (“ADLs” in the Assisted Living world) and tips on Long Distance Caregiving and Traveling. My hope is that this book, with ideas that I have gleaned and tried from so many sources, will serve as a springboard for others to offer their own creative caregiving ideas ... and the book will grow. As a caregiver, you ARE creative. You do

have something to offer other caregivers who might be facing a similar situation. Together we will strive to preserve the dignity of those on all sides of a caregiving relationship, while we celebrate the value of caregivers everywhere.

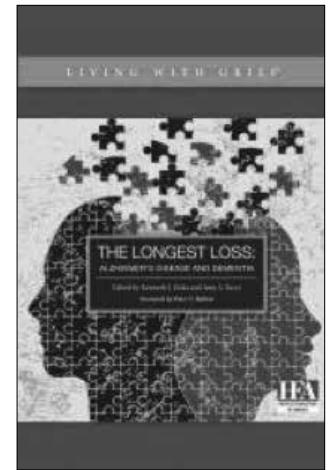
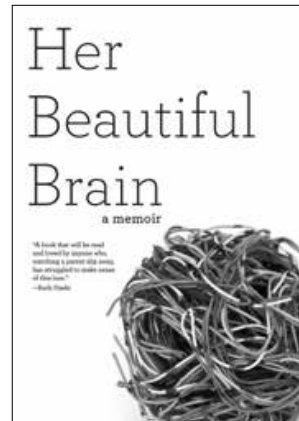
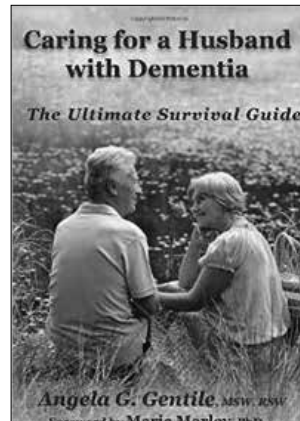
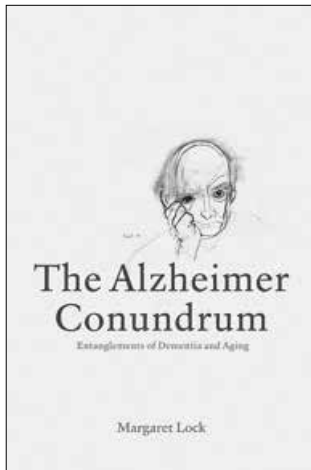
Maggi Grace lives in Durham where she cares for her parents, who stepped in as models for many of the photographs in this book. To learn more about the book or to order, visit www.sixthsensecaring.com



Two Helpful Tips from “Sixth Sense Caring”

I took snapshots of my mother’s doctors, to be able to better prepare her for her next appointment. It is understandably difficult to remember a specialist just by name, so I keep a photo album of her care providers.

A physical therapist suggested elastic shoelaces that convert regular athletic shoes into slip-ons. They don’t reduce support at all, but they do minimize the need to bend over to tie shoes, which often leads to falls.



BOOKSHELF

Activities to Do with Your Parent Who Has Alzheimer's Dementia, by Judy Levy, 2014. Levy provides a selection of activities that caregivers can do with a parent with Alzheimer's disease. The activities encourage success, self-worth, and consistency and help the parent to maintain self-care skills.

The Alzheimer's Conundrum: Entanglements of Dementia and Aging, by Margaret Lock, 2013. The history of Alzheimer's disease in the context of current efforts to slow down the disease through early detection of biological changes in healthy older individuals.

Buried Seed, by Martha O. Adams, 2015. A book of vivid and inspiring poems that invite the reader to see the world through a new perspective, delve into the depths of human emotions, and find the strength to bloom.

Caring for a Husband with Dementia: The Ultimate Survival Guide, by Angela Gentile, 2015. A survival guide and workbook for caregiving wives. This resource provides tips and advice to help caregivers prevent stress and burnout as well as to navigate challenges throughout the entire caregiving journey, starting from early diagnosis to bereavement and beyond.

Contented Dementia: 24-Hour Wraparound Care for Lifelong Well-Being, by Oliver James, 2009. Oliver James of the U.K. provides practical methods and guidance for families and professionals in managing dementia by creating links between past memories and emotions with daily routines of life in the present.

A Guide to Coping with Alzheimer's Disease, by Harvard Health Publications with John H. Growdon, M.D., 2015. This report provides in-depth information about diagnosing and treating Alzheimer's. It contains helpful tips for both caregivers and individuals with Alzheimer's in coping with daily challenges, managing financial and legal documents and exploring long-term care options. Visit <http://www.health.harvard.edu/special-health-reports> for more information.

Her Beautiful Brain: A Memoir, by Ann Hedreen, 2014. A daughter becomes a mom just as her brainy mother develops younger-onset Alzheimer's disease. Ann Hedreen's memoir tells the story of her journey navigating the changes brought about by her mother's younger-onset Alzheimer's disease.

The Longest Loss: Alzheimer's Disease and Dementia, from the Hospice Foundation of America, 2015. This book addresses the grief experienced by people living with Alzheimer's, their families, and health providers by exploring how individuals with dementia respond to the loss of their own cognition and changes in other aspects of their lives. Available at <http://hospicefoundation.org>.

Online Help



AGING

http://www.iom.edu/~media/Files/Report%20Files/2015/Cognitive_aging/Action%20Guide%20for%20Individuals%20and%20Families_V3.pdf “Cognitive Aging: An Action Guide for Individuals and Families,” explains what to do to protect your cognitive health as you age. This four-page guide also describes what cognitive aging is and how it differs from Alzheimer’s disease. Part of a groundbreaking Institute of Medicine 2015 report on cognitive aging written by a committee chaired by Duke’s Professor of Psychiatry Dan Blazer and committee member Lisa P. Gwyther, director of the Duke Family Support Program.

http://www.nia.nih.gov/health/publication/online-health-information?utm_source=20150323_onlinehealth&utm_medium=email&utm_campaign=ealert The National Institute on Aging provides information about how to find trustworthy and reliable health information online. An AgePage brochure version of the information is also available in PDF format.

http://www.silvercentury.org/polBlogs.cfm?doctype_code=Blog The Silver Century Foundation blog posts provide stories and discussion about issues involved in aging.

<https://www.youtube.com/user/NatlInstituteOnAging> The National Institute on Aging’s YouTube channel offers free videos about Alzheimer’s Disease research, healthy aging, exercise and other aging-related topics.

ALZHEIMER’S DISEASE AND RELATED DISORDERS

http://www.nia.nih.gov/alzheimers/early-onset-alzheimers-disease-resource-list?utm_source=20150302_earlyonset&utm_medium=email&utm_campaign=ealert The National Institute on Aging provides an expanded online resource list for individuals and families with questions about younger- or early-onset dementias.

<http://makingsenseofalzheimers.org> Making Sense of Alzheimer’s is an online gallery of creative works that tackle the challenge of understanding Alzheimer’s Disease and its role in people’s lives. This website includes videos, stories and ideas from a wide variety of individuals, including people living with Alzheimer’s, doctors, caregivers, and artists.

CAREGIVING

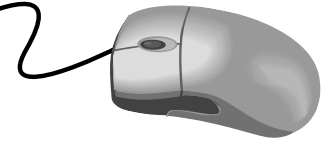
<http://memorycare.org/outreach-caregiver-education> Caregiver Network News is an eNewsletter for caregivers provided by Western NC’s MemoryCare. The newsletter includes information about upcoming caregiver events as well as support and education groups provided by MemoryCare and in the community. To subscribe, sign up with your email address online. Previous eNewsletters can also be found in the archives on the MemoryCare website.

<https://nccih.nih.gov/health/herbs/understanding-interactions?nav=upd> Many individuals may be at risk from simultaneously taking dietary supplements and medications. The NIH offers this helpful and interactive online tool that provides information about interactions between supplements and prescription or over-the-counter drugs.

<http://www.knowyourotcs.org> A helpful website that provides information and warnings about using, storing, and disposing of over-the-counter medicines for a variety of symptoms.

<http://www.memorycareplays.org> The MemoryCare Plays are a collection of plays that aim to entertain, educate, and bring awareness to issues of cognitive impairment and its impact through dramatic dialogues between people living with Alzheimer’s disease and their families.

Online Help *(continued from page 17)*



LEAVING THE HOSPITAL

http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf Care for the Family Caregiver is a booklet that provides an overview about the basics of and the issues involved in caregiving. It includes examples of caregiving stories, tips and information about other caregiver resources.

<http://www.medicare.gov/Pubs/pdf/11376.pdf> The Discharge Planning Checklist for individuals living with Alzheimer's and their caregivers provides a guiding list of important information to remember as they prepare to leave a care setting such as a hospital or nursing home. A list of resources and related agencies is included at the end of the checklist.

PLANNING, INSURANCE & LONG-TERM CARE

<http://www.lambdalegal.org/publications/take-the-power> A life and financial toolkit for long-term care planning for the LGBT community. Lambda Legal's Take the Power includes tools for protecting individuals, their families, wishes and assets. Available for free in hard copy (order online) or as a PDF.

http://www.aarp.org/ppi/issues/livable-communities/?cmp=RDRCT-livpol_JAN21_015/ Livable communities are safe and accessible environments that improve the quality of life for older adults. The AARP provides information about livable communities, including tools to assess housing, transportation, and access, among other livability topics.

TECHNOLOGY

<https://letstalkaboutdementia.wordpress.com/2014/11/13/living-it-up-creatively/> A blog post from Let's Talk About Dementia about the "Living It Up Creatively" digital project. The project aims to establish links between rural and urban sites to share therapeutic activities and experiences routinely as well as to connect professionals with people via digital technology.

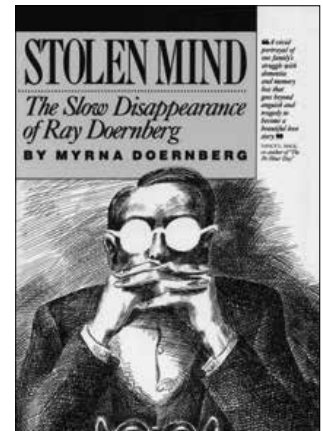
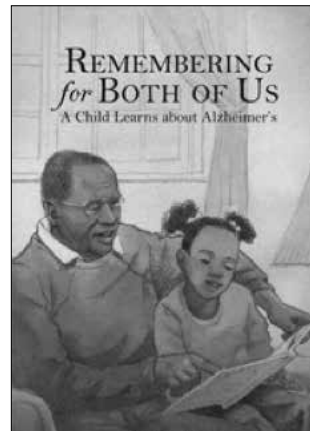
BOOKSHELF *(continued from page 16)*

Remembering for Both of Us, by Charlotte Wood, 2014. A touching story about a child's first glimpse at Alzheimer's disease. This illustrated children's book provides a reminder that love transcends age and illness.

Resource Workbook, Conversation Guide and Visual Toolkit, by Viki Kind, 2014. A workbook containing step-by-step guides and tools for caregivers dealing with issues such as denial and guilt. The resources offered include visual tools, articles, and conversation guides. Visit <http://www.kindethics.com>.

Stolen Mind: The Slow Disappearance of Ray Doernberg, by Myrna Doernberg, 1989. Myrna Doernberg became one of the Duke Family Support Program's earliest clients when, in 1982, her 46-year-old husband was diagnosed with Binswanger's Disease, a rare progressive dementia that mimics Alzheimer's.

Lisa Gwyther, director of the Duke Family Support Program wrote the Forward. Doernberg's memoir still holds true in her depiction of a caregiver's pain watching worsening dementia.



Bookshelf and Online Help were written by Lily Huang. Lily is a rising senior at Duke University and has been working in the Duke Family Support Program for two years.

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