

The CAREGIVER

*A Bridge to Understanding
Your Options*

Newsletter of the Duke Family Support Program

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SUMMER 2018

What Is Lewy Body Dementia (LBD)?

LBD is not a rare disease. It affects an estimated 1.4 million individuals and their families in the United States. Because LBD symptoms can closely resemble other more commonly known diseases like Alzheimer's and Parkinson's, it is currently widely underdiagnosed. Many doctors or other medical professionals still are not familiar with LBD.

Lewy body dementia (LBD) is a progressive brain disorder in which Lewy bodies (abnormal deposits of a protein called alpha-synuclein) build up in areas of the brain that regulate behavior, cognition, and movement.

A complex disease, LBD can present with a range of symptoms including problems with thinking, memory, moving, sleep and/or changes in behavior, to name a few of the physical, cognitive, and behavioral symptoms.

LBD also affects autonomic body functions, such as blood pressure control, temperature regulation, and bladder and bowel function. Progressively debilitating, LBD can also cause people to experience visual hallucinations or act out their dreams.

Reprinted from the Lewy Body Dementia Association website. <https://www.lbda.org>

Get the Facts about Lewy

FACT: Lewy body dementia (LBD) is the most misdiagnosed form of dementia.

FACT: LBD is the second most common cause of progressive dementia behind Alzheimer's disease.

FACT: LBD affects approximately 1.4 million Americans, most often after the age of 50.

FACT: LBD is NOT usually hereditary.

Reprinted from the Lewy Body Dementia Association website. <https://www.lbda.org>

Many Names

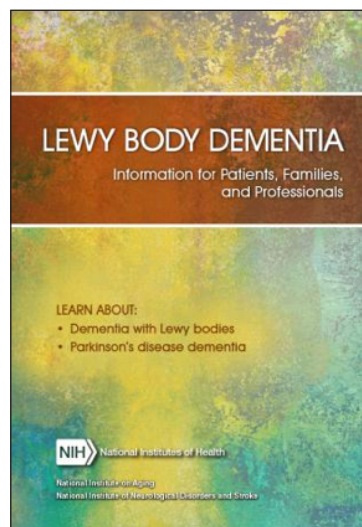
Lewy Body Disease; Diffuse Lewy Body Disease; Dementia with Lewy Bodies; Autosomal Dominant Diffuse Lewy Body Disease; Cortical Lewy Body Dementia; Lewy Body Variant of Alzheimer Disease; Parkinson Disease with Dementia; Senile Dementia of Lewy Type

Compassionate Allowance

People diagnosed with Lewy Body Dementia may qualify for Social Security's Compassionate Allowance program. For more information, see page 2, call the SSA at 800-772-1213 or learn more at <https://www.ssa.gov/compassionateallowances/>

For additional Resources see page 13.

See pages 5-6 for thoughts from Brenda, who openly talks about her life with Lewy body, and from three Triangle-area caregivers who have lovingly faced the challenges of caring for spouses with Lewy body.



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Go to www.dukefamilysupport.org to view this newsletter online or to request an electronic subscription



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 Chicago, IL 60601-7633
 312-335-8700
 800-272-3900 (24/7 Helpline)

www.alz.org

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

5171 Glenwood Avenue, Suite 101
 Raleigh, NC 27612
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 800-272-3900 (24/7 Helpline)

www.alz.org/nc

Email: encinfo@alz.org

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Chapter Headquarters:
 4600 Park Road, Suite 250
 Charlotte, NC 28209
 Satellite Offices:
 Asheville, Greensboro and Hickory
 800-272-3900 (24/7 Helpline)

www.alz.org/northcarolina

Email: infonc@alz.org

The Association for Frontotemporal Degeneration (AFTD)

Main Office (Radnor, PA): 267-514-7221
 AFTD Helpline 866-507-7222

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

Email: info@theaftd.org

**Dementia Alliance of North Carolina
(formerly Alzheimer's North Carolina)**

9131 Anson Way, Suite 206
 Raleigh, NC 27615
 919-832-3732 or 800-228-8738

<https://dementianc.org/>

Email: Info@DementiaNC.org

Lewy Body Dementia Association

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

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

Family Caregiver Alliance, National Center on Caregiving

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

<https://caregiver.org/>

COMPASSIONATE ALLOWANCES (CAL)

The CAL program identifies diseases that meet Social Security's standards for disability benefits. CAL gives people with certain diseases expedited access to Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Among the diseases that qualify for CAL:

- Corticobasal Degeneration
- Creutzfeldt-Jakob Disease
- Early-onset Alzheimer's Disease (Younger-onset)
 - Anyone with any younger onset dementia should check their eligibility
- Frontotemporal Dementias
- Lewy body dementia
- Mixed Dementias
- Primary Progressive Aphasia
- Progressive Supranuclear Palsy

SSDI applicants must be younger than age 65 and have enough "work credits" to qualify. After receiving SSDI for two years, a person receiving disability will become eligible for Medicare. SSI is a "means-tested program" for individuals who are over 65, blind or disabled AND have limited income and resources; and it is not based on work history.

For more information on CAL, go to <https://www.ssa.gov/compassionateallowances/>

For more information on SSDI and SSI, go to <https://www.ssa.gov/disability/>

Or call Social security at 800-772-1213

COMMITMENT, EXPERIENCE & FRESH IDEAS: A NEW LEADER

By Lisa P. Gwyther, MSW, LCSW



From left to right: Natalie Leary, Lisa Gwyther, Bobbi Matchar, Janeli McNeal

Last month Duke acknowledged my forty years of service to the Duke Center for Aging and Department of Psychiatry and Behavioral Sciences. The Duke Family Support Program's Caregiver newsletter and its Durham Evening Support Group qualify for about the same number of service years.

Now our Duke Family Support team, including myself and the invaluable Janeli McNeal, MSW and Natalie Leary, MSW, LCSW-A, is thrilled to announce that Bobbi Matchar, MSW, MHA is the new Director of the Duke Family Support Program.

Our six-year old Early-Stage & Beyond Community set a new bar for programming under Bobbi's leadership in collaboration with our loyal community partner organizations. Memory Makers, the core entry point for all new programs, welcomes its 17th educational support group this fall; and What's Next, Kinship support groups and Booster Club events are firmly established. (See description on page 4)

Bobbi's foresight and broad experience created and expanded the reach of our Triangle-Area Monthly E-newsletter over the last three years. She revamped

our communications and solidified our four-year-old series of monthly programs with Duke's Nasher Art Museum Reflections Program. The Alphas' monthly Saturday lunches and spontaneous gatherings thrive with her steady presence after six years.

Three anonymous gifts totaling 3.1 million dollars and many new generous donors assure individuals living with cognitive decline and their families will have access to our lessons learned and a recently doubled team of Duke Family Support Program social workers. It is time for a new team leader.

We are seamlessly ready to roll with Bobbi's innovations, strategizing, experience, unsurpassed knowledge base and commitment.

Some say "Change is Good – you do it." I am eager to follow Bobbi's lead as our program continues to focus on changing for the better the lived experience of people challenged by memory and thinking disorders. So look for me, just not as "Director," as we commit to reach more individuals and families in meaningful ways in the years ahead.

Duke Family Support Program

EARLY-STAGE & BEYOND COMMUNITY

**Programs to help families
live their best with
Alzheimer's or a related
cognitive impairment**

Our Early Stage & Beyond Community
provides education and support
from the time of diagnosis
through the course of the illness

DUKE FAMILY SUPPORT PROGRAM TEAM

Lisa Gwyther, MSW, LCSW
Natalie Leary, MSW, LCSW-A
Bobbi Matchar, MSW, MHA
Janeli McNeal, MSW

DUKE FAMILY SUPPORT PROGRAM

www.dukefamilysupport.org
919-660-7510

**"A lifeline for families
facing dementia"**

– participant

**"I have been given
a 'roadmap' for the
days ahead"**

– participant

WHAT IS MEMORY MAKERS?

MEMORY MAKERS is an eight-week educational support group for individuals with early-stage memory loss and their care partners

PURPOSE: To offer a comfortable opportunity for learning and support with others who are living in the early stage of Alzheimer's disease or a related disorder, and their care partners

CURRICULUM

- Introduction & Overview
- Basics of Alzheimer's & Related Disorders
- Disclosure & Changing Relationships
- Legal & Financial Planning
- Balancing Safety & Autonomy
- Medications
- Emotions & Communication
- Advocacy & Staying Connected

ELIGIBILITY: Open to families regardless of where health care is received; you do not need to be a Duke Health patient

REGISTRATION: Pre-registration is required. For more information, please email dukefamilysupport@duke.edu or call 919-660-7510

AFTER PARTICIPATING IN MEMORY MAKERS

After participating in MEMORY MAKERS, families may continue to learn and socialize with current and past group participants

ALPHA LUNCH: Monthly lunch at a Triangle restaurant

LOOK, LISTEN & LUNCH: Monthly art and music program at the Nasher Museum of Art

PERSON WITH DEMENTIA & CARE PARTNER SUPPORT GROUP AT GREY STONE: Monthly support group

WHAT'S NEXT?: A series of education and support workshops for care partners dealing with mid-stage and beyond

KINSHIP: Monthly support group for **WHAT'S NEXT?** care partners

BOOSTER CLUB: Quarterly lecture series for care partners

ES&BC WEBSITE: Password protected access

LEWY BODY DEMENTIA

REFLECTIONS FROM LOCAL FAMILIES

We asked some families who participate in our Duke Family Support Program groups to share their stories.

Brenda, who was diagnosed with Lewy body dementia in 2017, at age 59.

This is an excerpt of a talk Brenda gave to her church group in spring 2018

I was diagnosed with the Mild Cognitive Impairment with Lewy body disease in April 2017. I was waiting to hear that I had Alzheimer's disease, but I was not given that diagnosis. I told the doctor that is great news and you can cure me, right?? He said not so fast...well I sat back in my chair and waited for what he was about to say. He said you have Mild Cognitive Impairment with Lewy body disease. Lewy body disease can be treated, but not cured! We will start you on the strongest Alzheimer's drug possible to slow down the progression of your disease immediately. I had never heard of Lewy body disease. He tried to explain the disease, but honestly I do not think I heard another word during the entire visit. I was given a brochure regarding the disease and the Duke Family Support Program. I read about the disease online for about a week over and over....the doctor nailed my diagnosis. It was exactly what I was experiencing. I was relieved and scared to death all at the same time.

My husband and I attended Memory Makers Early Stage Memory Loss Educational Support Group, a four-week program that changed our lives.

I can identify with almost all of the symptoms I read about. I see things that I know are not real like people or animals but they are so real to me. My husband verified the items I see are wood, chairs, a fire hydrant or other objects.

I miss my job, boss and friends at work, but I have a new life now not working, but I have new friends (still stay in contact with old friends from work, just do not get to see them often).

Most importantly with GOD's HELP...I take one day at a time and I have accepted my diagnosis. I just get frustrated that I cannot remember names. I try to carry on a conversation and embarrass myself because I am talking to the wrong person about a subject.

I cannot multitask and I have been an executive assistant, project assistant, and event planner my entire career. This is what I was born doing I think! I have a basket to help me put my make-up and toiletries on each day. I have brushed my teeth with hair gel and sprayed my hair with scrubbing

bubbles. I cannot remember what happened yesterday unless I relate it to something that happened in my past or review my paper calendar. I am beginning to transpose numbers when writing. Have to keep a to-do-list of all things that I need to do today throughout the day or I will not accomplish anything. I have started not to recognize people that I have known for years, but do not see often. This has happened to me a couple of times in the last 3 or 4 months now. I have good days and days with hours that are not so good. If I am confused or frustrated, I go lay down and rest.

I am so sorry that I cannot remember everyone's name because I work so hard at it. I get cards in the mail and I have to call M and ask if she has a picture to help me put a face with the name. M solved a frustration for me with the dishwasher. I could not remember if dishes were clean or dirty. I tried post-it notes (clean/dirty), but I didn't remember to change the note. She surprised me with the "DishWinkle" and it was like she gave me a car! It is the small things in life. Please forgive me if I do not remember your name, but I do remember your smiling faces. Thank you for accepting me as I am today and the way I may be tomorrow!

My husband, Robert is my guardian angel every day of my life. Some days he looks at me when I tell him I cannot remember what you told me two minutes ago. He stops in his tracks and has to walk away. He will tell me later that he forgets that I do not remember because I look the same to him every day and he just does not get it that I cannot remember. We talk all the time about things that happen in the past and I can carry on a normal conversation with him.

Sharon, a caregiver whose husband W was diagnosed last year.

What were some of the signs that W was having a problem?

I began to notice W's early memory problems late in 2014, but, in hindsight, I see things I attributed to his natural quirkiness had been happening infrequently before then (impulsive, cavalier decisions about money coupled with anxiety about money; reluctance to socialize; OCD-type behavior). He had sporadic short-term memory loss—i.e., sometimes he would ask a question several times with no memory that he'd asked it before; he had increasing trouble with words and names; once in a while, he got lost when he was driving in familiar places or couldn't remember how to get from one place to another. These issues were sporadic for about a year, but by mid-2015, others were noticing something was wrong. W had trouble remembering how to use his computer, smart phone, and the

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LEWY BODY *(continued from page 5)*

microwave. His doctor did some preliminary tests and then referred him to a specialist for more detailed tests. Ultimately, W had an MRI, which showed some spaces in his brain in areas that are normally associated with degradation of motor functions. At that time, January 2016, W had exhibited trouble with executive function, but not motor function. The specialist gave W a diagnosis of mild cognitive impairment and we had follow-up appointments every six months.

In the summer of 2017, W started losing his balance occasionally, and fell down twice in a short time. He also started to have very restless sleep, and was acting out his dreams, which almost always consisted of people trying to harm him, and his efforts to run or fight back. He fell out of bed twice in the month of August. One other new symptom surfaced: he came into the living room one day and started laughing. When I asked why, he said he saw a rabbit on the couch, but he knew that there couldn't be a rabbit on the couch. There wasn't; it was a pillow. When we went to see the same specialist in September 2017, these incidents led to the tentative diagnosis of Lewy body dementia.

How did W react to the diagnosis of LBD?

W and I went home and started reading about LBD on our computers. I don't know if we were reading the same articles, but both of us stopped reading very shortly and looked at each other. I think we were both horrified. I know I was. For the next few days, W was very somber, kind of depressed.

Do you see yourself and W being in a position to help fight the stigma associated with all dementias?

This is a tough question. I believe our attendance at the various support groups and activities has given W and I the willingness to share with others, be more open about his diagnosis. At the first Nasher Museum Look and Lunch we attended, W asked one of the women leading the art therapy session if she had worked with any Lewy body dementia patients. That was the first time he named it to anyone other than me. He shared about his diagnosis with the wider world by posting on Facebook, and got many messages of encouragement and support. Both of us have greater acceptance of reality of the situation, and the number of people we have encountered at the functions we've attended has in some ways created a new "normal". I'm not sure if that means we are in a position to help fight the stigma associated with dementia.

Lynette, wife of Jerry, who died from Lewy body in 2015.

What do friends or health professionals need to know about Lewy body dementia?

First comes the fear of an unwanted diagnosis. However, the earlier one knows, the better. Then begins the long and sad journey dealing with an incurable disease and a slow death. It's a big shock. One realizes that life is dramatically changed, will be difficult, requires flexibility, and involves an unwanted shift in outlook. It's overwhelming.

Early and later symptoms are profoundly disturbing. They may vary in different people. However, here are the big scary ones.

1. REM sleep disorder and acting out bad dreams
2. Hallucinations and delusions
3. Dementia advances from memory loss and depression to a growing loss of a sense of self.

Overall, the unpredictability and fluctuations of symptoms causes big-time stress in the caregivers and those receiving care. One feels helpless.

So the key is finding adequate professional support, good advice and much information from good resources.

One recognizes the extensive care needed, not knowing for how long or what is coming next. It seems like a never-ending journey. Support and help are needed at any level of care. One cannot provide care alone.

Debby, whose husband Tony lived with Lewy body dementia for several years

What, if anything, did you know about LBD before the diagnosis? What was different or unexpected as a result of LBD?

I knew nothing and had not really heard the name before. The doctor started talking about it and gave me a book to read about it. Scared me at first. As I learned more about it, I realized that unfortunately, Tony was showing many of the symptoms. What was different was probably his temperament and irritability. Tony prior to the disease was a quiet, gentle and very intelligent man and rarely if ever did he lose his temper. He always had more patience than me about almost everything. It was very difficult to understand what was going on with him and I realize that the speech difficulties certainly made it all worse, but the LBD certainly added to everything. The problems with the bathroom and wetting everything all the time was one of the most difficult things to handle.

I look at others who have Alzheimer's and when they say they are even tempered, I am so glad for them that they don't have to handle that problem. I think the last year of Tony's life was the hardest thing I have ever had to do in taking care of a man I loved for 57 years. I surely know I lost it many times and probably didn't do all things right, but I really tried and loved him always.

Wish I could have him back but know I wouldn't want him to suffer the way he was and I now realize that I think he

LATE-LIFE DEPRESSION AND COGNITIVE RISK

By Guy Potter Ph.D., Duke Department of Psychiatry and Behavioral Sciences

At present, there is no cure for Alzheimer's disease (AD), but many factors may delay onset of the disease or reduce its likelihood. One of these factors is depression, which is associated with increased risk of AD as well as a worse course of illness when these two conditions are present together. For individuals and families, recognizing depression symptoms and seeking appropriate treatment may be an important way to slow or avoid a range of adverse outcomes, including more rapid cognitive decline, greater loss of functional independence, increased hospitalization, and a higher rate of mortality.

Late-life depression

Depression is a mood state characterized by pervasive sad mood and loss of interest or pleasure. A clinical diagnosis of Major Depressive Disorder (MDD) encompasses a range of symptoms that must include sadness or decreased interest, but may also include loss of concentration, physical slowing, sleep disturbance, appetite disturbance, guilt, feelings of worthlessness, and suicidality. Depression in older adults is more varied than in younger adults, which may reflect different underlying causes, and perhaps differences in effective treatments. This is where the idea of depression phenotypes becomes important. Phenotypes are observable characteristics that are associated with an underlying disease, and they often provide important insight into diseases like depression and AD, where the pathology is uncertain.

When considering late-life depression, researchers have identified a potential phenotype based on whether the first onset of MDD occurred prior to age 60 (early onset) or after age 60 (late onset). Both early onset and late onset of depression are associated with higher risk of developing AD, but late onset depression is potentially of greater concern because it may reflect an early (prodromal) symptom of AD, rather than an independent mood disorder. Our research at Duke, with the Neurocognitive Outcomes of Depression in the Elderly study, has found that individuals with late onset depression are more likely to progress to a diagnosis of

AD within five years of study entry than individuals with early-onset depression. Individuals with late onset depression who develop AD are also more likely to have characteristics of memory loss during their depressive episodes, in a pattern consistent with early Alzheimer's disease. They are also more likely to report appetite and/or weight loss, which some researchers have identified as a sign of impending AD.

When accompanied by late onset depression, both memory loss and appetite/weight loss could be the product of impending AD rather than a primary mood disorder, and could warrant further evaluation. One concern is that a misdiagnosis of MDD as the primary disorder may delay or obscure the diagnosis of early dementia. Even though there is no cure for AD at this time, some lifestyle modifications related to nutrition, physical activity, and cognitive and social engagement

may slow progression of cognitive decline. Perhaps more importantly, the presence of depressive symptoms can potentially speed up the rate of cognitive decline and lead to other health changes that decrease quality of life. Because antidepressants are less effective in treating depression associated with

Physical activity is an effective treatment for depression, and an important factor in maintaining healthy cognitive function with age, including potential improvement in people living with AD.

AD, psychological and behavioral interventions may produce greater benefit. We hope our work on this type of late-life depression will lead to a more accurate diagnosis of impending AD so timely and appropriate treatment can be provided.

Persistent cognitive impairment

Our research suggests another group of individuals with late-life depression may also be at risk of AD or another dementia. Many individuals in our study with early onset depression demonstrate what we describe as persistent cognitive impairment. These individuals do not meet criteria for the combination of cognitive and functional impairments that characterize dementia, but their performances on cognitive testing do reveal clinically significant deficits that persist over several years. These deficits are most prominent in information processing speed and complex attentional abilities. Individuals with persistent cognitive impairment may

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LATE-LIFE DEPRESSION *(continued from page 7)*

still experience cognitive deficits despite improvement of depression symptoms, but their rate of decline is slower than that of individuals with impending AD.

One characteristic associated with persistent cognitive impairment includes greater frailty and more co-occurring medical conditions compared with those whose depression appears linked to early AD. Frailty is a geriatric syndrome that reflects decline across multiple bodily systems. Individuals with frailty syndromes tend to grow more frail with successive episodes of medical illness, which is associated with higher rates of hospitalization, disability, and mortality.

Another characteristic present in persistent cognitive impairment is white matter disease, which reflects a loss of integrity in the brain tissue that helps different parts of the brain communicate with each other.

There is some indication that white matter disease predisposes individuals to both persistent depression and persistent cognitive impairment in later life. The burden of multiple depressive episodes across their lifespans may contribute to these underlying health risks. We predict that many of these individuals with persistent cognitive impairment and depression will eventually develop dementia, but with a more gradual decline, and with vascular dementia as well as AD. In this case, behavioral and medical management of frailty and cerebrovascular risk factors are important treatment strategies, but even more important as approaches to prevention starting in midlife.

Late-life depression and normal cognition

Now for some reassuring news: to date, our research has found that approximately half of depressed individuals in our study are cognitively normal, at least over the first five years of their participation in our study, and typically longer. It is important to remember that even though depression is a risk factor for dementia, not all individuals experiencing depression will develop this condition. Two characteristics that appear to distinguish the depressed-but-cognitively normal group from the groups with cognitive impairment are 1) a different profile of depression symptoms, and 2) greater sensitivity to stressful life events. We find that compared to the depression symptoms of the individuals who are at risk for AD, individuals who

remain cognitively normal have more symptoms related to worry, guilt, and feelings of worthlessness. While these cognitively normal individuals do not report more stressful life events than the other two groups, they do report finding the same events affect them more negatively. This suggests that individuals with this depression type may be more sensitive to stress, which is manifest in more classic psychological symptoms of depression, which are less common in those who go to develop AD. We hypothesize that the depression in the cognitively normal group is more likely to be reactive to specific events or circumstances, and it is less driven by underlying changes in the brain.

As might be expected, individuals with late-life depression who remain cognitively normal generally have better indicators of brain health, including less brain shrinkage and better integrity of white matter tissue. These individuals are more likely to have had a first onset of depression in early life, and we hypothesize that sensitivity to stress and negative moods are likely

...even though depression is a risk factor for dementia, not all individuals experiencing depression will develop this condition.

to be longstanding personality characteristics that represent a vulnerability to depression under conditions of stress. Generally, these individuals are more responsive to treatment with antidepressant medications than the groups with cognitive impairment, but building resilience to psychological stress would appear to be an important non-pharmacological treatment for this group.

Provisional Recommendations

Based on prior and ongoing research in the Neuro-cognitive Outcomes of Depression in the Elderly study, we can make some provisional recommendations. If depression symptoms occur after age 60 for an individual with no prior history of depression, and in the absence of a major loss or stressor, it is important to visit a health care provider to discuss potential medical causes for this change, including early AD. Memory changes and unintended weight loss increase concern for early AD. For individuals who have a prior history of depression, taking care of physical health, treating chronic medical conditions, and undertaking treatments to minimize depression relapses are important strategies for maximizing cognitive health.

Although the three profiles of late-life depression

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ALZHEIMER'S MEDICATIONS: STARTING AND STOPPING

By Anne Dunbar Johnson, MD

Duke Division of Geriatric Psychiatry and Duke Department of Psychiatry and Behavioral Sciences

To begin any discussion on the discontinuation of cholinesterase inhibitors (ChEIs), we should start by exploring why these medications are started in the first place for the treatment of Alzheimer's disease (AD). After receiving an initial diagnosis of AD, many patients and family members will ask about treatment options. Despite major research efforts into prevention or reversal of cognitive decline, there remains no cure for this illness. The ChEIs are typically tried as first line therapy for symptomatic treatment of AD. ChEIs that you may be familiar with include donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne). Typically, these medications are continued through advanced disease stages.

After ChEIs came on the market, several randomized controlled trials were conducted to determine if they improved the well-being of patients with AD. Most of the trials focused on patients with mild-moderate AD and concluded that there was statistically significant improvement in cognition for patients on donepezil at 5mg and 10mg/day doses at six months and at one year compared with placebo (Birks, 2006). This improvement was measured by standardized cognitive testing at the time that showed an average improvement in scores of 1.84 points. It is uncertain how clinically relevant or meaningful this number is. However, it was concluded that patients with AD experienced benefits in cognitive function, activities of daily living and behavior. Side effects were also emphasized in these studies. Many more patients withdrew from treatment when on higher doses of donepezil (10mg vs. 5mg) due to nausea, vomiting, diarrhea, anorexia, fatigue, muscle cramps, dizziness. The debate on whether donepezil is effective continues despite the evidence of efficacy from the clinical studies because the treatment effects are small and not always apparent in a patient's typical day.

Before starting a ChEI, a thoughtful conversation with your health professional is essential. Before making a decision, you should know the natural progression of AD, expectations of treatment, medication side effects, and non-drug alternatives which may be used in conjunction with meds or alone. It is vital to know that the expectation of treatment is "not absolute improvement but rather an improvement compared

with what the condition would have been like in the absence of treatment." (Renn, 2018) The goal is to slow progression of the illness. For this reason, upon initiation of a ChEI, it can be helpful to develop realistic goals over a certain time. For example, over the next 6 months while on donepezil: dad will be more alert and engaged in family discussions at dinner. These goals should be personalized to the patient. A collaborative effort with your primary care or specialist professional can assist in creating attainable goals to determine if the ChEI is indeed effective in meeting your realistic person and family-centered goals. After the set time, revisit these goals with your provider to determine if continuation of the medication is warranted.

Remember ChEIs can have side effects such as nausea, vomiting, diarrhea, anorexia, fatigue, muscle cramps, dizziness, and disrupted sleep. If the person with AD experiences any of these, you should alert his/her provider. A change in dose or time of administration can sometimes be helpful. Besides medications, there is evidence behind many other interventions that can preserve one's cognition. This topic warrants an entire

The debate on whether donepezil is effective continues despite the evidence of efficacy from the clinical studies because the treatment effects are small and not always apparent in a patient's typical day.

article in itself! In brief: maintaining a daily schedule which includes regular physical exercise, consuming a Mediterranean diet, social engagement, intellectual stimulation and having a consistent sleep/wake cycle can all be beneficial. Your provider can discuss each of these in more detail and/or direct you to a social worker familiar with local educational and support services.

Health professionals have very good reasons to start and continue patients on chronic medications for conditions such as diabetes, hypertension, and depression. There is limited scientific study of deprescribing but it is just as important to identify and

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ALZHEIMER'S MEDICATIONS *(continued from page 9)*

discontinue drugs when the potential harms outweigh the potential benefits of ongoing treatment. Doctors routinely face practical decisions about whether to continue or stop medications. The input of patients and their families is appreciated. For each individual,

Polypharmacy from meds that are minimally beneficial may be placing a patient at unnecessary risk.

the balance of benefits and risks may warrant discontinuation of ChEIs at different points during the disease course. Besides the common side effects mentioned above, long term ChEI treatment can be associated with weight loss, slowed heart rate, urinary retention and drug-drug interactions. Loss of appetite is prevalent in advanced stages of dementia and can be worsened by these medications. It is worth considering discontinuation of any medication when the associated side effects require the addition of more medications. Polypharmacy from meds that are minimally beneficial may be placing a patient at unnecessary risk. (Vetrano, 2013) Other factors to consider for Alzheimer's and ChEI discontinuation are more personal but worth asking yourself: "Is my family member receiving overly aggressive care that does not align with person-centered care goals?" "Are we as a family giving this medication as a way to show that we have not given up hope, to demonstrate that we care and love him/her?" (Renn, 2018). These are tough conversations. Promoting care in the best interest of the person living with AD remains the goal.

Are there any negative consequences of discontinuing ChEIs in AD? There have been some randomized controlled trials that have examined this question. In 2015, an analysis of relevant studies in patients with possible or probable AD concluded that there were poorer cognitive outcomes among those who discontinued ChEIs (O'Regan, 2015). However, the clinical significance was again difficult to determine and most patients showed deterioration in the first 6 weeks after stopping the medication. There is no harm in restarting the medication in these patients. There is some evidence that patients who had initially responded to ChEIs were those who showed the greatest declines after discontinuation. It is also important to note that none of these patients had advanced dementia

or were living in nursing homes. A follow up trial in 2016 focused specifically on patients with advanced dementia (mostly patients in nursing homes, average age 89 years old) and found that when ChEIs were discontinued, there was no significant difference in cognition, function, and neuropsychiatric symptoms. (Herrmann, 2016)

These study results remind us how crucial it is to maintain a close relationship with a provider over time for ongoing conversations as the illness progresses. Since these studies have been completed, there remains little guidance for providers in making the decision to discontinue these medications. (Renn, 2018) In published guidelines and textbooks, there is no consensus about discontinuation. Well designed, long-term studies of discontinuation are not available and will be needed in order to provide scientific evidence for practice guidelines.

At this time, health professionals are encouraged to use an individualized approach to discontinuation while engaging patients and families in treatment decisions. For this reason, it is my hope that you feel comfortable openly communicating with your provider about your family member's treatment plan. Some reasons to consider discontinuation include lack of treatment response, burden of side effects, cost, cognitive or functional worsening such that treatment benefit is no longer evident.

A fundamental dilemma in dementia care surfaces here. Given the progressive course of AD, it can be difficult to define what a meaningful response to treatment might be. When a patient is no longer able

Some reasons to consider discontinuation include lack of treatment response, burden of side effects, cost, cognitive or functional worsening such that treatment benefit is no longer evident.

to interact meaningfully with others, it is likely that the severity of impairment from AD is beyond a level that would benefit from these medications. As dementia progresses, it is crucial to re-evaluate individual care goals which will evolve over time. You might think about transitioning from active treatment to palliative care. Some suggested triggers for this transition to

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LATE-LIFE DEPRESSION *(continued from page 8)*

we are currently studying have different pathways associated with cognitive health, they share common factors that may reduce the risk of cognitive decline. The first, of course, is minimizing the severity and duration of any depression symptoms that do occur by bringing them to the attention of a family physician or psychiatrist and seeking the appropriate approach to treatment. This is important at any time of life as repeated episodes of depression over the lifespan can raise the risk of cognitive impairment.

Other factors are more preventive in nature, as described by Gorelick and colleagues in a 2018 article in the journal *Stroke*. These include ideal health behaviors of 1) not smoking, 2) engaging in regular physical activity, 3) following a healthy diet, and 4) maintaining a healthy body mass index (<25 kg/m²). They also include aiming for optimal health conditions, including 1) a healthy level of blood pressure, 2) low total cholesterol level, and 3) low blood glucose. These factors have been referred to as the “Simple Seven,” though many of us will find meeting all of these goals to be far from simple!

Rather than becoming discouraged, it is important to

strive for as many of these targets as possible, preferably by setting goals with a spouse or other partner. Couples working together on these targets starting in midlife are likely to see the greatest benefit, but there are benefits from starting in late life as well. One good starting point is physical activity, which can trigger a cascade of events in the body that can improve blood pressure, body weight ratio, and blood glucose regulation. These factors in turn can improve vascular health and prevent frailty. Physical activity is an effective treatment for depression, and an important factor in maintaining healthy cognitive function with age, including potential improvement in people living with AD. Physical activity may encourage persons with mild cognitive decline to engage with others. If you are currently physically active, keep it up! If you are not, consider seeing your health care provider for recommendations on how to start. Your brain and body will thank you for it!

Guy G. Potter, PhD is an associate professor in Psychiatry and Behavioral Sciences and a clinical psychologist who sees patients at the Duke Neurological Disorders Clinic.

ALZHEIMER’S MEDICATIONS *(continued from page 10)*

palliative care include when the person with Alzheimer’s has severely impaired functioning requiring a move to nursing home care, when the person is no longer able to find comfort in visits with family members, or when s/he is no longer able to perform basic daily functions including eating. (Budson, 2016) It is important to reassess goals. I encourage you to seek guidance about advanced dementia care from your health professional. A medication review in which risks/benefits of ChEIs are reviewed can be a vital piece of this reassessment.

Anne D. Johnson, MD is a medical instructor in the Department of Psychiatry and Behavioral Sciences and a geriatric psychiatrist who sees patients at the Duke Behavioral Health Broad Street Clinic.

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A DIFFERENT VOW

By Kate Arnold

As seen in caregiver.com*

“Do you know where my husband is? Because he’s a good one and I’d hate to lose him.” This is her third husband, so Holly, my 80-something-year-old patient, has room to judge. I tell her he’s reading his book downstairs and she says, “He’s such a patient husband.” She asks this question every five minutes of her two-hour-long visit. She doesn’t know what city she’s in, but she knows she’s in love with her husband.

I was finishing my post baccalaureate premedical program at Georgetown. I was twenty-four, taking physics with 19-year-olds, and trying to find a job for the year I would spend applying to medical school. In an effort to convince myself that the work was worth it, I read *Final Exam* by Pauline Chen, MD. Dr. Chen says that good doctors recognize when death is inevitable and then strive to make the transition to death more comfortable and peaceful. Believing her, I decided to spend my year learning how to be with patients with hard diagnoses. I got a job as a research coordinator for clinical trials for Alzheimer’s disease, which is how I met Holly.

It struck me that Holly was so in love with her husband when she had lost touch with every other part of her life. In marriage vows, you promise to love each other forever. In over 50 percent of marriages, people are unable to keep this promise, and that’s both frightening and depressing to people in their twenties considering marriage—myself included. And yet, as I watch, my patients and their spouses face the hardest thing I can imagine together, in the process, they restore my faith in marriage as a sacred commitment. To love another in sickness and in health is a profound promise; and yet, it’s the tip of the iceberg when Alzheimer’s is involved. On your wedding day, you didn’t promise not to get mad when your spouse forgets a dentist appointment, forgets your wedding anniversary, forgets how to converse, forgets your name. And if you’re the one with Alzheimer’s you didn’t promise to never give up and to do your best to fight the disease you’ll eventually lose your life to. With a diagnosis of Alzheimer’s, these are the vows some choose to make, spoken or unspoken. And patients who can do that save their marriages.

Interspersed throughout the struggle are funny moments, and the only way to keep your sanity is to laugh. The patients tend to be disinhibited and, given that most of them were somewhat proper 80-year-olds, the things they say can be unexpected. When I asked Mr. O’Farrell, my Irish patient, if he helps out with chores, he said, “Well, sometimes I’m an ass.” Later in the visit, I asked him to address an envelope to himself



and he wrote, “Mr. Wonderful.” I made a copy of the envelope and taped it above my desk to keep me smiling. One caregiver, who’s usually heartbroken at visits, laughed while telling me that on Valentine’s Day, two beautiful bouquets arrived because her husband accidentally ordered flowers twice.

But the funny moments fade because they showcase how impaired the patients are becoming, and then it’s back to reality. When I got the job, my boyfriend at the time asked me if I would be able to handle it. It was a valid question and I wasn’t sure, but my goal was to learn to handle it and, I hoped, to learn to support patients and families facing Alzheimer’s.

I knew the job would make me cry, I knew sometimes I would feel heartbroken, and I knew I would often be emotionally overwhelmed.

And that’s been true because just as there are funny moments, there are also powerful moments

that grant you more insight than you ever wanted into what it’s like to live with Alzheimer’s. Like when Ralph told me Helen woke up disoriented one day, asking when it was time to go to school; and then sat on his lap and cried on his shoulder because she was disoriented and scared. Or a husband who simply stated that within two years, at the age of 54, his wife’s mind will be “shot.”

I never expected to be so emotionally engaged with my patients. When I started the job, I used to say hello and chat congenially; I now hug almost all of them. It might seem unprofessional, but I’m not their doctor. My job is to make coming to their study as enjoyable as possible. That’s not my job description, but it’s how I do the maximum amount of good. Now I’m invested in my patients’ fights, while knowing

To love another in sickness and in health is a profound promise; and yet, it’s the tip of the iceberg when Alzheimer’s is involved.

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VOW (continued from page 12)

they will most likely all lose.

My scariest moment came when I identified fully with one of my patients. I empathize with all of them. They tell me, after cognitive testing, they they're astounded and terrified at how easy the questions were and how they didn't know the answers. They read books about the progression of Alzheimer's and learn what will happen. But Martha was different; Martha was who I wanted to grow up to be. I would love to be her. She was tan, athletic, casually elegant, and ate healthy foods, but always caved when chocolate was involved. She had the family life I hope to have at her age; she had two grown kids, one granddaughter, and a husband who was in love with her. When I first met her, she was funny, light-hearted, kind, gregarious, and happy; but at 55, she has early onset Alzheimer's. At her last visit, Martha couldn't recognize the food on her plate. In the hall, she had trouble following me; and in the bathroom, she couldn't find the soap or faucet. I'm sure 15 years ago, she thought these would be the best years of her life. She had set herself up for it; it was time for her to travel and spoil her grandkids. Instead, she's slipping away. I looked at her and I wondered what she would have done if she had known this was coming and I felt overwhelmed. I could be her; this disease can happen to anyone and that's how I ended up at my mom's house crying.

My mom and I were watching "To Gillian on her 37th Birthday," which is about David, a man whose wife died two years ago, but every night he goes out to the beach where he can talk to her. Both David and all of my patients and their spouses have been robbed of the future they wanted. My patients and their families are losing the 20 years of vacations, new babies and quality time with each other they had expected to have. And they're living in a dual reality. The person they love is still

right in front of them; and yet, their partnership is ending and every day that person is a little more gone. I cried on the couch and couldn't breathe for what everyone at work has lost and what they will lose.

What gives me hope is seeing my patients fight for their love. I never expected to learn so much about marriage; but watching my patients fight for their marriages has been my favorite part of the job. My parents got divorced when I was in third grade because, simply put, it just wasn't working. While I'm not second-guessing the decision, it's healing for me to see couples face huge obstacles together and win.

Martha and her husband John are terribly in love. Just as Martha's visit is ending, John walks into the room. He usually goes and works while she stays at the hospital, stopping by to have lunch from the cafeteria with her. As John walks into the room, they smile at each other and their eyes twinkle. John asks her if she's ready to go home, she says yes, and they get ready to go. Martha can't tell which shoe goes on which foot, so John helps. They joke as John puts her shoe on; and if a stranger walked by, he would surely think it was an act of romance, not of necessity. John sees everything that's happening, but they've chosen to live together in good spirits despite the circumstances, and they convince me that it is better to have loved and lost than never to have loved at all. As they get ready to leave, his hand brushes her stomach with ownership and tenderness as he tickles her. With that one sign of affection, I see that they've won the battle. They will love each other until death do them part and that gives me hope.

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LEWY BODY RESOURCES

Lewy Body Dementia Association

LBD Caregiver Link: 888.204.3054 • <https://www.lbda.org>

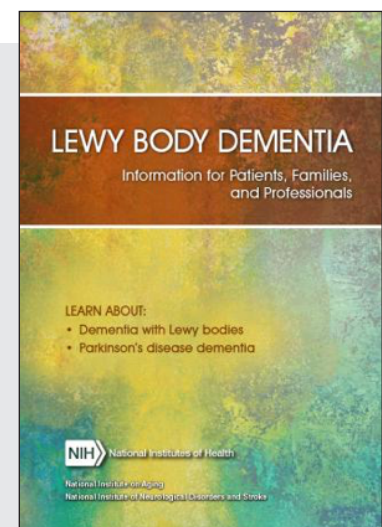
Family Caregiver Alliance

Dementia with Lewy Bodies • <https://www.caregiver.org/dementia-lewy-bodies>

University of California San Francisco Memory and Aging Center

Lewy Body Dementias • <https://memory.ucsf.edu/lewy-body-dementias>

Go here to order a free copy of the book on the right: <https://order.nia.nih.gov/publication/lewy-body-dementia-information-for-patients-families-and-professionals>



ACCESS TO GUNS DEBATED FOR PEOPLE WITH DEMENTIA IN NORTH CAROLINA

By Thomas Goldsmith

*This article originally appeared in the North Carolina Health News, 6/27/18**



This year's news of school shootings in Parkland, Fla., and elsewhere heightened a national debate over the ability of young people to buy and possess guns.

In North Carolina, a related discussion has proceeded – a mostly quieter one – about the level of access to firearms that should be available to people with incipient or full-blown dementia.

A graphic illustration of the danger possible in such situations emerged in the June 2016 death of Charlene Norris, 79, of Charlotte. Her husband, James Nelson Norris, 84, faces a July 19 court date on a charge of first-degree murder in her death. According to a media account, Michael Greene, Norris's attorney, claimed both Jim and Charlene had dementia at the time of the shooting. Greene declined a request for comment. A bill in the General Assembly, as previously reported by NC Health News, is intended to restrict access to firearms by people found at risk of harming themselves or others. The measure, HB976, would allow a family member or law enforcement to ask a district court for an "extreme risk protection order," or ERPO, to avert danger.

There's a larger question behind the gun issue: At what age or condition do people lose the right to make risky decisions? A middle-aged person who makes an unwise investment is likely out of luck, but an older person encouraged to buy a money-losing product may be the victim of an illegal scam. The issue of access to guns by older people has been compared

to seniors' ability to keep driving at advanced ages, a question that requires balancing an older person's need for mobility against safety concerns for himself and others.

The right to decide

"It's a dangerous situation for everyone," said state Rep. Marcia Morey (D-Durham), a former district court judge and one of the ERPO bill's lead sponsors. "We certainly don't want to stigmatize dementia, but that (ERPO) would absolutely definitely apply. It could very important for a family's safety." Under the proposed statute, sometimes referred to as a "red flag law," a judge could grant an emergency protection order to take away firearms, ammunition and carry permits from a person judged to be at risk of harming himself or others. While brought to public attention as a means to forestall school shooters, the ERPO procedure could also be used in cases where a person with Alzheimer's disease or dementia owns a weapon and causes concern to people near him.

Paul Vallone, president of the gun rights group Grass Roots North Carolina, strongly opposes the use of risk-based protection orders to take away people's guns. Nonetheless, he acknowledges that some people with dementia should not handle guns.

"The devil's in the details," Vallone said. "The bottom line is that I want to see due process in a court of law. There needs to be a hearing and there needs to be judicial adjudication that

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GUNS *(continued from page 14)*

the person is a danger to himself or others.”

“There are probably a lot of people in the early stages of dementia who can be responsible gun owners, and they have owned guns for years, particularly if they are a sportsman and have been a hunter,” said Mary Bethel, president of the state Coalition on Aging. “As with older adults and driving, it is an individualized issue.”

For those contemplating suicide, owning a firearm can guarantee “success.”

A study by the Violence Policy Center found only 8 percent of homicides were committed by people over the age of 55, but about 35 percent of suicides fell in that age group. According to detailed reports by the Centers for Disease Control and Prevention, about 80 percent of North Carolina suicides of people 65 and older were committed with a firearm. Among men older than 85, the 296 suicides by firearm between 2000 and 2016 represented about 95 percent of the total. And between one-quarter and one-half of people older than 85 typically show signs of dementia.

“It’s a really interesting and important problem particularly given the increasing population of older people and the fact that there’s going to be more people in North Carolina with age-related diseases, that are progressive, who have access to firearms,” said Jeffrey Swanson, a medical sociologist and professor at Duke University.

“An effective tool”

In 2017, Swanson and several colleagues published research on a law passed by the state of Connecticut in 1999, in the wake of a mass shooting at the state’s lottery offices. The law “established the legal practice of preemptive gun removal as a civil court action based on a risk warrant, a process that neither requires nor generates a record of criminal or mental health adjudication as its predicate,” researchers said.

Relatives or caregivers of people in long-term care shouldn’t have to worry about gun possession by residents, according to Ken Burgess of Raleigh, a partner at the law firm Poyner Spruill. Burgess wrote a post on the issue for the *National Law Review* in 2010 and confirmed this week that its information remains current law.

People who operate assisted living facilities or nursing homes can ban gun usage on their property, although the provision should be put into a written policy and supplied to relatives and families in advance, Burgess wrote.

“The U.S. Constitution’s guarantee of the people’s right to bear arms is found in the Second Amendment to the Constitution,” Burgess wrote. “Its reach is limited in that it only prevents the Government from infringing on a citizen’s right to possess guns for legal purposes. It does not reach private action by private persons, including those who operate residential or health care facilities.”

Although the law was intended to prevent homicides, the research showed that the principal result has been to reduce gun-related suicides.

“Laws that authorize police to remove guns from persons at risk of violence or suicide appear to be a logical and complementary approach to background checks in preventing gun violence,” the authors wrote.

Said Swanson: “I do think ERPOs could be an effective tool to prevent suicide in adults with age-related cognitive decline or a diagnosis of a major progressive neurocognitive disorder.”

GOP leaders at the General Assembly sent Morey’s ERPO bill to the House rules committee, from which many bills never progress. But she’s not giving up.

“We have a lot of people very supportive of it and we will keep trying and trying,” Morey said.

Nationally, the debate continues. A May 8 editorial in the *Annals of Internal Medicine* promotes the Alzheimer’s Association’s use of safety checklists that include the presence of firearms in the home of a person with dementia.

“Delusions about home intruders or confusion about the identity of persons in their lives may lead persons with dementia to confront family members, health aides, or other visitors,” the editorial says. “Access to a firearm may increase the potential for injury or death in such a situation.”

And a recent review conducted for the national Kaiser Health News estimated that of the 6.7 million residents of Washington state, about 15,000 people older than 65 reported “both cognitive decline and that they stored their guns unlocked and loaded.”

Bethel, from the state Coalition on Aging, says discussions are in order by relatives concerned about the presence of firearms.

“This is an issue which families should have conversations about and if the decision is made to continue to have guns, then safety precautions such as removing the ammunition from the gun and storing the gun in a gun safe should be followed,” she said.

Any move to establish a red flag law in North Carolina will likely face intense scrutiny, if not outright opposition, by strong proponents of Second Amendment rights. Grass Roots North Carolina’s Vallone said that older people should only have guns taken away by government under carefully designated conditions and only by a court of law.

“Driving is not a right,” he said. “The right to bear arms is enshrined in the Constitution.”

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BOOKSHELF

Age in Place: A Guide to Modifying, Organizing and Decluttering Mom and Dad's Home by Lynda Shrager, OTR, MSW, 2018. A practical guide to making the home safe for successful aging in place.

At Peace: Choosing a Good Death After a Long Life by Dr. Samuel Harrington, February 2018. This book outlines specific active and passive steps that older people can take to ensure family members live their last days comfortably at home and/or with hospice when further aggressive care is distressing. *At Peace* was recommended by a participant in Memory Makers.

Dadland, a biography by Keggie Darew, 2018, paperback version. For her adult life, Keggie was kept at arm's length from her father's personal history, but when invited to join him for the sixtieth anniversary of Operation Jedburgh, a new door opens in their relationship. As dementia stakes a claim over his memory, Keggie embarks on a quest to unravel her father's story, and soon finds herself in a far more consuming place than she had bargained for.

The Dementia Caregiver: A Guide to Caring for Someone with Alzheimer's Disease and Other Neurocognitive Disorders by Marc Agronin, 2017. This geriatric psychiatrist author believes that with the right resources and tips, caregivers can become expert at caring for the person with the diagnosis and themselves.

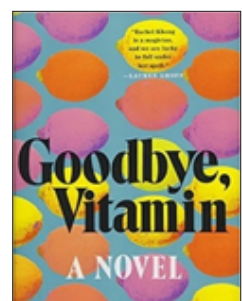
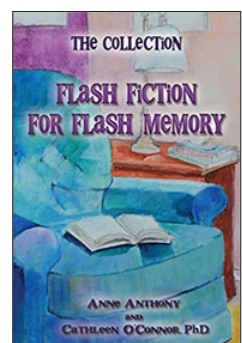
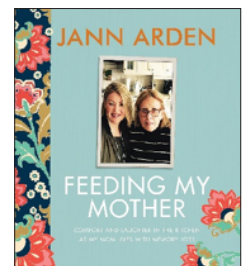
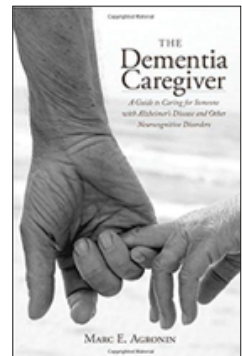
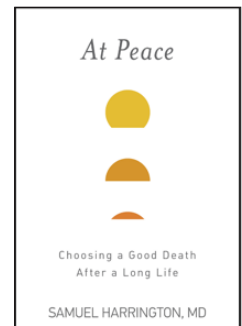
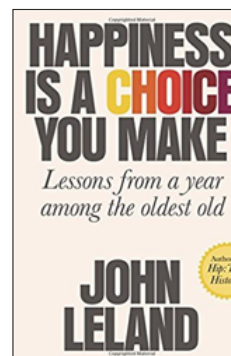
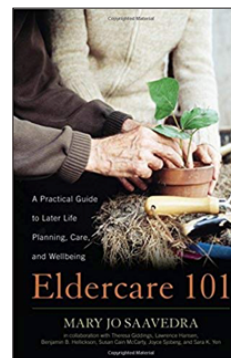
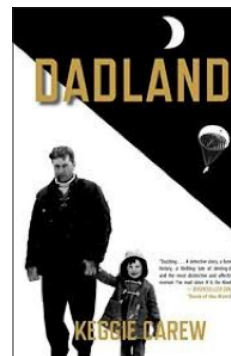
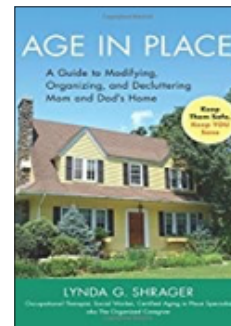
Eldercare 101: A Practical Guide to Later Life Planning, Care, and Wellbeing by Mary Jo Saavedra, 2017 paperback. *Eldercare 101* is a guide for families in need of help as they care for their aging family members. The book is organized into "6 pillars of aging wellbeing": legal, financial, living environment, social, medical, and spiritual.

Feeding My Mother by Jann Arden, 2017. Jann and her mother find comfort in shared time in Jann's kitchen. In cooking and mealtime, they both find a little peace in the midst of crazy uncertainty with her mother's Alzheimer's diagnosis. In her book she shares the affirmation and community she has discovered from people she never would have met due to her transparency.

Flash Fiction for Flash Memory by Anne Anthony and Cathleen O'Connor, Ph.D., 2018. This is an anthology of flash fiction stories selected for adults with memory and thinking changes. It includes 60 original stories between 500 and 750 words which can be read in a few minutes -- short enough and entertaining enough to follow along.

Goodbye, Vitamin: A Novel by Rachel Khong, 2017. This novel tells a fictional story of Ruth and her friends' attempts to shore up her father's career. In the absence of a cure for his dementia, she and her mother obsess over the ambiguous health benefits of dried jellyfish supplements and vitamin pills. They all attempt to forge a new relationship with the new man her father has become in the face of dementia.

Happiness Is a Choice You Make: Lessons from a Year Among the Oldest Old by John Leland, 2018. This is a collection of lessons that emphasize the extraordinary influence we wield over the quality of our lives. Using heart and wit, well-known journalist Leland has crafted a reflection on how to "live better" informed by those who have mastered the art.



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BOOKSHELF *(continued from page 16)*

Just Like Jackie by Lindsey Stoddard, January 2018. A children's book, this story explains the relationship between Robinson Hart and her grandfather. Grandfather's memory is changing and Robinson is unclear how to handle this within herself and with others. Recommended for ages 8-12.

The Long Hello: Memory, My Mother, and Me by Cathie Borrie, paperback 2018. This book recounts the seven years the author spent caring for her mother. During that time, the author recorded conversations she had with her mother that revealed the transformations of her mind.

Making Tough Decisions about End-of-Life Care in Dementia (A 36-Hour Day Book) by Anne Kenny, 2018. The author, a palliative care physician, describes how to navigate the difficult journey of late-stage dementia. Dr. Kenny offers practical advice based on her personal experience caring for a mother with dementia and her professional knowledge of dementia and end-of-life care.

Memory's Last Breath: Field Notes on My Dementia by Gerda Saunders, paperback 2018. In Saunders' autobiographical narrative of her journey with dementia, she outlines how her diagnosis changed her daily life.

Remembering for Both of Us: A Child Learns about Alzheimer's by Charlotte Wood, 2014. Drawn from personal experience, this is a story of an African-American child's first glimpse of Alzheimer's and a reminder that ties of the heart transcend age and illness.

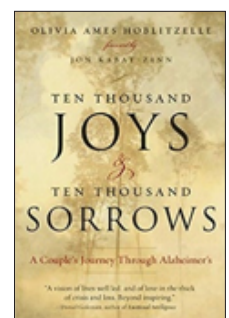
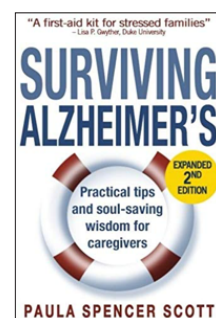
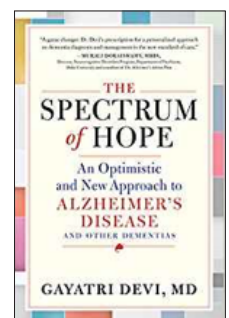
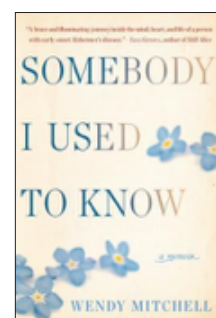
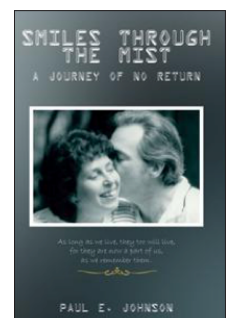
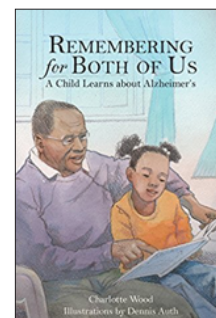
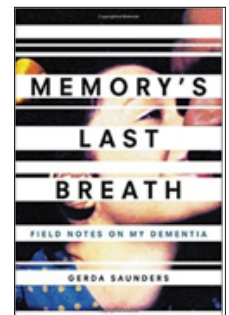
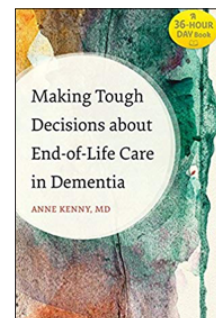
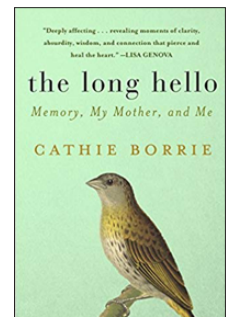
Smiles Through the Mist: A Journey of No Return by Paul E. Johnson, November 2017. A local author and active participant in Duke Family Support Program support groups, Johnson writes of loving care for his wife, Helene, who had Alzheimer's. Johnson believes that strength is garnered in sharing our story and struggle.

Somebody I Used To Know by Wendy Mitchell, 2018. Diagnosed at 58, this British National Health Service employee found herself facing young-onset Alzheimer's. This chronicles her journey to accept her shifting world.

The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias by Gayatri Devi, MD, 2017. Dr. Devi uses the experiences of her patients to convey that each experience with dementia is different. She offers tips for families from recognition through late-stage care.

Surviving Alzheimer's: Practical Tips and Soul-Saving Wisdom for Caregivers by Paula Spencer Scott, 2nd Edition released January 2018. This expanded edition offers current, practical and wise counsel from professionals and families who care about how to help someone in your family with memory loss without sacrificing the caregiver.

Ten Thousand Joys & Ten Thousand Sorrows: A Couple's Journey Through Alzheimer's by Olivia Ames Hoblitzelle, 2010. This is a wife's memoir of her experience when her 72-year old husband is diagnosed with Alzheimer's. They are forced to live and practice spiritual teachings learned over the course of their marriage. This book is highly recommended by a participant with the Duke Family Support Program.



NORTH CAROLINA

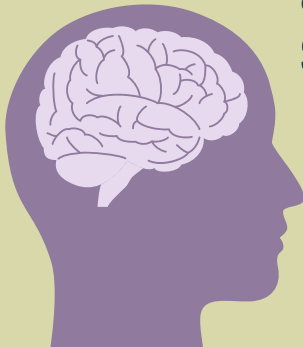
SUBJECTIVE COGNITIVE DECLINE

NC

2016 Behavioral Risk Factor Surveillance System (BRFSS): People Aged 45 Years and Older

1 in 9

people aged 45 years and older are experiencing

Subjective Cognitive Decline

SCD is self-reported MEMORY PROBLEMS that have been GETTING WORSE over the past year.

85%

of people with SCD have at least one chronic condition

**49%**

of people with SCD had to give up day-to-day activities

**less than half**

of people with SCD have discussed their symptoms with a healthcare provider

**nearly half**

of people with SCD say it interfered with social activities, work, or volunteering

**40%**

of people with SCD need help with household tasks



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alzheimer's
association®

cdc.gov/aging

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June 2018

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The CAREGIVER

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