living with or caring about someone with Alzheimer's disease is no walk in the park. Individuals and families want programs to “Stand By Me”.

A uniquely flexible $1.1 million anonymous gift, the largest single gift to the Duke Family Support Program in its 35-year history, expands the scope and reach for Duke’s Alzheimer’s Early-Stage Community Programs. Non-profits like the Duke Center for Aging’s Family Support Program are only as effective as our capacity to make up for shortfalls in research and contract funding. This generous gift will allow us to support individuals and families now and in the future who are living with neurocognitive diseases, while we wait for preventive or biomedical answers to Alzheimer’s and related diseases.

Dr. Harvey J. Cohen, Director of the Duke Center for Aging, announced this gift for Duke’s Early-Stage Alzheimer’s Community Program on September 25, 2015, at the 60th anniversary celebration of the Duke Center for Aging. A newly endowed Duke Family Support Program Fund assures our capacity to sustain, enrich and expand education and support programs for new and progressing early-stage Alzheimer’s individuals and families throughout their diverse family experiences.

This gift will build on and expand successful key collaborative partnerships like our original partnerships with the Alzheimer’s Association, the Durham-Chapel Hill Jewish Family Services, Duke’s Bryan Alzheimer’s Disease Center and Clinic, and the Nasher Museum of Art at Duke.

The gift ensures what is learned in Durham does not stay in Durham. The anonymous donor encourages the development of innovative strategies to prepare other professionals and communities to offer quality information and support to individuals and families, regardless of location.

Future goals with our endowment funding include expansion of programs for persons living with mild cognitive impairment and for people with early-stage dementia without care partners. What we learn will be participant-centered, rigorously evaluated and shared widely.

We began in September, 2015 with an expanded pilot workshop for our participant-named “Alpha” families. These families are part of a community of “graduates” of all the eight-week education and support programs who continue to gather monthly in support groups, weekend luncheons and museum...
programs. The September workshop addressed questions about what’s next for early-stage families.

This gift further builds upon new Duke Alzheimer’s services and education programs. In June, 2015, Dr. Richard O’Brien, chair of the Duke Department of Neurology, provided funding to hire a first-ever third full-time social work team member for the Duke Family Support Program, Janeli Smith, MSW, LCSWA (see p. 4). Janeli splits her time with the Duke Memory Clinic, closing the gap between clinical and support services.

New federal grant support will further expand the DFSP Fund’s reach. Drs. Mitch Heflin and Eleanor McConnell from Duke’s Geriatric Medicine Division successfully competed for a three-year federal Health Resources and Services Administration grant (one of 44 national and 3 NC grants) for a Geriatric Workforce Enhancement Program (GWEP). Duke's GWEP will build on our early-stage Alzheimer's community program to expand teaching and learning communities of people living with Alzheimer’s, their families and current and future health and social service professionals.

Looking for a program to stand by you on your Alzheimer’s journey? Call 919-660-7510 or visit www.dukefamilysupport.org.

Lisa and Bobbi
There are more than thirty people gathered in the back room of a Durham café, chatting away as waiters carry in plates of tuna salad sandwiches and Greek salads.

“Are there any more chairs?” someone asks, as more people enter, two by two. “It’s a huge bunch today.”

Welcome to the Alpha Group. The three dozen or so people gathered here today are graduates of the Duke Family Support Program’s Early-Stage Alzheimer’s Education and Support Group, an eight-week program for people diagnosed with early-stage Alzheimer’s and their care partners. After finishing with the support group, many members had grown so attached to the community they’d developed they wanted it to continue. So now they all meet here at the café once every month. They talk. They share what’s new. Sometimes they laugh. Sometimes they cry.

There’s a little bit of both laughing and crying today. Group members go around the room giving updates on what’s happened since the last Alpha Group. One woman has had a new grandchild. A retired New York City policeman makes a joke about his wife dressing him. Another woman shares that she’s recently moved her husband to an eldercare home.

“I think we’re both a little sad,” she says.

“I’m glad you came,” says the woman next to her.

A man shares that his wife has fallen and broken her hip. After the injury, her neurological state has declined dramatically.

“I’m hoping for the best, but planning for the worst,” he says, his voice breaking.

“I’m glad you came,” someone says, again.

Debby and Tony have found the Alpha Group invaluable. The couple moved to North Carolina from Saint Michaels, Maryland to be closer to their daughter after Tony was diagnosed with Alzheimer’s and aphasia. He later received a diagnosis of Lewy body dementia as well. They heard about the early-stage support group from their son-in-law and signed up immediately.

“It was absolutely wonderful because we had nothing like it in Saint Michaels,” says Debby, a 78-year-old retired school employee. “It was like I was the only person in the world with this kind of problem.”

After graduating from the early-stage group, they knew they wanted to continue to see the friends they’d made. They both feel relaxed socializing with fellow group members, knowing they understand their situation and will remain patient if Tony, an 84-year-old retired engineer, has trouble remembering words.

“A person who has not been around somebody with aphasia and Alzheimer’s, they just don’t have a clue,” Debby says. “A lot of regular people who don’t have ailments like this don’t necessarily want to be around us.”

In the Alpha Group, they can talk about anything and everything, Debby says.

“Sometimes everything is really funny, and other times it might be very serious,” she says. “You never know, but you come out of there with a really good feeling that I have people who are like me and who care.”

Gary and Janet feel similarly. The longtime North Carolina residents have been regular attendees at Alpha Group get-togethers.

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THE ALPHA GROUP (continued from page 3)

“You enjoy seeing the people, right?” Gary, a 68-year-old retired IBM employee says to Janet, a 70-year-old retired administrative assistant.

“Yeah,” says Janet, who received an Alzheimer’s diagnosis about three years ago. “It’s something we look forward to,” Gary says. “You get a chance to connect with folks who are traveling the same journey.”

Sometimes Janet is a bit confused when they get in the car to head to Alpha Group, Gary says. But once she’s there, she’s always enthusiastic to see old friends. “By the time we’re leaving, she’s always ‘up,’ if you will,” he says.

“It’s a good place,” Janet says.

While Janet relishes the opportunity to socialize, Gary also enjoys exchanging useful information with fellow members. People talk about what medications are working for them and which ones aren’t, swap therapy tips and discuss potential future living situations.

“There are discussions like ‘we should all sell our houses and get a big piece of property and buy one of those communities,’” he says, laughing.

Though an elder commune may not be in the works just yet, it’s clear that group members are serious about supporting each other for the long haul.

As the group at Saladelia finish with their lunches, a woman stands up and begins to cut a cake decorated with pink, yellow and purple balloons. There are four birthdays in the group today.

“We feel this is our family group,” says the woman slicing the cake. “So we brought this cake to celebrate with our family.”

Emily Matchar is a freelance writer living in Hong Kong and Chapel Hill.

Though an elder commune may not be in the works just yet, it’s clear that group members are serious about supporting each other for the long haul.

WELCOME, JANELI SMITH
The Newest Voice of the Duke Family Support Program (DFSP)

We are delighted that Janeli Smith, MSW, LCSWA joined our staff in June. Last year Janeli was an advanced standing student at UNC-Chapel Hill School of Social Work, and she worked with our Early-Stage Alzheimer’s Education and Support Group while completing her field work internship with Duke’s Geriatric Evaluation and Treatment Clinic. Prior to attending graduate school, Janeli was a case manager at the Council on Aging for Henderson County. In that position Janeli coordinated services for seniors living in their homes. Her direct experience providing community-based aging services is invaluable to our Program.

Janeli is co-facilitating three of the DFSP Alzheimer’s support groups, working with Bobbi Matchar as a NC Project C.A.R.E. family consultant and she is even the technical wiz behind our Triangle monthly e-news. When not in our office, Janeli can be found working with individuals and families at the Duke Memory Disorders Clinic.

It’s a pleasure to see Janeli, Daniel and their dog Rylee start to call the Durham-Chapel area home. And we feel very fortunate to have Janeli on our team!

Janeli can be reached at janeli.smith@duke.edu or by phone at 919-660-7510.
REFLECTION

By Margaret Toman

In the beginning my mother’s Alzheimer’s disease appeared as the loss of a word or a name, an item strangely placed, a social engagement forgotten. She was in her 70’s, the incidents were rare and fleeting and I dismissed them as “senior moments.” Now I see clearly what I could not see then – she was being stalked by a cunning illness stealthily taking its time. I didn’t suspect a thing. In many ways the early years of her illness were the worst because in my confusion and denial I, who love my mother so dearly, was my worst self.

By her early 80’s, the disease was gaining. A polished raconteur, my mother entertained listeners with lively anecdotes delivered with style and authority. Her stories were true, her punch lines sharp, her words concise, until at some point I noticed that all her sentences ended with “and” as she launched into one interminable story after another, seeming to make things up as she went along. Other listeners still hung on her words but I grew irritable and impatient, knowing privately that much of what she was saying was simply not true. Mystified by her embellishments I challenged her, sparking sharp denial and increasing her confusion. It did not occur to me to question her health, which had been sturdy throughout her life.

Unusual rocks, fallen bird nests, arrowheads and other treasures she found during her beloved walks in the woods made her small apartment more eclectic than pristine. Still, she had always been a conscientious housekeeper. She was in her middle 80’s when I began to notice on my visits that she was hoarding outdated catalogs, old magazines, circulars, newspapers, unopened mail. When I ventured into her drawers I found decades-old bank statements intermingled with church bulletins, scraps of paper with unidentified phone numbers, ratty bedroom slippers, bird eggs, eye glasses, half eaten orange peels, shredded pine cones, theater tickets she requested for her birthday and didn’t use, although she had related to me how wonderful the shows were. I confronted, she denied. Usually easy going and happy, she became critical, suspicious, and combative – a phase of her illness that, in my ignorance, I likely exacerbated. Uncustomarily, we sparred. “Depression,” I surmised, because she was a widow living alone. She was still driving, still baking, still wearing her trademark red carnation and pearls, still warm and social.

When the thick, rich chocolate icing that she skillfully swirled into peaks and waves on my birthday cake every year became circular and flat, I thought, “she’s just growing old.”

Once she complained that she couldn’t remember anything, how strange dreams ran through her head constantly when she slept – frame after frame of odd, unrelated images that left her exhausted on awakening. I sympathized, bought her magnesium and melatonin, encouraged her to drink water, and read up on insomnia. I began to call and visit more often. But I still didn’t consider the possibility of dementia, a disease I knew little about but that I was sure would not afflict someone so sharp. Surely my devotion alone would protect her.

In her late 80’s the falls began – two fractured hips, a broken coccyx, a cracked right elbow that forever ended her baking, sewing, writing and painting. She would insist that she slipped on a small spot of water in the kitchen or in the bathroom or that her shoe had hooked onto the sidewalk curb. She was authoritative, convincing. I believed her. So did everyone else. Even the medical professionals who treated her during these years never brought up the possibility of dementia.

Then, on one pivotal visit she told me in anguish that she felt she was deep in a hole with no ladder. On that same visit she wandered away for several hours, terrifying me and resulting in an emergency visit to her physician, who authorized a brain X-ray and tests by a neuropsychologist. “Alzheimer’s disease,” he pronounced, naming an enemy that, I would come to learn, sets its own rules of engagement. Alzheimer’s disease held up a mirror to me that demanded truth. Did I see the signs? Yes. Did I know what they were? No. Was I in denial? Yes. Was I resistant to how our lives might change if I knew the truth? Yes. Was I selfish? Yes – and scared. Did I love my mother? Yes, with all my heart. Would I, could I, do whatever had to be done at this crossroads? I didn’t know. I balked. As an only daughter I had altered my

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GET WITH THE PROGRAM

By Liz Seegert

Once you and your family member have absorbed the reality of the Alzheimer’s diagnosis, it's time to think about the practical matters of care and daily life.

While changes may be subtle at first, the truth is that learning to cope with a continually shifting “new normal” can be daunting. This article documents all the early steps you can take – and decisions to consider – to make the transition as smooth as possible.

Setting Out

“The change is always in us,” says Kerry Mills, nationally recognized dementia coach and author of I Care: A Handbook for Care Partners of People with Dementia. “We can’t change a person with dementia, so we will always have to change ourselves to be able to see a difference in the situation.”

Building Your Team

Ideally, you and your family member have already had a lengthy discussion about what lies ahead. If you are not going to be the primary caregiver, whoever is taking on this responsibility should be included in meetings from as early a stage as possible.

Specialists are often more current on new clinical studies and are experts in dealing with issues like agitation, sleep disturbances, paranoia and coping with impaired thoughts. Make sure to review any new medications or changes in medications with each practitioner.

Local support groups are very helpful. “Finding a good group that is just for spouses will help you find out the things doctors and other professionals don’t tell you,” says Allen Vann, whose wife Claire was diagnosed with early-onset Alzheimer’s eight years ago at age 63.

Partner with a primary care provider to coordinate all facets of health care and manage medications. If the doctor or nurse practitioner is already part of a patient-centered medical home – a model of care where one provider is the point person to coordinate all other services: specialists, tests, medications or home care – then it will be easier for everyone to stay on top of changes in disease progression, medications or manage problems.

“Most older people are already juggling several chronic conditions, with multiple providers and multiple medications,” said Susan Reinhard, PhD, RN, Senior Vice President for Policy at the AARP. “When you lay Alzheimer’s on top of that it can be a real challenge to ensure that people get the right care at the right time.”

Check your family member’s current health plan and consider alternatives during the open enrollment period if you’re not satisfied with the level of care coordination or communication among providers.

Then, of course... family. Gerry Polnivy, 86, relies on her daughter to help keep track of the many clinical appointments and medications for her husband, who is in the mild stage of the disease. “She keeps a calendar and writes all the appointments on it and when to give each medication,” she explains.

Polnivy’s husband sees a cardiologist, neurologist, and urologist in addition to regular visits to their primary physician. “I don’t know how I’d manage all of this without her help,” she says.

Get Organized, Stay Organized

Financial planning and health directives are critical issues that must be addressed shortly after diagnosis, say experts at the American Bar Association. Many families are unprepared for the consequences of this disease because of inadequate planning and poor communication among caregivers, and other family members.

Finding a good group will help you find out the things doctors and other professionals don’t tell you.

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Basic documents such as an **advance directive** should be updated and discussed with providers to ensure that medical decisions are carried out according to your relative's wishes.

Virtually everyone should create a financial power of attorney and a health directive, said Charles Sabatino, Director, ABA Commission on Law and Aging, American Bar Association. Although generic forms are available online, Sabatino says that they usually only cover 75 to 80 percent of what's needed.

“Spending time with an attorney who specializes in eldercare addresses issues that you may not have even thought about, like protecting assets, creating trusts and avoiding potential abuse or exploitation.”

An advance directive is the most important health document to draw up immediately. This allows your family member to name a designated health agent. The primary provider, adult children, and other caregivers should be told of the provisions.

Some providers may refuse to share health information, citing HIPAA (Health Insurance Portability and Accountability Act) privacy rules. This is a federal law that sets rules for health care providers and health insurance companies about who can look at and receive a person's health information.

Or, they may insist on having the patient sign a proprietary waiver.

That's just wrong, Sabatino advises. “It should be legally sufficient for anyone named in the advance directive, including other family members, to access and discuss health information with a provider.”

Laws vary by state so be sure to work with someone who is familiar with requirements where your relative lives. Although the basic framework is similar in most states, many provisions are idiosyncratic, Sabatino says.

“And that’s, I think, the scariest part, because you’re responsible all of a sudden for this other person and paying the bills and making all these really big decisions that maybe you haven’t thought about before.”

“Many people are just not comfortable handling this; it can become overwhelming very quickly.”

**Location, Location, Location**

Wisconsin resident Jennifer Zaijaick was “constantly on the phone” long distance with her father’s physician in Florida. It’s been anything but an easy experience. “We're working to find a respite facility here [in Wisconsin] that will help care for him, but it’s getting too complicated and his health has really declined,” she explained.

“It’s been a difficult journey finding the resources all the way around to help take care of him, and know what to expect.” She ultimately had to change jobs to free up more time to devote to caregiving.

The lesson here is that the reality of dealing with Alzheimer’s and other forms of dementia varies from state to state, and from city to city. This is simply a fact of American life, and is something that should be taken into account as you chart your course.

**Talking the Talk**

An important part of the caregiver’s journey is learning a new language. Here are some useful definitions:

**Advance Directive** is a document by which a person makes provision for health care in the event that, in the future, he or she becomes unable to make decisions. There are two types of advance directives – a living will and a health care proxy (also called durable medical power of attorney).

**Living Will** is a signed, witnessed (or notarized) document called a “declaration” or “directive.” Most declarations instruct an attending physician to withhold or withdraw medical interventions from its signer if he or she is in a terminal condition and unable to make decisions about medical treatment.

**Health Care Proxy**, sometimes called a “health care surrogate” or “durable medical power of attorney,” is a signed, witnessed (or notarized) document in which the signer designates an agent to make health care decisions if the signer is temporarily or permanently unable to make such decisions. Unlike most Living Wills, the Durable Medical Power of Attorney for Health Care does not require that the signer have a terminal condition. An agent must be chosen with great care since the agent will have great power and authority to make decisions about whether health care will be provided, withheld or withdrawn from the signer.

**Palliative Care** includes pain and symptom management and emotional and spiritual support when someone faces a chronic, debilitating or life-threatening illness. Palliative care specialists work with the person, the family and the care team to help improve quality of life during and after treatment for your specific medical concern. It is provided in tandem with life-prolonging therapies.

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REFLECTION (continued from page 5)

I would be more observant of my mother’s “senior moments” and not deny them. I would not ignore behavioral changes simply because they irritated me. I would listen and watch with greater discernment. I would offer more comfort, steady patience, sturdy reassurance. I would learn everything I possibly could about aging and about Alzheimer’s disease. I would turn the community upside down in search of resources, wisdom and the experience of caregivers who have gone before me. I would question prevailing assumptions about the elderly, including assumptions of my own. I would not evade for so long the mirror that Alzheimer’s disease still holds up to me every single day. I would choose love over fear.

Margaret Toman is the sole caregiver for her 101-year-old mother. She is also a writer, public speaker, caregiver advocate and community volunteer. Margaret and her mother live in Garner, NC.

GET WITH THE PROGRAM (continued from page 7)

Research, Research, Research

Here are some examples of good places to turn for guidance.

Patients Rights Council http://www.patientsrightscouncil.org/site/advance-directives-definitions/


ABA Estate Planning FAQs http://www.americanbar.org/groups/real_property_trust_estate/resources/estate_planning/living_wills_health_care_proxies_advance_health_care_directives.html


Family Caregiver Alliance: End of Life Decision Making https://caregiver.org/end-life-decision-making

U.S. Living Will Registry http://uslivingwillregistry.com/ The U.S. Living Will Registry electronically stores advance directives and makes them available to health care providers 24 hours/day via secure Internet or telephone-facsimile. The registry stores ALL types of advance directives: living wills, health care proxies, health care power of attorney, as well as organ donor information. Phone: 800-LIV-WILL (800-548-9455)

Liz Seegert is an independent health journalist who covers aging and related issues. This article originally appeared in www.Alzlive.com. Alzlive.com is a free, daily, digital lifestyle and news platform designed specifically for the unpaid family caregivers of people with Alzheimer’s and dementia in the United States and Canada.
PREDICTING ALZHEIMER’S THROUGH THE EYES

Parts of this article originally appeared in the Duke Center for Aging’s Spring 2015 “Center Report.”

By Bobbi G. Matchar, MSW, MHA

Most issues of The Caregiver include an article about a current research study. This month we take a slightly different approach by featuring a specific researcher, geriatrician Heather Whitson, MD, MPH of the Duke Center for Aging. We recently spoke with Dr. Whitson in her office – an office filled with books, journals and photos of her two young sons – to learn about her work linking cognitive and brain changes with late-life vision loss.

Dr. Whitson traces her interest in geriatrics to her first year of medical school at Cornell where she landed a summer internship in clinical aging research. After medical school she hightailed it back to the South (where she grew up) to begin her residency in internal medicine, and became involved in research at the Duke Center for Aging. Working with senior researchers on projects in the Center, Whitson became interested in multimorbidity – the coexistence of two or more chronic medical conditions in one person. This is an important area of study because the health changes people experience as they age are rarely attributable to one cause.

“I realized that the thing that fascinated me about these projects was the complex interplay between chronic conditions and how one condition may alter the risk or the optimal management of another condition,” she says.

Whitson’s grandparents influenced her career path. Her grandfather was an accomplished scientist and public health official with the CDC who saw public health as a patriotic duty. Her grandmother, an educator with a PhD (who got her pilot’s license in her 60’s!) influenced Whitson’s decision to go into academics. At the time Whitson was sorting out which comorbidities to focus on, her grandmother began experiencing mild cognitive impairment (MCI), in addition to her ongoing macular degeneration. Watching her grandmother struggle to maintain independence while dealing with MCI and macular degeneration (this was a time before there were drugs to stabilize the condition) led Whitson to begin studying the consequences of coexisting cognitive impairment and vision impairment. Her goal has been to understand how to “improve outcomes for people with this pair of conditions.”

Vision problems and cognitive impairment are two of the most common and devastating issues in aging. The two problems frequently co-occur, which can be overwhelming for seniors and their families. Whitson’s research looks into why these issues often seem to travel hand-in-hand. What kind of changes might occur in the brains of people who lose their eyesight late in life? Is Alzheimer’s disease perhaps associated with distinctive changes in the retina? If so, could finding these eye changes help diagnose Alzheimer’s early in its course?

Whitson is currently the principal investigator of two studies that look at the link between changes in the eye and the brain. In the “Center Report,” Whitson explains, “One study investigates biomarkers as a potential means of detecting early Alzheimer’s disease, while the other study…investigates brain and cognitive changes that develop in the context of age-related macular degeneration.”

Alzheimer’s starts years before symptoms are apparent. By the time a diagnosis is made, brain cells have already been destroyed. Whitson and her Duke colleagues are looking at the eyes, using new retinal scanning software, to diagnose Alzheimer’s before the damage has begun. Retinal scans capture images of the layers of the retina. These scans are fast, painless, non-invasive and inexpensive. The retina is part of the central nervous system and it is the only place in the body where you can see central nervous system tissue without a biopsy. Researchers look at these retinal images for abnormalities that could signal early signs of Alzheimer’s.

Learning how to diagnose Alzheimer’s earlier is a crucial area of research. Currently, by the time Alzheimer’s is diagnosed it’s too late for medications
FINDING YOUR EXERCISE SWEET SPOT: HOW MUCH IS ENOUGH?


By Miriam C. Morey, PhD

Physical activity enhances wellbeing and quality of life; it’s finding the balance of quantity and quality that’s tough.

Miriam C. Morey, PhD.

Anything More than Sedentary Is Better

It’s a well-known fact that many people don’t like to exercise. Nonetheless, exercise is often touted as the best medicine ever. It’s cheap, safe, with many benefits and minimal negative side effects. In the 1990s, exercise scientists called upon the government to issue public health recommendations promoting exercise. First, they decided to call it “physical activity” because “exercise” sounded too hard. Second, because the greatest health benefit was observed among people moving from being sedentary to becoming moderately active, they worded the recommendation in a way that focused on the minimum amount of physical activity needed to gain a health benefit. Lost to the public were the messages about “more” being better. These articles provide convincing evidence that indeed more is better; more amounts, more intensity, and yes, anything more than sedentary is better.

The first Physical Activity Guidelines for Americans, published in 2008 by the Department of Health and Human Services, state “some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits. For substantial (emphasis added) health benefits, adults should do at least 150 minutes (two hours and 30 minutes) per week of moderate-intensity activity, or 75 minutes (one hour and 15 minutes) of vigorous-intensity aerobic physical activity.”

The recommendation further says that additional health benefits will accrue when higher doses of physical activity are added beyond the recommended amount.

DOSE-RESPONSE RELATIONSHIP. A current study (JAMA Archives of Internal Medicine, April 6, 2015) of 661,137 men and women over a 14-year period documents a dose-response relationship, and adds some new knowledge to the existing body of evidence. Researchers found that those who enjoy moderate exercise of 150 minutes/week are 31 percent less likely to die prematurely compared to people who never exercise. But if you triple the amount of moderate exercise, to 450 minutes/week, you are 39 percent less likely to die prematurely than people who never exercise. Even exercising less than the recommended amount lowers risk of premature death by 20 percent. The small population that exercises 10 times the recommended amount of time (1,500 minutes/week) was found to have no health risk due to the more vigorous activity.

Researchers concluded that meeting the recommended guidelines (of 150 minutes/week) provided almost the maximum longevity benefit. So if you’re inactive, small amounts of activity will confer substantial benefits, while very active people need not fear premature death.

ADDING INTENSITY. A second, Australian study of 200,000 people found that even if a person exercised moderately, an occasional dose of vigorous exercise conferred a reduction in premature mortality risk. Thus, if you exercise the recommended 150 minutes/week, and spend 20 to 30 minutes of that time exercising vigorously, you’ll be a leg up in the mortality sweepstakes. Researchers defined vigorous as activity “that makes you breathe harder or puff and pant, like jogging, cycling, aerobics, competitive tennis, but not household chores or gardening.” Moderate activity examples cited were “gentle swimming, social tennis, vigorous gardening or work around the house.”

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PREDICTING ALZHEIMER’S THROUGH THE EYES
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to work. The most commonly prescribed drugs may help manage symptoms of the disease, but cannot cure Alzheimer's or stop it from progressing. Accurately identifying people early on the path to Alzheimer's is important because medications to slow the progression could be more effective when started early. Whitson's hope is that earlier diagnosis of Alzheimer's via retinal imaging might even lead to the development of entirely new treatments.

One of Whitson's other major projects is the study of cognitive changes in Age-Related Macular Degeneration (AMD). This study enrolls both people with AMD and healthy controls. The participants undergo cognitive testing and brain MRIs, which look for brain signatures to help explain why people with AMD have a higher risk of developing certain cognitive deficits.

Whitson is also working with the Durham VA Medical Center to develop enhanced rehabilitation services for blind and low-vision veterans who also have cognitive deficits. She originally developed and piloted this rehabilitation program at the Duke Eye Center, and she is now carrying on her work in the VA system, a longtime major provider of low-vision services.

Whitson's work comes too late to help her grandmother. But hopefully it's in time for her children and grandchildren's generations.

FINDING YOUR EXERCISE SWEET SPOT
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BOTTOM LINE. Choose your physical activity according to your preferences and abilities, bearing in mind that vigorous activity is more time-efficient, if time is an obstacle for you. The important thing is to get up and move.

EXAMPLES OF PHYSICAL ACTIVITY

**Moderate Intensity**
Requires a moderate amount of effort and noticeably accelerates the heart rate.

- Brisk walking
- Dancing
- Gardening
- Heavy Housework
- Walking pets
- Carrying / moving moderate loads (<44 lbs.)

**Vigorous Intensity**
Requires a large amount of effort, causes rapid breathing and a substantial increase in heart rate.

- Fast swimming
- Running
- Aerobics
- Walking / climbing
- Fast cycling
- Carrying / moving heavy loads (>44lbs.)

Miriam C. Morey, PhD is a Professor of Medicine in the Department of Medicine, Division of Geriatrics at Duke Medical Center.

Cognitive aging—a process that involves physical changes in the brain and its ability to carry out various functions—affects every segment of society, but has received little national attention, according to a report sponsored by multiple agencies and issued by the Institute of Medicine.

The report was based on two years of study by a committee chaired by Duke University School of Medicine’s Dan G. Blazer, MD, MPH, PhD. It has raised awareness of the issue and suggested what can be done about it, individually and collectively. A summary of the findings was published online April 15, 2015, in *JAMA—the Journal of the American Medical Association.*

“Many people think that because cognitive aging isn’t classified as a disease, it isn’t something about which we should be concerned,” says Dr. Blazer, who also serves as Editor-in-Chief of DukeMedicine HealthNews. “Changes in mental function and capabilities, such as memory, speed of processing information, attention, and decision-making, are a part of aging and occur with everyone,” he continues. The extent and nature of these changes vary widely and are gradual, and aging can have both positive and negative effects on cognition.”

The process of cognitive aging can affect daily functions like paying bills, understanding complex instructions, taking the right medications at the right time, and driving. It could have an effect on a person’s ability to enjoy favorite activities. Among other key features characterizing the condition, cognitive aging:

- Is inherent in humans and animals
- Occurs in individuals regardless of their pre-existing cognitive function
- Varies widely within and between individuals
- Includes mental capacities that may not change, may decline, or may improve
- May hold the potential for older adults to strengthen some cognitive abilities
- Is not a clinically-defined neurological or psychiatric disease, and does not inevitably lead to dementia or Alzheimer’s.

**COGNITIVE AGING VERSUS COGNITIVE IMPAIRMENT.** “Even though some of the symptoms are the same, there are two important ways in which cognitive aging and mild cognitive impairment (MCI) differ,” explains Dr. Blazer. “With cognitive aging, there is not a significant loss of neurons (nerve cells), as there is in mild cognitive impairment which leads to Alzheimer’s disease. What you do see is a progressive disconnect between neurons. One reason for hope is that you might actually be able to restore those connections and improve cognitive function.

“The second distinction is that while mild cognitive impairment doesn’t happen in every person, it can lead to an increased risk of Alzheimer’s. With cognitive aging, there is no increased risk. Everyone ages cognitively.”

**WHAT YOU CAN DO.** The Institute of Medicine committee identified three actions, all supported by scientific evidence, that people can take to maintain cognitive health and perhaps reduce the negative effects of cognitive aging:

- Be physically active.
- Reduce and manage cardiovascular disease risk factors, including hypertension, diabetes, and smoking.
- Regularly discuss and review health conditions and medications that might influence cognitive health with a health care professional.

**WHAT YOU SHOULD KNOW:**

**Aids For Dealing With Memory Lapses**

- Take notes (for names, directions, key points when listening).
- Make lists (for groceries, things to do, telephone numbers, email addresses).
- Take pictures (with your smartphone of signs, parking spaces, directions).
- Maintain a calendar (for doctors’ appointments, business meetings, birthdays).
- Use timers (for medications, hydration, exercise).
- Ask for help (from a friend or family member) to help you remember names, events, places

— Adapted from Weill Cornell Medical College Women’s Health Advisor

In addition, the committee identified other steps supported by evidence. They include:

- Being socially and intellectually engaged
- Seeking opportunities to learn
- Getting adequate sleep
- Receiving treatment for sleep disorders

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COGNITIVE AGING (continued from page 12)

- Taking measures to avoid the risks of cognitive changes due to delirium, if hospitalized. This is especially important for older adults who have undergone surgery.

“In general, people who remain intellectually engaged do better (in adjusting to cognitive aging) than individuals who don’t,” says Dr. Blazer. “We don’t know exactly what it is about intellectual engagement that enhances cognitive function, but we know it helps.”

“We also know things that don’t work,” he says. “Among them are supplements and drugs. Medications may come along that could be of benefit, but we haven’t seen them so far.”

“Possibly more important are questions about brain stimulation games and activities. There is no evidence at this point that improvement in these activities can be transferred to other areas of life, nor that there are long-term benefits. Still, further research is needed to adequately determine the value of these types of activities.”

Dr. Blazer’s Message:

“Cognitive aging is real, but there is hope.”

FAMILIES CAN HELP. The first signs of cognitive aging in older adults are often memory loss (or taking a longer time to remember something), a slow decline in reaction time, and difficulty in making quick decisions.

Individuals and their families also should be aware of the potential for financial fraud, impaired driving skills, and poor consumer decision-making. They should be encouraged to make health, finance, and consumer decisions based on reliable evidence and trusted sources, and to have a built-in system of checks and balances to protect themselves from bad decisions.

Even though relatively little research has been conducted and very few guidelines have been established, the committee recommends that cognitive health be promoted during regular medical and wellness visits for people of all ages.

Patient visits could be used to identify and minimize risk factors, review medications that might affect cognition (opiates, antidepressants, and anticonvulsants, for example), provide information regarding the process, and encourage patients and family members to talk about cognitive health.

WHAT’S NEXT? “We hope that, as a result of the report, follow-up education, and increased awareness, a number of groups will get together and develop an action plan to address cognitive aging,” says Dr. Blazer. “We would like the National Institutes of Health to fund more research, and we encourage companies that market brain stimulation programs to conduct and publish peer-reviewed studies to determine their effectiveness.”

The Institute of Medicine committee emphasizes that cognitive aging is not just an individual, family, or health care system challenge. It is an issue that affects every facet of society and requires action at many levels.

Dr. Blazer’s message: “Cognitive aging is real, but there is hope.”

COGNITIVE AGING: SEPARATING FACT FROM FICTION*

Misconception

✗ Maintaining cognitive health means preserving your memory.
✗ Cognitive function always declines with age.
✗ There is nothing you can do to improve cognitive health.
✗ Brain neurons die as you age, so there is no way to prevent cognitive decline.

Fact

✓ Cognitive health involves memory, decision-making, preserving your memory, attention, and problem-solving.
✓ Aging can have positive effects, including wisdom, expertise, and greater satisfaction with life.
✓ Individuals and families can take action to adapt to age-related cognitive changes.
✓ In the absence of disease, neuron death is minimal. You can take steps to support cognitive health.

*Adapted from “Cognitive Aging: An Action Guide for Individuals and Families”

MY JOURNEY TO FIND A PLACE FOR TERRY

By Jane Johnson

Jane Johnson is a member of the Duke Bryan ADC Person with Dementia and Care Partner Support Group. Jane’s husband Terry had Alzheimer’s disease and Jane cared for him at home for many years. When Jane could no longer care for Terry at home, she moved him into a nearby memory care facility. Below is an excerpt from a piece Jane wrote for her support group about her experience.

As 2014 was coming to a close, I realized that he was fading, sleeping more and more, restless at night, not eating the things he always liked and losing weight, and more incontinent and confused. He no longer recognized family members, including me many times, although I was the only person he called by name most of the time. After talking with his MD and the folks at the Duke Geriatrics Clinic, I realized I needed to find an inpatient facility for him. His MD told me it would be easier for me if he didn’t die at home. I knew he was right even though I felt guilty being an RN. Terry reminded me of my parents in their last months. I was with my Mother in PA in their home when she died and my Father lived with us here for about six months before his death in one of our bedrooms as I watched. Terry was different in that he filled every room of our home of 30 years together, and I knew I didn’t want him to die here. I felt I may not be able to live here after if he did.

So, again I began the process of finding places in a similar way as for home care. At no time had I mentioned what I was doing to Terry for fear he would rebel or worry needlessly until I came to a decision.

I settled on a Memory Care Center that was a 10 minute drive from home – very convenient. This was a small place – only 38 residents at maximum capacity which I liked, with three shifts of caregivers and a fulltime RN and LPN on day shifts during the weekdays and on call on weekends. I met the activities director and all the administrative staff. I got pamphlets and booklets about the facility, rules and added costs to read. It was overwhelming.

Once a space opened – a man had “transitioned” is what they called it when he died, I was called and agreed to take the space for a month of respite. I felt this would give Terry a month to adjust as well as myself – or not. I outfitted his side of the room with nice bedding, got his clothes ready, labeled, and toiletries assembled. I had tons of paperwork to fill out and decisions to make. I still had not told him of any of this yet. It was killing me to think of telling him, and I lost many hours of sleep over it. Our families all supported me emotionally and agreed it was for the best.

At this point I had not been sleeping in the same bed with him for about a month. He was too restless. It had been years since we had had a solid night’s sleep. Maybe that helped him get used to us not sleeping together – that month before he was admitted to Memory Care, I will never know. Just as I never knew what was going through his head ever with this disease. I think that was

continued on page 15
The one thing he never lost was his sweetness and loving spirit. For that I will always be grateful.
Online Help

*See Duke Family Support Program website for an expanded and updated list of online resources.

AGING

HHS.gov Aging The US Department of Health and Human Services offers information about important topics in aging, including healthy habits, health issues, long-term care, elder justice, and retirement planning. The new website also provides links to state resources.

Eating Well as You Get Older This NIH Senior Health feature provides basic information on healthy eating for aging adults. Topics include choosing what foods to eat and staying within budget.

Older Drivers NIH Senior Health provides information about the effects of aging on driving and offers tips for staying safe.

NIH Study Shows No Benefit of Omega-3 A recent large NIH clinical trial raises doubt about any benefits omega-3 and dietary supplements like these may have for slowing cognitive decline.

Curious about the Aging Brain A video about Saul Villeda and his research on how age-immune changes affect the ability of brain cells to regenerate. Villeda hopes to find ways of reducing the effects of aging on the brain.

Brain Health This brand new website from the Administration for Community Living includes info about the changing brain, tips for staying sharp and links to other “brainy” resources. Go there to learn about brain health and how you can make the most of your brain as you age.

StoryCorps Launches ‘The Great Thanksgiving Listen’ On Thanksgiving weekend 2015, StoryCorps will use smartphone technology to record interviews between high school students and their grandparents or other elders across the county. Interviews from this “Great Thanksgiving Listen,” will be uploaded to the StoryCorps archive at the American Folklife Center at the Library of Congress.

ALZHEIMER'S DISEASE AND RELATED DISORDERS

Physician Compare Physician Compare is a new Centers for Medicare and Medicaid Services (CMS) website that helps you find and choose physicians and other health care professionals enrolled in Medicare. At this time you can only compare group practices, but you’ll be able to compare individual professionals in the future.

Alzheimer's Disease and Down Syndrome Alzheimer's disease and Down syndrome share a genetic connection, and individuals with Down syndrome may face an increased risk of dementia at a younger age. The National Down Syndrome Society provides an introduction to Alzheimer's disease and a guide to caregiving principles for dementia.

Responding to Wandering A paper discussing the needs of people at risk of wandering and person-centered approaches to meeting these needs. The paper also provides resources to help caregivers address wandering and exit-seeking behaviors.

His Neighbor Phil “His Neighbor Phil” is a not-yet-released movie about Harvey and his wife Mary, who has younger-onset Alzheimer's disease. The movie shows the impact that Alzheimer's has on the person with the diagnosis, their family and the entire community.

CAREGIVING

The Caregiver Space A website designed to provide support and understanding for caregivers, including practical tips and short personal narratives from other caregivers.

What to Ask When Interviewing a Home Care Worker Hiring an in-home care worker on your own? This article lists 15 questions to ask the potential home-care worker during the interview to find the best match for your family member.

Caregiver Training: Refusal to Take Medication A YouTube video from UCLA offering recommendations to help caregivers when the person they are caring for refuses to take their medication.
BOOKSHELF

**Being Mortal: Medicine and What Matters in the End**, by Atul Gawande, 2014. Gawande, a practicing surgeon and gifted storyteller, shares his personal views on the inescapable realities of aging, illness and death and how changes in modern medicine could better support “a good life to the very end.”

**Caring for a Loved One with Alzheimer’s Disease**, by Dr. Peter Rabins and Dr. Ann Morrison, 2015. This practical guide for caregivers covers topics ranging from everyday issues of bathing and behaviors to larger decisions such as moving a relative to residential care. Available for purchase ($49.95) here: [http://www.healthafter50.com/special_reports/memory_reports/HomeCaregiver_landing.html?s=EMH_150706_001&st=email](http://www.healthafter50.com/special_reports/memory_reports/HomeCaregiver_landing.html?s=EMH_150706_001&st=email).

**Caring for a Person with Alzheimer’s Disease: Your Easy-to-Use Guide from the National Institute on Aging.** A guide for people who care for family members or others with Alzheimer’s disease at home, written to help care partners learn about and cope with the changes and challenges of the disease. Download or order free here: [https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide](https://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease/about-guide).

**Coping with Behavior Change in Dementia: A Family Caregiver’s Guide**, by Beth Spencer, Laurie White, 2015. This new handbook is intended to help families understand possible causes of common behavior changes and to learn how to respond effectively. There are also sections about communication and problem-solving, a glossary and an extensive list of other resources.

**Life in the Balance: A Physician’s Memoir of Life, Love, and Loss with Parkinson’s Disease and Dementia**, by Thomas Graboys, 2008. A nationally renowned cardiologist, Graboys was diagnosed with Parkinson’s disease and the onset of dementia at age 60. Despite the daily challenges he faced, Graboys continued to provide hope for others in his inspiring memoir.

**The Mindful Caregiver: Finding Ease in the Caregiving Journey**, by Nancy Kriseman, 2014. Caregiving can be enormously challenging, rewarding, and potentially draining. Caregivers often wonder how they will navigate the tumultuous waters of caregiving and not lose themselves completely. Remembering to care for oneself when someone else is in great need can be difficult, but with the suggestions and tips in this book, caregivers can cultivate routines and practices that benefit everyone.

**The Other Side of Alzheimer’s: What Happens to You When Your Spouse Has Alzheimer’s**, by Martha-Lee Ellis, 2012. This is a collection of personal experiences, ranging from confusion, loneliness and fear to understanding and peace. Ellis, a North Carolinian, describes the physical, mental, and emotional challenges, while incorporating humor and hope.


**The Theft of Memory: Losing My Father, One Day at a Time**, by Jonathan Kozol, 2015. Kozol, a National Book Award winner, tells the story of his father’s work as a renowned neurologist and his subsequent slow decline with dementia. The beauty of the memoir is Kozol’s portrayal of the bond with his father, and the ways that bond intensified as the elder Kozol’s illness worsened.

**When Caring Takes Courage: A Compassionate, Interactive Guide for Alzheimer’s and Dementia Caregivers**, by Mara Botonis, 2014. This book provides tools designed to assist caregivers with daily challenges such as bathing and managing difficult behaviors as well as communicating with healthcare professionals and finding affordable care options.

*Lily Huang, a Duke senior and work-study student at the Duke Family Support Program,* wrote this Bookshelf section.
Online Help (continued from page 16)

MEDICATIONS

**Herb-Drug Interactions**  Herbs and botanical products may interact with other pharmacologically active compounds in prescription and over-the-counter drugs. The National Center for Complementary and Integrative Health provides information about several herbs and their potential interactions with various medications.

**Avoiding Drug Interactions**  This article provides a comprehensive overview on preventing medication problems when taking multiple medications. The overview includes brief discussions of medication-medication interactions, herbal remedies, food-drug interactions, and reactions to drugs.

**Vaccination Info for Older Adults**  A handout from the Health in Aging Foundation covering essential vaccination information for older adults. Check with your healthcare professional about other immunizations for you, including shots for shingles, tetanus, diphtheria and pertussis.

PLANNING, INSURANCE & LONG-TERM CARE

**Online Resources to Start Advance Care Planning Conversations**  Six resources that can help start the advance care planning conversation. Advance care planning allows you to express preferences for medical care in advance of a crisis which may affect your ability to speak for yourself.

**New Guidelines May Encourage End-of-Life Discussions**  A PBS podcast about the national movement to encourage end-of-life discussions among family and friends. The podcast discusses the importance of talking openly about dying and a new Medicare guideline which may promote these conversations.

**Durable Medical Equipment**  A guide on durable medical equipment (DME): what it is, what insurance covers, how to choose the right DME, who can help, and how to use and take care of DME.

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**Participating in Alzheimer’s Research: For Yourself and Future Generations**

Participating in a clinical trial or study helps medical researchers find new ways to treat and prevent Alzheimer’s and other diseases, and could help future generations lead healthier lives. A comprehensive pamphlet from the National Institute on Aging and the National Institute of Health with everything you wanted to know about participating in Alzheimer’s research.

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