

# The CAREGIVER

*A Bridge to Understanding  
Your Options*

Newsletter of the Duke Family Support Program

Volume 36, Issue 1

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## Understanding Frontotemporal Degeneration (FTD)

**F**TD causes progressive, irreversible changes to a person's personality, behavior, language and movement. Today, there is no cure.

FTD is distinct from other forms of dementia in two important ways:

1. *The hallmark of FTD is a gradual, progressive decline in behavior and/or language (with memory usually relatively preserved).*
2. *Onset of FTD often occurs in a person's 50s and 60s. Roughly 60% of cases occur in people 45-64 years old.*

Learn more at the AFTD website.

<https://www.theaftd.org/understandingftd/ftd-overview>

### When the Diagnosis Doesn't Fit: Challenges in Diagnosing FTD

*Dementia is often missed as a possible diagnosis for a younger person presenting with changes in mood or behavior. Early symptoms of frontotemporal degeneration (FTD) may overlap with conditions such as depression, Parkinson's disease or bipolar disorder and lead to an incorrect diagnosis. A person developing FTD may not be aware of their changing behavior and therefore may communicate ineffectively with doctors. The individual may continue with unhelpful treatments—or, alternatively, fail to follow up with doctors entirely—until a crisis in employment, in family life or in the community prompts further evaluation.*

Read more at Partners in FTD Care Summer 2017 newsletter.

[https://www.theaftd.org/wp-content/uploads/2017/08/PinFTDcare\\_Newsletter\\_Summer\\_2017.pdf](https://www.theaftd.org/wp-content/uploads/2017/08/PinFTDcare_Newsletter_Summer_2017.pdf)

### One Couple's Journey with FTD

Via this video clip, meet VJ and Chuck, college sweethearts who have journeyed through 40 years of life's ups and downs. Here they face VJ's eight-year journey with frontotemporal degeneration (FTD). Listen to VJ as you catch glimpses of their responses.

<https://www.youtube.com/watch?v=HZKj29faHwo>



*Dad no longer knows the word for "car."  
He's started to fall for no reason.  
When Mom died he had no reaction.*

THINK IT'S ALZHEIMER'S? THINK AGAIN.

Not all dementia is Alzheimer's. For people under 60, the most common form is actually FTD. If you or someone you know experience unexpected changes in behavior, language or movement, it could be FTD. Find out more about this disease and AFTD's work to address it here: [www.theaftd.org/learnmore#thinkFTD](http://www.theaftd.org/learnmore#thinkFTD)



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Go to [www.dukefamilysupport.org](http://www.dukefamilysupport.org)  
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225 North Michigan Avenue, Suite 1700  
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[www.alz.org](http://www.alz.org)

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**The Association for Frontotemporal Degeneration (AFTD)**

Main Office (Radnor, PA): 267-514-7221  
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<http://www.theaftd.org/>

Email: [info@theaftd.org](mailto:info@theaftd.org)

**Lewy Body Dementia Association**

LBD Caregiver Link: 800-539-9767  
 National Office (Atlanta, GA): 404-935-6444

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

**Family Caregiver Alliance, National Center on Caregiving**

Office (San Francisco, CA): 800-445-8106

<https://caregiver.org/>

## NO WRONG DOOR AND UNITED WAY OF NORTH CAROLINA TO PROVIDE ENHANCED SERVICES TO SENIORS

The NC Department of Health and Human Services, Division of Aging and Adult Services (DAAS) has partnered with United Way of North Carolina to make it easier for individuals, families, and caregivers of aging adults and/or people with disabilities to learn about and access the help they need to remain in their homes and communities. Through the *No Wrong Door* (NWD) initiative, United Way's NC 2-1-1 has been established as a "virtual front door" to long-term services and supports (LTSS); providing awareness, education and assistance with connection to services. Individuals and families call 2-1-1 to speak with a trained call specialist who accesses a robust database of LTSS resources. Now in its second contract year, the No Wrong Door partnership has expanded to include a focus on meeting the needs of families facing Alzheimer's and dementia and the complex challenges associated with those diseases.

North Carolinians trying to access LTSS frequently find themselves confronted with a maze of agencies, organizations and programmatic requirements; and the number of specialized services for long-term support is increasing. NWD planners, in conjunction with stakeholders across the state, have identified an urgent need to establish a centralized point of entry and information. United Way's NC 2-1-1 has been identified as the most appropriate partner.

NC 2-1-1 currently provides 24/7/365 service to NC residents seeking information on a wide array of health and human service needs. NC 2-1-1 is an easy-to-remember three-digit, toll-free call line; with a user friendly website, a call center answered by trained professionals, and a resource data base with up-to-date information on community health and human services agencies, organizations and programs.

NC 2-1-1 website: <https://www.nc211.org/>

# A PATH TO MEANINGFUL DAYS

*By Natalie Leary, MSW, LCSW-A*

The object of the game is to keep the oversized balloon from touching the ground by using shortened pool noodles as the bat or sword. All are vigilant with their eyes following both the balloon and Ed, who uses all of his muscles to swing at the moving target while sporting a huge grin and a grunt. It is easy to sense the familiarity and camaraderie between the participants; one can tell this group has a certain ability to predict the moves, preferences and patterns of the others. A camaraderie only born from time spent together.

This is not a group of long-time friends who have done life together for many moons. No, this group was thrust together by stage of life and changes in their ability to be independent. What started, for some, as a place met with great resistance is now a space to gather with semi-familiar faces and do things that evoke laughter, contemplation and community.

Every season of life promotes the benefits of physical activity and continued socialization. When diagnosed with dementia both the value and the challenge of said recommendation increases. As the disease progresses, those living with the diagnosis lose initiative and care partners add to the already weighty task of ensuring safety and providing medical care, the role of activity coordinator. This is the point in the game when it can be beneficial to contemplate the introduction of an adult day program.

Senior Centers and Adult Day... Are they not the same thing? I'm glad you asked. While similar, there are important differences between the two. Senior Centers provide activities and services for those not requiring supervision and who are able to attend to their own needs. Three types of adult day exist. Some adult day programs operate on a social model, indicating they are equipped to provide activities, meals and a safe environment without nursing care. Others offer adult day health; meaning they are additionally licensed to address medical needs by an RN on staff. Some programs offer both. The difference is important to note in an effort to choose the best center for the care recipient.

Adult day programs have a daily schedule that aims to offer a balance of physical and social interaction with time for rest. Though not required to participate in activities, all are encouraged and invited. Often the day begins with a discussion of current events. Staff



read filtered news on the hot button topics in the press and initiate group conversation.

The perfect balance of routine and flexibility continues as participants navigate through exercise, trivia, shuffleboard, guests dropping by to sing or play the piano, crafts, and much more. The schedule for each day is not compiled of trivial activities that demean the experience and wisdom of the participants; it's quite the opposite. Activities reflect a balance of mentally stimulating, socially engaging and physically active ways to ensure a more meaningful day.

Prices vary based on the number of days and the required level of care. The range is anywhere from \$58-\$100 per day. Some facilities offer reduced pricing for half-day attendance while others charge the same price for whole and half-day. In addition to all the center offers in care and activity, they also provide morning and afternoon snacks and a hot lunch. Most centers accept VA benefits, Medicaid, long-term care insurance and private pay.

Most programs invite the potential participant to spend time at the center before beginning full-time. This multi-purposed visit allows the staff and participant to interact and provides the care partner the opportunity to further assess their comfort. The application process differs based on facility.

What about the care partner? How is it beneficial

*continued on page 4*



## ADULT DAY *(continued from page 3)*

to the care partner to try adult day programs? There are two primary contenders for the pros list: respite and more members on the care team.

Respite may seem like an obvious benefit; nonetheless, it is incredibly valuable. Adult day programs make it possible for care partners to continue to work, take a time-out, or practice rejuvenating activities, confident a family member is receiving quality care.

During a visit to the Ruth Sheets Adult Day Care Center in downtown Raleigh, I observed the benefits of having other members on the caregiving team. Participants were playing corn hole when a care partner arrived to pick up her spouse. The executive director excused himself from our conversation to spend time with the obviously overwhelmed care partner. Though I continued to observe the fierce corn hole competition, it was obvious the two were collaborating and exchanging information about the participant. He was able to share, in detail, the changes noticed in continence, mood, willingness to interact, appetite and energy level. Not surprisingly, there was continuity between what was happening at home and the adult day program. The process didn't stop with a simple exchange of information; together, the two brainstormed next-step options. The quality and quantity of information he shared clearly portrayed the mutual investment in the care recipient's well-being.

Matt Frazier, Director of Ruth Sheets Adult Day, sees adult day programs as one way to add additional members to the care team. While other members might include physicians, pharmacists, neighbors or other family, the staff at adult day programs see the care recipient with frequency. They monitor a myriad of things including changes in bowel and bladder, appetite and behavioral changes. It is helpful to know another set of eyes is assisting the care partner in monitoring any changes.

I would be remiss if I did not mention some

potential challenges associated with adult day programs. One obvious hurdle is resistance to starting any new program. One wife describes the experience of constantly repeated questions from her husband, "Where are you taking me?" Though he is slightly annoyed, she is able to leave him for the day. Upon return, she notices that he is smiling, pleasantly bidding everyone goodbye. "Don't ever take me there again," he proclaims once in the car. Confidently and calmly she consistently responds, "This your job and we'll be coming back tomorrow." If given the choice to stay home or go to the program, he would choose to stay home. However, his wife knows that at home he will refuse to participate in any activity. The adult day program is a greater benefit for both of them.

Difficult behavior that disrupts or potentially threatens the safety of other participants can lead to removal from an adult day program. As a group care model, staff are charged with ensuring the safety of all in attendance. It is recommended to inquire about the policy on behavioral challenges.

The decision to try an adult day program stretches beyond the obvious of providing a safe and stimulating environment. The benefits extend to the care partner. One care partner said, "I originally thought it was too simple for him, but I thought, 'Let's go!'" After approximately three successful years of Adult Day, her recommendation to others is, "Give it a try!" Over the three years, this care partner's use of adult day started at one day per week and increased to five consecutive days.

One care partner advises, "For your own peace of mind, do it! It has helped me (the care partner) as much as it has helped him (the care recipient)." Check out adult day options in your community; try it, you might like it!

*Natalie Leary is a social worker in the Duke Family Support Program.*

To find out more information about adult day programs in North Carolina visit this website:

<https://www.ncdhhs.gov/assistance/adult-services/adult-day-services>

Learn more about adult day programs by visiting the National Adult Day Services Association's website:

<https://www.nadsa.org/>

See "Deliverance" on page 9 for a daughter's essay on adult day programs.

# ALZHEIMER'S DISEASE 2017: FOCUS ON LIFESTYLE APPROACHES FROM THE AAIC MEETING

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

The Alzheimer's Association International Conference (AAIC) is the largest annual forum for presentation and discussion of the latest Alzheimer's and dementia research. The AAIC in 2017 in London convened more than 5,000 Alzheimer's disease researchers from 64 countries, and featured more than 2,200 scientific presentations. We will focus on lifestyle interventions.

A focus of the meeting was on science that will lead to the effective treatment of Alzheimer's disease and approaches to reduce its global impact. Underscored were a number of developments in interventional approaches to prevent or delay disease onset.

New research is focused on avoiding risk-laden behaviors and health conditions well before the pathology begins to accrue. The Lancet Commission on Dementia Prevention, Intervention and Care reported that more than one-third of global dementia cases may be preventable by addressing lifestyle and health factors that affect an individual's risk. The Commission reported that the following factors increase risk of dementia (1) less education in early life; (2) hearing loss, obesity and hypertension in mid-life and (3) smoking, depression, physical inactivity, social isolation, and diabetes in late life. Minimizing these factors, particularly if implemented early, can significantly reduce the odds of developing Alzheimer's disease, the most common type of dementia.

Common sleep problems, such as obstructive sleep apnea, have also drawn attention as treatable conditions that contribute to Alzheimer's disease impact. Researchers from Wheaton College in Wheaton Ill studied cognitively normal individuals and people with mild cognitive impairment using data from the Alzheimer's Disease Neuroimaging Initiative study. They found that individuals with obstructive sleep apnea were more likely to have biological markers associated with Alzheimer's disease such as increased brain amyloid deposition, decreased cerebrospinal fluid levels of amyloid (which is thought to indicate increased buildup in the brain) and increased tau protein levels. Obstructive sleep apnea occurs in an estimated 3 in 10 men and 1 in 5 women. Because it is treatable in many cases, obstructive sleep apnea may be one more modifiable risk factor to add to the list of factors that contribute to Alzheimer's disease.

Single focused lifestyle interventions included work examining healthy eating habits. Results from four large population-based studies support a connection between

good dietary practices and better cognition in old age. The idea that a healthy diet is good for the heart, body and brain is not new, but these four studies provide more robust evidence of the benefit of good nutritional practices in maintaining cognitive health. The first study from a group of U.S. scientists found that, among nearly 6,000 older adults, those who consistently followed diets long known to contribute to good heart health were also more likely to maintain strong cognitive function as they got older. Close adherence to the MIND diet and Mediterranean diet was associated with 30 to 35 percent lower risk of cognitive impairment in healthy older adults. The MIND diet includes 10 brain healthy food groups (green leafy vegetables, other vegetables, nuts, berries, beans, whole grains, seafood, poultry, olive oil and wine) and 5 unhealthy food groups (red meats, butter and stick margarine, cheese, pastries and sweets, and fried/fast food). Another study from the Karolinska Institute in Sweden found that people sticking to a Nordic Prudent Dietary Pattern (including non-root vegetables, fruit, fish, poultry and tea) had better cognitive function.

The results from all of these studies investigating modifiable risk factors for cognitive decline and Alzheimer's have led to the development of multimodal interventional studies such as the MAPT and FINGER studies in Europe which combine diet with other lifestyle approaches to maximize brain health. A new large clinical trial in the United States was announced at the AAIC meeting that will explore the benefits of lifestyle interventions on cognitive decline. The study is called "U.S. ProTect through a lifestyle INTERvention to Reduce risk" (US POINTER) and will include physical exercise, nutritional counseling and modification, cognitive and social stimulation, and improved self-management of medical conditions. Recruiting for the study will begin in 2018 at many sites throughout the U.S.

Collectively, the message from all of this new research is that while we work on therapeutics to stop the disease once it has begun, *prevention is possible and to some degree, we hold the key to our own brain health.*

Translating the findings from lifestyle trials into action will require societal efforts to support healthy lifestyle practices from early adolescence throughout the lifespan to have maximal impact on brain resiliency to disease and successful aging.

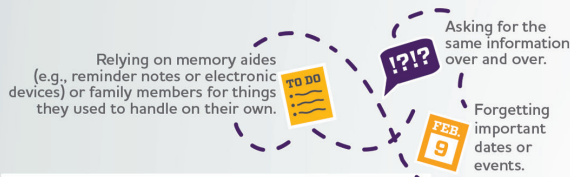
# KNOW<sup>the</sup> 10 SIGNS

EARLY DETECTION MATTERS

If you notice any of the 10 Warning Signs of Alzheimer's in yourself or someone you know, don't ignore them. Please consult your physician.

## #1 Memory changes that disrupt daily life

One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. For example:



**Typical age-related changes:** Sometimes forgetting names or appointments, but remembering them later.

## #2 Challenges in planning or solving problems

Some people may have difficulty concentrating and take much longer to do things than they did before.



Some people may experience changes in their ability to develop and follow a plan or work with numbers.

**They may have trouble following a familiar recipe or keeping track of monthly bills.**

**Typical age-related changes:** Making occasional errors when balancing a checkbook.

## #3 Difficulty completing familiar tasks

People with Alzheimer's often find it hard to complete daily tasks such as:



**Typical age-related changes:** Occasionally needing help to use the settings on a microwave or record a television show.

## #4 Confusion with time or place

People with Alzheimer's can lose track of dates, seasons and the passage of time.

They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.



**Typical age-related changes:** Getting confused about the day of the week but figuring it out later.

## #5 Trouble understanding visual images and spatial relationships



Some people may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not realize they are the person in the mirror.

**Typical age-related changes:** Vision changes related to cataracts.

## #6 New problems with words in speaking or writing

People with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name.

**Typical age-related changes:** Sometimes having trouble finding the right word.



## #7 Misplacing things and losing the ability to retrace steps

A person with Alzheimer's disease may put things in unusual places.

They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time.



**Typical age-related changes:** Misplacing things from time to time.

## #8 Decreased or poor judgment

People with Alzheimer's may demonstrate unusual changes in judgment or decision making.



For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers.

They may pay less attention to grooming or keeping themselves clean.

**Typical age-related changes:** Making a bad decision once in a while.

## #9 Withdrawal from work or social activities

A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may also avoid being social because of the changes they have experienced.

**Typical age-related changes:** Sometimes feeling weary of work, family and social obligations.



## #10 Changes in mood and personality

The mood and personalities of people with Alzheimer's can change.

They may be easily upset in places where they are out of their comfort zone.

They can become confused, suspicious, depressed, fearful or anxious.



**Typical age-related changes:** Developing very specific ways of doing things and becoming irritable when a routine is disrupted.



# 7 ESSENTIAL DO'S AND DON'TS FOR PEOPLE CARING FOR CAREGIVERS

By Lisa Lopez

My father was diagnosed with Wernicke–Korsakoff syndrome, a form of dementia resulting from chronic alcohol abuse. My dad, who worked hard his entire life, raised a family and built a strong reputation in his community, spent the last 10 years of his life succumbing to this terrible disease that befalls so many. After the official dementia diagnosis, I was appointed his guardian and my family and I made the excruciating decision to place him in an assisted living facility. This past year, I've experienced everything from anger to guilt, from optimism to despair.

Since becoming one of my dad's caregivers, the people I've leaned on the most are my friends. Somehow, my friends just get it. I don't need to tell them what questions to ask, when to ask them or when to leave me alone. In the beginning, however, my husband and some other close family members had to be reminded how to react to the very fragile and stressed side of me. I am happy to report that after a few meetings of the mind and heart, my own circle of caregivers, including husband and family, is right on track. I decided to write this article to provide some tips to the wonderful people who are caring for caregivers.

*A word of advice to those caring for caregivers: when your loved one is stressed or wants to talk about their day, just listen. Stop what you're doing and give them your full attention. You don't even have to speak. A hug every once in a while wouldn't hurt either!*

## The Do's and Don'ts

**DO LISTEN** - It may seem like a simple concept; but for some people, the idea of listening can be a hard job. Once, early on in my dad's journey, I returned home from one of the worst days of my life. The day involved a neurologist, an escape attempt by my father and a deputy sheriff. You get the picture.

When I walked into my house that evening, I was distraught and grief-stricken. My poor husband had

no idea how to react to me. When I tried to describe the day, his response was, "Well, you're home now. Don't worry about it." He then proceeded to watch TV. After a little yelling and a lot of crying on my part, we came to an understanding. A word of advice to those caring for caregivers: when your loved one is stressed or wants to talk about their day, just listen. Stop what you're doing and give them your full attention. You don't even have to speak. A hug every once in a while wouldn't hurt either!

**DON'T OFFER UNSOLICITED ADVICE** - This is another toughie for the folks who love and care about caregivers. It's hard because you hate to see your loved one in pain. Each time the caregiver in your life comes to you with another problem or unpleasant situation, you try to fix it. It's very common and well-intentioned. In my case, a few family members were very eager to give unsolicited advice.

During his first memory care unit experience, my father was involved in an altercation with another resident. As with most of these cases, there were about five sides to the story. In the end, however, it was my father who was discharged from the facility. We all believed, including me, my aunt and the ombudsman I had enlisted for help, that my father had been treated unfairly. In the one or two hours my aunt and I had to make vital decisions about my father's immediate care, I'm sure we made a few mistakes and in hindsight, probably would have done things a little differently. However, we did the best we knew how under the circumstances. But that didn't stop a few family members from telling us exactly what we had done wrong. If you're caring for a caregiver, stop before you offer advice. Remember, chances are the caregiver in your life has never had a dress rehearsal for this role. They're doing the best they can and will ask you if they need your advice.

**DO GIVE THEM THEIR SPACE** - Space, the "vital" frontier. When you're given the enormous responsibility of caring for someone else, you feel like you're in a fishbowl. Family members, doctors, bill collectors, you name it are constantly in need of something. Occasionally, I need time and space to recharge my

*continued on page 8*

## DO'S AND DON'TS *(continued from page 7)*

batteries. Whether it's a nap, time with friends, a massage or a weekend away, caregivers need to take the time to care about themselves. When the caregiver in your life says they need a break, don't hesitate – pack a suitcase, make reservations for a weekend away, or just follow their lead. Time and space away from the duties and responsibilities of caregiving is essential to avoiding burnout.

*When the caregiver in your life says they need a break, don't hesitate – pack a suitcase, make reservations for a weekend away, or just follow their lead. Time and space away from the duties and responsibilities of caregiving is essential to avoiding burnout.*

**DON'T GIVE THEM A GUILT TRIP** – I live in the South and down here, guilt is something we pass down through generations, like broaches and pound cake recipes. Before I became my dad's caregiver, my husband and I spent a lot of free time together. We don't have children, so we had the luxury of spending the weekends hiking, gardening or doing a whole lot of nothing. When my dad was diagnosed with dementia, my home life and much of my work life was sucked away. I had to spend days on end with my dad and family visiting assisted living facilities, meeting with lawyers, and talking to social workers. When I was at home, I was either on the phone talking to my dad, talking about my dad or doing paperwork. My husband quickly felt abandoned. He got in the habit of making me feel guilty about any time I spent attending to my dad's needs. I explained that this only made my highly stressful situation worse and it only made me resent him. He eventually came to understand that this was my choice and the only way for us to be a functional, happy family was for him to support me. Again, the tough parts are only temporary and it's a lot easier if you support the caregiver in your life.

**DO HAVE EMPATHY** – As Atticus Finch said in the wonderful novel, *To Kill a Mockingbird*, "You never really understand a person until you consider things from his point of view—until you climb into his skin and walk around in it." If your caregiver's family member doesn't already live with you, make a point to accompany them

to visit their loved one from time to time. This will give you a glimpse into their world and what they are going through. In my case, my dad lives two and a half hours away. It takes every ounce of energy I have to get in the car, drive to see him, spend time with him and then drive another two and a half hours back home. Doing it alone can be downright drudgery. It's nice to have my husband along so that I can vent, cry or even laugh. This has also really helped him see what I go through and why I sometimes need that two-hour nap when I get home!

**DON'T JUDGE** – No matter what your loved one's relationship is to the person they're caring for, remember, it's their choice to be the caregiver. In my case, my husband didn't understand why I wanted to take on the responsibility of becoming my father's guardian. My father and I weren't very close when I was growing up. Add this to the fact that his dementia was most likely brought on by alcoholism and my husband had a couple of handy rationales as to why I should wash my hands of the whole thing. I had to explain to my husband that the past doesn't matter and I wouldn't be able to forgive myself if I didn't do everything in my power to make the rest of my dad's life comfortable. So, no matter the circumstances, leave the judgment out of it, accept your loved one's choice and support them in any decision they make.

**DO LAUGH** – It's been said that laughter is the closest distance between two people. No truer words have been spoken, especially when it comes to caregiving. Laughter is the main thing that has gotten me through this past year. My aunt and I have a saying, "If we didn't laugh, we'd cry." Even though there have been a few times when we never thought we'd ever see another ray of sunshine, my aunt and I have somehow been able to find humor, and sometimes in the most bizarre, morbid places. When I try to explain some of the perversely funny things I've seen and heard since taking over my dad's care, some of my friends and family look at me as if I have two heads. I want to say to them, "Hey, lighten up! It's okay to laugh." So, loosen up and follow your loved ones' lead. If they're laughing, join in. It's contagious and that's a sickness everyone can afford to catch.

*Lisa Lopez is a writer and nonprofit consultant in Greensboro, NC. For eight years she has been caring for her father who lives with dementia.*



# CAREGIVERS' SUPPORT GROUP

*By Jessica Bryan*

Moving through time and space, doing what must be done.  
Filling the moments of despair with distractions.  
Reminding myself that I must engage in self-love to love another.  
I know, I know. But oh how difficult, how seemingly impossible to take the time,  
To take away from the things I must do, the care I must give.  
With effort I paint a vacant smile that masks the sorrow, the grieving, the pain.  
I go, I gather with others. I gaze at them...the strangers who have come together to share.  
They are burdened just as I am, but in their own ways.  
We are standing on shifting sands,  
Custodians of another's soul, as it exists in a failing body of fragility.  
We observe without the power to alter the course of what is to be.  
We are merely witnessing the steady progression of life.  
Just as the sandcastles built along the shore in the blazing midday sun,  
Are soon washed away by the pounding waves of the ocean,  
We are reminded of the impermanence of the body.  
But the sand...the sand that built the fortresses,  
It is still there in the vast sea that stretches across the horizon.  
It goes on and on and on, beautifully mixed with the living soup of creation.  
We sigh, and find solace in this thought, this knowledge.  
For it provides us with the will to continue.  
Strong arms comfort, enveloping each other in understanding,  
Without truly knowing.  
We speak, we cry, we confide,  
Knowing that somehow this will help ease but not remedy.  
Too much...TOO MUCH to bear alone,  
And so we find meaning, purpose, love, and will to continue,  
As we group together in support and love.

---

*Jessica Bryan is the author of I Am Not a Village, Fine Tuning My Life, and There's a Stranger in My Room (a trilogy on caregiving). She and her husband live in Chapel Hill, NC; and for several years have been caring for her 98-year-old mother with Alzheimer's in their home.*

# DELIVERANCE

By Margaret Toman

For ten of the sixteen years that I took care of my mother she attended adult daycare, an option which allowed me to work and to remain connected to the community while she enjoyed socialization, enriching activities and a healthy lunch. It was a wise choice.

Adult daycare programs function more like summer retreats for grownups than like institutions, offering diverse activities such as crafts, memory exercises, singing, bowling, cards, puzzles, board games, parties and dances and frequent visits by speakers, pets, museum animals, and entertainers. It was not unusual when I went to pick my mother up at the end of the day to walk in on a jubilant salsa party or a sock hop. My mother would be bouncing her legs in her wheelchair while other participants gyrated merrily on old bones. Interaction with staff, participants and visitors by my inherently social mother almost surely slowed the progression of her Alzheimer's disease. There is no easy passage through such an illness but the availability of adult daycare moderated stress and ensured our togetherness at home during her final years. That she was loved and cared for by many others over that time cemented the wisdom of that choice. In a perfect world, the adult daycare system would be well-funded and recognized as the most loving and practical solution to long term elder care. At \$62 a day compared to \$260 a day for a nursing home, it was certainly the most economical.

High standards are required of adult daycare staff, who must take continuous training and adhere to strict state regulations. Considerable strength, sensitivity and patience are needed to care for a roomful of older people for a full day, some of whom have dementia and want to wander, some on oxygen tanks or in wheelchairs, some who need help with eating, each of whom have particular medication requirements, dietary preferences, and varying opinions and tastes often set in many decades of stone. High quality care for older people requires recognition that they are entitled to their identities and peculiarities, that genuine respect is an essential component of love, and that a ready sense of humor is the best remedy for frustration. Among other

things, staff members must be able to feed, medicate, toilet, comfort, answer questions, anticipate events, explain regulations, remember birthdays, follow a daily itinerary, watch for symptoms, devise new activities, clean up messes, remain upbeat. They must be patient when talking to home caregivers, many of whom they encounter at the end of a long day, many of whom are under stress themselves. It is useful to remember that caring for people is a loving decision that requires full acknowledgement by everyone involved that no human being does everything right every time. Ideally, home caregivers and institutional caregivers collaborate and forge a healthy relationship based on mutual trust and

*There is no easy passage through such an illness but the availability of adult daycare moderated stress and ensured our togetherness at home during her final years. That she was loved and cared for by many others over that time cemented the wisdom of that choice.*

mutual dedication to a participant. The fact that this doesn't always happen may be disillusioning but it is not surprising. Caregivers both paid and unpaid are in the continuous self-correcting process engaged in by mere mortals doing angels' work. It is right to expect high standards of care and a striving for excellence. It is not fair or helpful to expect perfection.

When you love someone, it is also hard not to want it anyway. I recall insisting on the use of tissues for my mother's allergic nose, dismayed by the repetitive use of paper towels and napkins for this purpose. My mother's lifelong practice of closing her eyes when she wanted peace and privacy was misinterpreted as her needing an afternoon nap. Adult daycare staff had no way of knowing this before I discovered that they were placing her in a dark room in the middle of the afternoon. It was up to me to explain this idiosyncrasy. Sometimes when I thought music was too loud I remained silent,

*continued on page 12*

# GLIMPSES – EXCERPTS FROM ONE DAUGHTER'S JOURNAL REFLECTIONS

*By Terry Moore-Painter*

**2004**

One afternoon while at the beach, Mother and I painted together out on the deck on a picnic table. For hours, she was absorbed by form and color, and for a while, she was her old self. Then she couldn't remember why she was cutting onions before dinner . . . and she says her father was one hundred and ten years old when he entered the military in World War I. (He weighed 110 pounds.)

But at the beach, we had fun with games and swimming, good food, some good conversations and a few great laughs. There were instances where time stood still and we could pretend for a moment that we weren't careening toward upheaval and change, where life seemed normal as we've known it for years. There were moments when Dad's constant and undying love for my mother and for us moved me deeply. Times when in spite of all the underlying themes and tensions, I felt grateful to be in this family.

**2005**

My dreams during this time are vivid. In my most recent dream, I was helping my parents move again, this time from their home to a small cottage. I had living space in the cottage in the basement. Although I tried to honor their space, I was putting up my aqua china in their kitchen, just to add color. Dad was on a step stool in an adjacent room. I heard Mom pull down the attic stairs, and I saw her disappear into the attic, even though I called for her to come back. Dad fell off the stool, painfully injuring his knee.

Mom does drift away. Last week, she even gave herself a new name, as though she already does not exist anymore. She announced her name is not Betty, but Elizabeth Auten Moore. Dad reports that this week Mom poured her coffee into the toaster to heat it. I am hopeful that tonight he attended a support group for caregivers of people with dementia.

**October 11, 2005**

A poem:

Chunks of your personality break off  
like frozen, blue icebergs calving in the Arctic Sea.  
The thunderous splintering leaves me stunned.

Coffee now goes into the toaster to be warmed.  
Dark brown pencil etches your eyebrows into a  
shape of constant surprise.

Spilled food cascades down your blouse.  
And at Sunday lunch you spread tartar sauce  
on your roll  
and eat your ice cream with your fork.

Perhaps knowing how much you've changed,  
you even give yourself a new name.  
Obstinately, proudly, confidently, you instruct  
me to fill in the blank  
with a new name that has never been your own.

**2006**

These last six weeks have been challenging. Mom developed a major urinary tract infection, broke her wrist, and has exhibited increasingly delusional behavior. The continuing most difficult piece of that has been her growing inability to recognize Dad, although the behavior comes and goes and is not consistent. It breaks his heart when it happens. He devotes his life to her, making sure that she's dressed properly, fed, takes her meds, etc. And then she tells him she's not his wife, that he's not her Durham.

This past weekend Mom and Dad stayed at our house, and while here, Mom seemed like she was prior to the UTI. It was almost like having her back. She knew Dad, she swept the leaves off the porch and cleaned the kitchen, and she enjoyed watching a movie with us. But then back at their home, she became confused and didn't know Dad again. I don't understand the difference.

*continued on page 12*



## DELIVERANCE *(continued from page 10)*

choosing not to be a thorn. I advocated strongly for my mother when I felt it was in her best interests. I lobbied hard to keep pedals off her wheelchair. Fortunately, her physician agreed, which meant that she could retain her decades-long habit of holding her legs up and kicking her feet, which was good for her heart, her core strength, her bowels, and her happy spirit. From the staff's viewpoint, rules are rules by which they must abide, often set by distant regulatory and governmental bodies with whom they could get in trouble by making decisions on their own. Only a physician could provide the appropriate persuasion to make such an exception. Wise caregivers practice patience and forbearance with their caregiving peers, both paid and unpaid. Listening can be the most important and challenging work of any caregiver's day.

At the end of a full day of activities, my mother was tired and she slept well. On week nights and weekends I had her to myself and I loved her more patiently and more wisely for having had the respite provided by adult

daycare. I had the pleasure of watching adult daycare staff and participants come to love her too. When she died at 102, I knew I had done everything I possibly could.

In years that were fraught with both great difficulty and great love, the availability of adult daycare was our deliverance. May it grow and thrive and become the solution of choice for long term care.

*Margaret Toman was the sole caregiver for her mother Lou. She is a writer, public speaker, caregiver advocate and community volunteer. Margaret lives in Garner, NC.*

*It is right to expect high standards  
of care and a striving for excellence.  
It is not fair or helpful to  
expect perfection.*

## GLIMPSES *(continued from page 11)*

On Saturday morning, the weather here was lovely and warm, and Dad and Rebecca and I ate breakfast on the back deck. I gave Dad a letter I had found in some of Mother's things. She had written it to him in 1942, the year they were married, after he had left to go to the Army. Only nineteen years old, she was filled with love and dreams for their future life together. She described learning to make spaghetti, something she would later do many times for her children and for my children, her grandchildren. Dad read the letter and cried, and then he asked if I would read it to both him and Mother. Mother sat in the rocking chair in the bedroom, with blue sky and a steady stream of falling leaves framing her in the window behind her. Dad sat next to her, holding her hand, and for a moment, they both seemed to connect to that place, that young couple so much in love in 1942. That young couple with their whole lives ahead of them. And both of them had tears in their eyes as I read the letter. What a poignant, precious moment. When my parents come to my house, I seem to be able through love and activity to give Mom back to my dad. But it takes so much effort and so much energy, and the results, it seems are so fleeting.

I also remembered a tender moment last weekend when Mom and Dad came for a visit to my house. We went to the Farmer's Market on Saturday morning, and when we returned, we went into the loft of our barn. Both Mom and Dad were still able to climb the stairs to the loft, and the four of us sat in lawn chairs facing the big, open window. All we could see from that vantage point was clear, blue sky and trees, whose leaves were beginning to change. A quiet and peace descended on us, that I had not felt since Mother broke her wrist. We sat and stared, in silence, hardly moving. Mom then said, "I want to look at this and memorize it, so that I can remember what it looks like when I'm not here." None of us wanted to move, to interrupt the magic of the moment. Sankey and I left my parents there briefly and went to the house to fix lunch, which we took and served in the barn. It was holy time.

*Terry Moore-Painter kept a journal during her parents' struggles with her mother's decline with Alzheimer's. She is a writer, former oncology chaplain, and UCC minister living in Oak Ridge, NC.*

# BOOKSHELF

**Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with Life-Threatening Illness (Sixth Edition)**, by Hank Dunn, 2016. The end-of-life brings medical decisions that demand a verdict often amid a swarm of confusion around what is best for your family member. In this updated book that is a favorite of families, Dunn makes an effort to define language in a way that is helpful and demystifies the quandary felt by so many.

**The Inheritance: A Family on the Front Lines for the Battle Against Alzheimer's Disease**, by Niki Kapsambelis, 2017. Meet the DeMoe family. Readers are introduced to this unique family with a rare form of early-onset Alzheimer's in the presence of an inherited genetic mutation. Of the six children, five have an Alzheimer's diagnosis. This family is committed to using their story to promote research.

**Why Can't Grandma Remember My Name?** by Kent L. Karosen and Chana Stiefel, 2016. This is a children's book explaining Alzheimer's disease using artwork created by children juxtaposed with art created by Ohio artists living with a memory disorder. It highlights the creativity within all of us, regardless of age or cognitive status. The authors hope to encourage others to see how you can live and love someone with dementia while enduring the many changes caused by the disease.

**The Lotterys Plus One**, by Emma Donoghue, 2017. Suma's grumpy grandfather moves in with the family and she gives up her room for him. The story describes how Suma and her family learn to live with, enjoy and relate to their grandfather on a new level despite his diagnosis.

**Memory's Last Breath: Field Notes On My Dementia**, by Gerda Saunders, 2017. A biography written by a former literature professor, Saunders recounts her experience of being remarkably aware of her irreversible memory changes. She delves into the cruel reality of knowing something is wrong and being unable to change the outcome. The Washington Post piece about Saunders' book can be found [here](#) and the NPR article [here](#). (Delete highlighted line on print version.)

**The Alzheimer's Medical Advisor: A Caregiver's Guide to Common Medical and Behavioral Signs and Symptoms in Persons with Dementia**, by Dr. Phillip Sloane, 2017. This is an at-home guide to common medical and behavioral signs and symptoms in persons with dementia. Experienced Duke Family Support Program family caregiver advisors collaborated for several years with UNC-Chapel Hill geriatric researchers and Duke social workers to create and test this novel, evidence-based book. Each condition is addressed with an easy-to-follow two-page illustrated guide with basic facts, signs that indicate a possible emergency, tips on what to do and what to watch for, and safety tips for families caring at home.

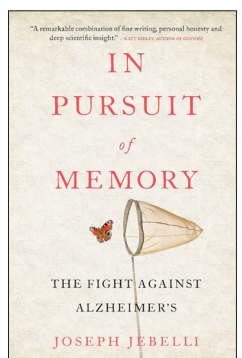
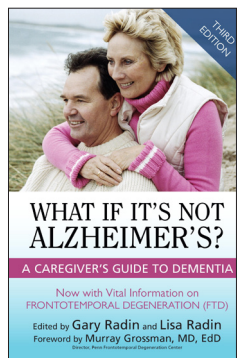
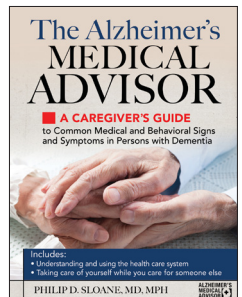
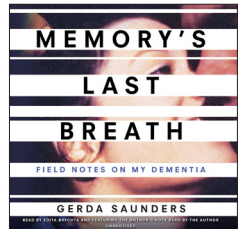
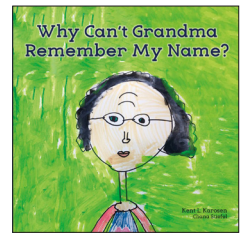
**What If It's Not Alzheimer's?: A Caregiver's Guide to Dementia (Third Edition)**, by Lisa & Gary Radin, 2014. Originally published in 2007, this is a comprehensive guide to frontotemporal dementia (FTD) and its different types as well information for families on Dementia with Lewy Bodies.

**In Pursuit of Memory: The Fight Against Alzheimer's**, by Joseph Jebelli, 2017. This is a neuroscientist's account of his personal connection to Alzheimer's. His grandfather had Alzheimer's and he's written the book he needed then – a human history of this frightening disease.

**The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss (Sixth Edition)**, 2017. The revised and updated sixth edition of this legendary dementia care guide is now available. Written by Nancy Mace and Peter Rabins, The 36-Hour Day remains the essential source for families of people with Alzheimer's disease or other forms of dementia.

**Surviving Alzheimer's With Friends, Facebook, and a Really Big Glass of Wine**, by Dayna Steele, 2016. This is a collection of updates posted on Facebook chronicling Steele's mother's journey with Alzheimer's. Steele's observations are filled with humor, raw emotion, love, wit, and wine. The book also includes sections from a neurologist, a long-term care insurance specialist, other caregivers, and an elder care attorney.

**Meaningful Connections: Positive Ways To Be Together When a Loved One Has Dementia**, by Nancy Kriseman, 2017. This book acknowledges the challenges of finding a connection with your family or friend who is experiencing memory changes. Her book provides examples and suggestions for maximizing and enhancing your visits.





The Center for Medicare Advocacy is partnering with the John A. Hartford Foundation to help people caught in the web of "outpatient" Observation Status. **HAVE YOU DEALT WITH OBSERVATION STATUS?** Share your story at [MedicareAdvocacy.org/ObservationStory](http://MedicareAdvocacy.org/ObservationStory)

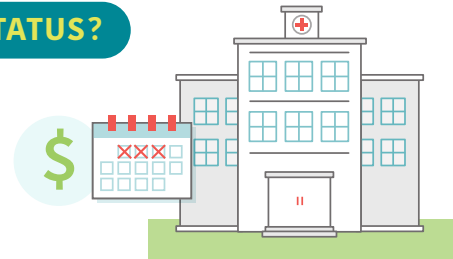
**SHARE YOUR STORY!**



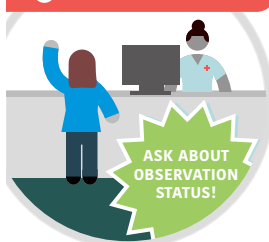
## WHAT IS "OUTPATIENT" OBSERVATION STATUS?

A hospital billing classification that can make **Medicare patients pay for the cost of their:**

- Hospital stay
- Hospital prescriptions
- Nursing home care
  - Patients must be classified as **inpatients for 3 days** in the hospital in order for Medicare to pay for subsequent nursing home care.



# AskAboutObservation



### OBSERVATION STATUS...

- May be called "outpatient," but it has **NOTHING TO DO** with where a patient receives care or the kind of care received.
- IS A BILLING CODE.** Hospitals use it to protect from overzealous auditors and Medicare readmission penalties.
- May just seem like semantics, but **for Medicare beneficiaries, IT CAN RUIN LIVES.**
- Saddles patients with increased out-of-pocket expenses. Patients who don't have Medicare Part B are responsible for the **FULL COST** of the hospitalization.

## WHY DOES OBSERVATION STATUS MATTER?

**Observation Status can be devastating.** It can result in thousands of dollars in hospital bills, and thousands more in nursing home bills after a hospital stay.



In 2012 an average hospital stay in the U.S. cost **\$10,400**, and the median monthly cost for a nursing home in the U.S. was almost **\$8,000**.

# AskAboutObservation



- The use of "outpatient" Observation Status isn't just wrong, **it can be DANGEROUS.**
- Many patients **CAN'T AFFORD** their care if Medicare won't pay.
- If post-hospital care in a nursing home won't be covered by Medicare, **many people GO WITHOUT** that care altogether, rather than face the enormous bills.
- The problem is growing: the number of patients cared for under Observation Status **DOUBLED** from 2006 to 2014.

## HOW TO FIGHT OBSERVATION STATUS

**Observation Status is very hard to fight.**

But here's what individuals can do:

### ASK

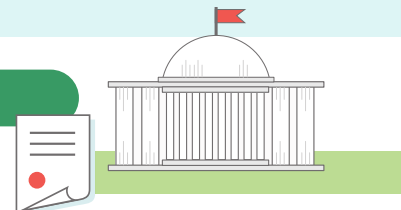
- Take action at the BEGINNING** of a hospital stay to try to stop Observation before it starts.
- Ask the hospital doctor to **"admit the individual as an INPATIENT"** based on needed care, tests and treatments.
- Ask the patient's regular physician to **CONTACT THE HOSPITAL DOCTOR** to support this request.

### SPREAD THE WORD

- CONTACT** The Medicare Agency (CMS), your Senators and Congressional Representatives.
- WRITE** to your local paper, **SHARE** this graphic on social media and **SUBMIT** your Observation story at [MedicareAdvocacy.org/ObservationStory](http://MedicareAdvocacy.org/ObservationStory)

### ACT

- FILE AN APPEAL** with Medicare, if the patient's nursing home coverage is denied.
- FILE A COMPLAINT** with the patient's state health department, if he/she did not get notice about "outpatient" Observation Status.



# AskAboutObservation





# Online Help



## YOU ARE NOT ALONE

**Love Remembered** Sometimes it seems as though all is lost. Your partner, your parent, your friend with memory changes seemingly does not remember those moments when you have loved each other deeply. Marie Marley shares her encouraging experience with her sweetheart and some old cards and photos. Take a look and remember that love runs deep! [https://www.huffingtonpost.com/marie-marley/love-remembered-alzheimers\\_b\\_13374178.html?b=1481287805](https://www.huffingtonpost.com/marie-marley/love-remembered-alzheimers_b_13374178.html?b=1481287805)

**Seven-Year Journey** As a clinical psychologist, Barry Jacobs presumed he had a good handle on the challenges ahead when he assumed the role as his mother's caregiver. Instead, he faced a seven-year journey striving to respect his mother while preserving her safety. Read the lessons he learned and be encouraged to acknowledge that each caregiver's journey is deeply personal and unique. [https://www.huffingtonpost.com/entry/my-vexinggratifying-7-years-of-caregiving\\_us\\_591a5986e4b0f31b03fb9e8d?ncid=engmodushpimg00000004](https://www.huffingtonpost.com/entry/my-vexinggratifying-7-years-of-caregiving_us_591a5986e4b0f31b03fb9e8d?ncid=engmodushpimg00000004)

**Consequences of a Diagnosis** A diagnosis reaches beyond the person with memory changes. It crosses over to the caregiver, shattering dreams, demanding new skills and making no promises to be quick and painless. The New York Times shares one care partner's battle with isolation. Not only did she gain new roles and responsibilities, but she also saw her freedom compromised in moving about her social circles. <https://www.nytimes.com/2017/08/04/health/caregiving-alzheimers-isolation.html?r=0>

**A Different Love** Dementia changes everything, even the marriage dynamic. This honest article addresses the delicate reality faced by spousal caregivers. What is one to do when your love for your partner changes? <https://www.aarp.org/caregiving/life-balance/info-2017/spousal-caregiving-divorce-fd.html>

**Talk about Anything but My Driving** Steve Petrow, both the journalist and son featured in this article, lives in Hillsborough, NC. In this article, the discord is between his mother and her children around the issue of driving. Well, Steve, many families will identify with your story. Driving is often a divisive, hot-button topic. <http://www.cetusnews.com/news/When-our-elderly-mother-refused-to-stop-driving--we-took-drastic-action.r1etgdztFW.html>

**I'm her Son** Caregiving opens the door to intimate moments with the care recipient that were never part of Plan A. Here a son's experience providing personal care for his mother includes his assumptions and surprises. <https://caregiver.com/cg-community/editors-pen/hal/>

## TIPS FOR FAMILIES

**Balancing Relationships** Sometimes family caregivers need to take a stand to make sure that they have the time, patience, and energy for children, spouses, partners and friends. Here are some ideas to assist with managing the stress of caregiving and balancing elder care with other relationships. <https://www.agingcare.com/articles/balancing-elder-care-with-other-relationships-133603.htm>

**How to Talk So Your Doctor Will Listen** Research documents that physicians may leave 23 seconds for a patient to state his/her concerns before interrupting. This AARP resource suggests tips on how to communicate concerns effectively in a short doctor visit. <https://www.aarp.org/health/healthy-living/info-2016/talk-to-doctor-patient-relationship.html>

**Nursing Home Evaluation Checklist** Choosing a facility capable of providing quality care for your family member can be challenging. It is to be expected that one might feel overwhelmed and at a loss when visiting various places. This tip sheet helps to keep you organized and aware of the marks of a good facility. [http://www.canhr.org/factsheets/nh\\_fs/html/fs\\_evalchecklist.htm](http://www.canhr.org/factsheets/nh_fs/html/fs_evalchecklist.htm)

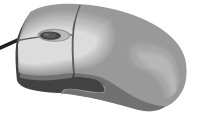
**Understanding Nursing Home Discharge** This handy document clearly outlines when nursing homes are lawfully able to involuntarily transfer or discharge patients. This is good information to review and store away for future need. Should the situation arise, it is helpful to know your rights. [http://theconsumervoice.org/uploads/files/issues/Revised\\_Nursing\\_Facility\\_Regulations\\_Involuntary\\_Transfer\\_and\\_Discharge.pdf](http://theconsumervoice.org/uploads/files/issues/Revised_Nursing_Facility_Regulations_Involuntary_Transfer_and_Discharge.pdf)

**Stranger Danger** Introducing an in-home aide is especially challenging when the care recipient is not receptive. Having extra hands to help provides the care partner an opportunity for respite. Click here to read more on how to introduce in-home care to your family member. <https://www.caregiver.org/introducing-home-care-when-your-loved-one-says-no>

**When the Sheep Fail You** Counting sheep is one tactic some might suggest to initiate a good night of sleep. This does not always work, however, and sleep challenges are common for those with a dementia diagnosis. This article offers guidance and tips to a better night's sleep. <http://www.nextavenue.org/how-to-get-your-loved-one-with-dementia-to-sleep/>

**A Spoonful of Sugar** Will it help the medicine go down? While Mary Poppins offers great insight on so many things, she might not have the best advice when it comes to medication compliance. Read this article for 11 tips for getting the medicine to go down without a fight. <http://dailycaring.com/11-ways-to-get-someone-with-dementia-to-take-medication/>

## Online Help *(continued from page 15)*



**Rummaging, Hiding and Hoarding Behaviors** Persons with dementia experience memory loss, confusion, disorientation, impaired judgment and behavioral changes. One of these changes may include “hoarding.” While hoarding may appear harmless, it can become a health and safety issue for the person with dementia. Here are some tips to help you understand, respond and cope. <https://www.alz.org/greatermissouri/documents/HoardingRummaging.pdf>

**Help, I'm in the Hospital** Regardless of the diagnosis, hospital stays can be challenging for both patient and family members. Care partners are often unclear about how to successfully advocate for the patient. This article has specific tips on advocating for a person living with dementia during a hospital stay. <http://www.alzheimersreadingroom.com/2016/12/how-to-take-care-of-a-dementia-patient-in-the-hospital.html?m=1>

**Making Plans** Here is a great resource with guides for advanced planning in easy-to-understand language. After clicking the link, click the four files found at the bottom of the page. <https://nadrc.acl.gov/node/96>

**Detecting Delirium** Delirium is a common, yet frightening, experience. This article and brochure are two resources to help care partners detect and respond to delirium. <http://www.nextavenue.org/protect-parent-delirium/>  
[http://www.hospitalelderlifeprogram.org/uploads/delirium/Delirium\\_Brochure.pdf](http://www.hospitalelderlifeprogram.org/uploads/delirium/Delirium_Brochure.pdf)

**Hide-n-Seek** Mom lost her purse again. Dad keeps pilfering through the desk drawers. Rummaging and misplacement of items is often part of daily life with memory and thinking disorders, but it can be stressful for everyone. Read here for some tips. <https://www.nia.nih.gov/health/when-person-alzheimers-rummages-and-hides-things>

**Choosing Wisely** The decision to move a family member is often not done lightly. This article provides tips on evaluating and choosing a quality care facility. The tips invite you to slow down and ask for help. <https://www.nytimes.com/2017/09/14/health/nursing-home-safety.html>

**Practice, Practice, Practice** The holiday season is approaching, along with it the potential for more time with family and friends. Time for reconnection, but also a prime time for difficult conversations, often connected to long-term plans. Take a look at these videos and the included resources. Now jump in front of the mirror and try it! <https://theconversationproject.org/practice-makes-perfect-video/>

**The Talk** No, not the birds and the bees, but dementia. From a desire to protect, parents may not talk about grandma and grandpa's changing memory with the children. As discussed in this article, kids are often more aware than one might suspect. The same article offers suggestions for how to have a conversation with the small folks in the family who might just notice that grandma is changing. <http://www.nextavenue.org/tell-kids-grandparents-dementia/>

**Gone but Still Here** Grief in the context of death and dying is intuitive, but what about grief prior to death? Ambiguous grief is the slow progression of losses before death. The person is there but, perhaps, the mind, behavior and personality have changed. The disease and diagnosis change your relationship with the person. Grief is an expectable and appropriate response in this season too. This article further explains and offers thoughts on processing ambiguous grief. <http://www.nextavenue.org/anticipatory-grief-ambiguous-loss/>

## DID YOU KNOW?

**What about Complementary Health Approaches?** The National Center for Complementary and Integrative Health concludes there is currently no convincing evidence that any dietary supplement can reverse or slow the progression of dementia or Alzheimer's disease. But, research on several mind and body practices has shown promise in preliminary clinical studies. Here are 5 things to know about the current research. <https://nccih.nih.gov/health/tips/alzheimers>

**To Move or Not to Move?** The first response to resolving the challenges of long-distance caregiving might be to move your parents closer to you or vice versa. Before you call the moving trucks, is that the best solution? Take a look at this article for tools on how to make this important decision. <http://www.nextavenue.org/move-closer-aging-parents/>

**Hi, I'm Your Representative** The Social Security Representative Payee program is not widely understood but it could be helpful in managing your family member's finances. To protect the person living with dementia, the payee is required to report spending. The payee role comes with additional accountability, but, for some, it is well worth it. Here are pros and cons. <http://www.nextavenue.org/social-security-program-dementia/>

**Imposter Syndrome** Delusions are a common experience for those with memory changes. Capgras, a little-known syndrome, is when a person believes that someone they know has been replaced by an imposter. Here is information on effective approaches for responding to Capgras and other, more common, delusions. <https://www.agingcare.com/articles/caring-for-a-loved-one-with-capgras-syndrome-197688.htm>

# THANK YOU, DONORS

*For the Joseph & Kathleen Bryan Alzheimer's Disease Center at Duke*

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*\* The Alpha Group refers to individuals and families who have completed the Memory Makers\*\* group and have chosen to stay connected to each other and the Duke Family Support Program staff through a series of monthly social, cultural and support programs. The name "Alpha" was suggested by one of the original members, the late Monte Dewey.*

*\*\* Memory Makers: An Early-Stage Memory Loss Education and Support Group for individuals living with memory loss and their care partners is offered three times a year in Durham. It is a partnership between the Duke Family Support Program, Jewish Family Services and the Alzheimer's Association.*

*Please mail donations for the Duke Family Support Program to:*  
Duke Family Support Program  
Box 3600 DUMC  
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## DUKE FAMILY SUPPORT PROGRAM: HOW WE HELP

The Duke Family Support Program (DFSP) has been answering questions about dementia and caregiving since 1980. The program offers telephone and email consultation, and educational services to North Carolina families, friends and professionals caring for any adult with declines in memory and thinking.

DFSP provides access to Project C.A.R.E. (Caregiver Alternatives to Running on Empty) a dementia-specific respite and consultation service for families who care for relatives at home. The Caregiver newsletter, published twice a year and the program's monthly e-news provide timely updates, events and tips for families. Both are available free beyond NC with online subscriptions. The program also offers (free of charge -- by phone, email or mail) to all NC residents:

- Help with care decisions and coping strategies.
- Personalized tips on caring for people with memory disorders.

- Research updates and options for participation in Alzheimer's treatment and prevention studies.
- Help selecting support groups, education programs, online help or books.
- A comprehensive, mailed information packet on Alzheimer's and caregiving.

We offer four Durham-based support groups. Call or go to [www.dukefamilysupport.org](http://www.dukefamilysupport.org) for more information. (If Durham support groups don't work, we can refer you to groups closer to your home.)

Caring for someone with a memory disorder can be overwhelming. Educating yourself about the disease and available services can change your perspective. Help is available. Call 919-660-7510 or go to [www.dukefamilysupport.org](http://www.dukefamilysupport.org).

## DUKE FAMILY SUPPORT PROGRAM WELCOMES NEW STAFF!

### Natalie Leary

Hi! My name is Natalie and I joined the team in June. After completing a joint internship with the Duke Geriatric Evaluation and Treatment Clinic and the Duke Family Support Program, I graduated from UNC-Chapel Hill in May with a Masters in Social Work.

A North Carolina native, I have been living in the Raleigh area for the past eight years working in non-profit volunteer recruitment and training. Born and raised in Eastern North Carolina near the Outer Banks, the beach is my "happy place" and I will always have an affinity for the waves and sand. In my personal time, I love to travel, bake, get lost in Netflix, and spend time with family and friends.

Personal interest in this line of work was born from watching my parents serve as care partners for my grandmothers. Our home was renovated to create a private apartment allowing them to live with us while maintaining their independence. At the appropriate moment in each of their lives, my grandmothers moved in and called that space home. During this time, I watched my parents journey through waves of gratitude, joy, stress, exhaustion, a sense of feeling lost and uneducated, relief, and back to gratitude. I am inspired by their courage and sacrifice to do this work!

I look forward to a continued partnership with you and your families for the coming years.





# The CAREGIVER

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