

The CAREGIVER

*A Bridge to Understanding
Your Options*

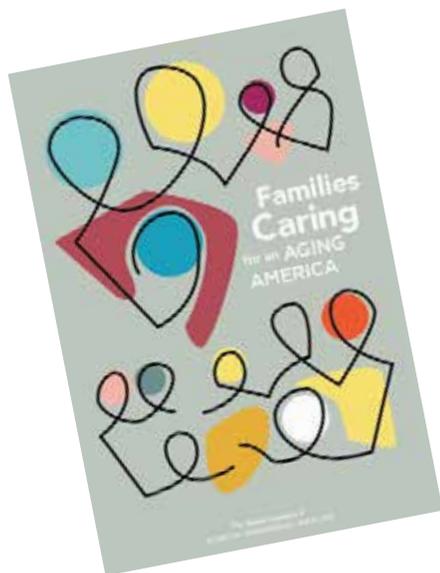
Newsletter of the Duke Family Support Program

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A Shadow Work Force: Invisible and Assumed

Families, often invisible and assumed, provide the lion's share of long-term services and supports for older adults, according to a 2016 report from the National Academies of Sciences, Engineering and Medicine. (See page 3 summarizing some recommendations.) In 2011, **8.5 million family caregivers provided help to 4.9 million high-need older adults, 70% of whom care for people with Alzheimer's or a related disease.** Families may prefer the assurance that a beloved family member is well cared for (see page 7 "Bridges"), but when dementia family care is especially complex, intense, and extends over years, family caregivers risk emotional, social, physical and financial harm. The report calls on our collective social responsibility to insure more person *and family centered* systems of care. In the meantime, the National Institute on Aging offers this reminder for family caregivers.



MAKE YOURSELF A PRIORITY, TOO
[TIPS FOR CAREGIVERS]

Nearly 15 million Americans provide unpaid care to an older adult.

Caregivers who provide substantial care are more likely to have physical & emotional health problems.¹

Take care of yourself.
It is one of the most important things you can do as a caregiver.

- Ask for help when you need it.
- Spend time with friends.
- Join a support group—in person or online.
- Take breaks each day.
- Keep up with hobbies.

Use these tips, and learn more about caregiving at www.nia.nih.gov/caregiving.

NIH National Institute on Aging

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



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Lewy Body Dementia Association

LBD Caregiver Link: 800-539-9767
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<http://www.lbda.org/>

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

Office (San Francisco, CA): (800) 445-8106
<https://www.caregiver.org/>

DUKE FAMILY SUPPORT PROGRAM: HOW WE HELP

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

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

The program also offers (free of charge – by phone, email or mail) to all NC residents:

- Help with care decisions and coping strategies.
- Personalized tips on caring for people with memory disorders.
- Research updates and options for participation in Alzheimer's treatment and prevention studies.
- Help selecting support groups, education programs, online help or books.
- A comprehensive, mailed information packet on Alzheimer's and caregiving.

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

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

A PRACTICAL TO-DO LIST FOR FAMILY CAREGIVERS

By Judith Graham

Reprinted with Permission from Kaiser Health News*

Ask Kathy Kenyon about what it's like to be a family caregiver, and she'll give you an earful.

On several occasions, doctors have treated this accomplished lawyer like she was an interloper — not the person to whom her elderly parents had entrusted health care and legal decision-making.

Kenyon wasn't told how to identify signs that her mother, who had low sodium levels, was slipping into a medical crisis. Nor was she given any advice about how to prevent those crises from occurring.

When her parents — both with early-stage dementia — moved to the Washington, D.C. area, it took months for medical records to be transferred because Kenyon's right to the information wasn't initially recognized.

An aberration? Hardly, according to a long-awaited report on family caregiving from the National Academies of Sciences, Engineering and Medicine, which acknowledges that the nearly 18 million caregivers for older adults are routinely marginalized and ignored within the health care system.

"Caregivers are, on the one hand, heavily relied upon but on the other hand overlooked," said Richard Schulz, chair of the 19-member expert panel that crafted the report and a professor of psychiatry at the University of Pittsburgh.

Deeming that unacceptable, the panel has called for extensive changes to the health care system, including a family-centered approach to care that would recognize caregivers' essential contributions.

What might that look like, practically, from a caregiver's perspective? The report doesn't say, but recommendations can be extrapolated from its findings.

Your identity needs to be documented in your loved one's medical records. "We need to start by having a clear sense of who the caregiver is" so that individual can be recognized as part of a team looking after an older adult, Schulz said. Currently, this doesn't happen routinely.

That's beginning to change. Thirty states, the District of Columbia, the U.S. Virgin Islands and Puerto Rico have now passed versions of the Caregiver Advise, Record, Enable (CARE) Act, drafted by AARP, which calls for information about family caregivers to be included in hospital medical records.

At every doctor's appointment with an elderly family member or friend, check that the record lists your name and phone number, and ask that you be contacted in any kind of emergency.

Your capacity to provide care to a loved one should be assessed. A classic example: An elderly man with diabetes and severe arthritis who weighs 220 pounds is discharged from the hospital, barely able to walk. His elderly wife, who weighs just over 100 pounds, is his caregiver and she's expected, somehow, to help him get in and out of bed and keep him from falling.

"No one asks you if you're comfortable doing the things you'll need to be doing, if you have the time or what other responsibilities you have," said Laura Gitlin, a member of the panel and director of the Center for Innovative Care in Aging at Johns Hopkins University School of Nursing.

Your job: Speak up and tell doctors, nurses or social workers what you can and cannot do.

Your capacity to provide care should be incorporated into your loved one's care plan. Your abilities and limitations need to be recognized and addressed in every care plan that's developed for your loved one. If you work from 7 a.m. to 3 p.m. and a parent needs help toileting, dressing and eating breakfast in the morning, for instance, that gap needs to be acknowledged and discussed.

There's a lot at stake: Unrealistic expectations about caregivers' capacities put the health of seniors — and caregivers' own health — at risk.

You should get training in medical tasks for which you'll be responsible. More than half of family caregivers don't receive training in the tasks they're expected to perform for loved ones at home: dressing wounds, changing catheters, administering medications or managing incontinence, for instance.

Although the CARE Act calls for training to be provided in hospitals and rehab centers, this isn't happening on a widespread scale, yet.

Nothing substitutes for hands-on instruction, usually from a nurse. Be sure to reach out to hospital, rehab or home health nurses and ask for help understanding what you need to do and how to do it.

You should be connected with community

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TO DO LIST *(continued from page 3)*

resources that can be of help. A variety of resources for caregivers are available in many communities: local Area Agencies on Aging, which offer assistance accessing services; centers on independent living, which help people with disabilities; and disease-focused groups such as the Alzheimer's Association, among other organizations.

But too often, "it's not at all clear where families should turn when they get a diagnosis," Gitlin said. "No one tells them who they should contact or which resources might be most helpful."

Ask for this kind of information from your physician's office, discharge staff at a local hospital and people you know in the community. The government's Eldercare Locator is a good place to gather names of local organizations that may be of help.

You should be given access to medical records and information. Misunderstanding of the medical privacy act known as HIPAA (Health Insurance Portability and Accountability Act) is common and creates barriers to family caregivers getting information they need to oversee a loved one's care.

In fact, medical institutions are obligated to hand over information when an older adult has granted a caregiver a durable power of attorney for health care decisions or a HIPAA authorization specifying that

they receive access to medical materials.

In written testimony to the government, Kenyon said she was once told she couldn't walk down a hall to see her father in a sleep center because doing so would violate HIPAA. That was an ill-informed interpretation of the law.

While there's no easy solution, standing up for yourself is essential. "Advocate for your rights and make sure your caregiving contributions are recognized and supported to the extent they can be," said the University of Pittsburgh's Schulz. "You're an important person in the health care system."

**Kaiser Health News <http://khn.org/> (KHN) is a national health policy news service that is part of the nonpartisan Henry J. Kaiser Family Foundation. KHN's coverage of late life and geriatric care is supported by The John A. Hartford Foundation.*

Judith Graham is a freelance journalist who has written for the New York Times, Kaiser Health News, the Washington Post, the Journal of the American Medical Association, and other publications. Her sister Deborah had frontotemporal dementia (FTD). Graham wrote about her sister's end-of-life with FTD in <https://www.statnews.com/2016/09/16/dementia-last-wishes/>.

THINK IT'S ALZHEIMER'S? THINK AGAIN.

SHE STARTED STARING AT ME WITH A BLANK STARE.

SHE RAN AFTER THE DUCKS AT THE PARK. SHE'S 55.

HE GOT LOST COMING HOME FROM WORK.

HE WOULD COMB HIS HAIR WITH A TOOTHBRUSH.

SHE HAD NO FILTER AND WOULD SAY THE RUDEST THINGS. HE COULD NO LONGER BALANCE

THE ACCOUNTS AT WORK. SHE WOULD PACE AROUND THE HOUSE FOR HOURS.

HE BOUGHT A YACHT. WE LIVE IN KANSAS.

HE STARTED TO FALL FOR NO REASON.

SHE WAS NO LONGER THE LIFE OF THE PARTY. HE BECAME SOMEONE WE DIDN'T KNOW.

Not all dementia is Alzheimer's. The most common form for people under age 60 is FTD, which brings dramatic, progressive changes in behavior, personality, language or movement.

The Association for Frontotemporal Degeneration (AFTD) is dedicated to a world without FTD, and to ensuring that people facing it today have the support they need.

Help us make a difference: www.theAFTD.org/learnmore

WISE & WELL

*Monthly Newsletter of the
Alzheimer's Disease Prevention Registry
of the Duke Alzheimer's Disease
Research Center, May 2016*



“What is good for the heart...is good for the brain” is now a common slogan of most healthcare professionals when asked how we might protect our brains against Alzheimer's disease. Lifestyle factors, including a “heart-smart” diet, have been shown to have a large impact on brain health in later life. But a number of questions remain: What nutrients are important? How often should they be consumed? Can too much of a good thing be bad? Recent work shared at the Lillian Fountain Smith Conference on Nutrition in Fort Collins Colorado addressed these questions.

Dr. Shukitt-Hale and her research team at Tufts University reported some compelling evidence that diets supplemented with blueberries and strawberries may improve both cognition and physical function in both humans and in animal models of Alzheimer's disease. In rodent models of accelerated aging, the researchers found that animals fed extracts of blueberries and strawberries for at least 30 days were protected from brain injury. The berries seemed to have positive effects on biomarkers of inflammation, oxidative stress, and cellular clean-up, a process called “autophagy.” This finding suggested that by boosting the brain's natural house-keeping processes, there is a reduction in the toxic proteins associated with Alzheimer's disease. Parallel studies conducted in older human volunteers (age range of 60-77) showed similar beneficial effects on cognition. In these studies volunteers received in pill form either freeze dried blueberries (~equivalent of 1 cup/day), freeze dried strawberries (~equivalent to 2 cups/day) or placebo for 3 months. The investigators showed that participants who were given the blueberries had improved problem solving ability on cognitive testing; whereas, those receiving the strawberries did better on tests of spatial and verbal memory.

The health value of berries was further underscored by work out of Rush University, led by Dr. Martha Morris, which examined diet patterns in older adults. Individuals who were on the MIND diet, that is consuming 2 servings of berries a week along with whole grains, fatty fish, nuts and legumes, did better on cognitive testing. Further work suggests that adherence to this diet can also partially offset the negative effects of the typical high-fat, high calorie Western diet. This is important since most people are not always compliant with a healthy diet.

Together, these studies suggest guidelines for berry intake to improve brain health. Eating more of these fruits is not likely to be unhealthy. However, one has to be a bit concerned about a potential downside if these fruits have been treated with pesticides. Recent reports suggest that pesticide use is common in blueberry and strawberry farming in the US. The jury is out as to how much (or whether) pesticides are harmful for brain health. A large study is being conducted by Duke and the National Institutes of Environmental Health Science to explore whether there is a risk for brain disease from pesticides (R01 ES024288). Led by Dr. Brenda Plassman of the Duke University Bryan ADRC, this study will provide more information about the effects of pesticides on later life cognition. As results become available in the future, we will share them with you. In the mean-time, one need not be daunted in eating healthy and choosing fruits. To avoid unhealthy exposures to pesticides, choosing organic is one option and washing fruit well can also help lessen the risk.

Learn more about Duke's ADRC Prevention Registry at <https://adrc.mc.duke.edu/index.php/research>.

LIFE AFTER CAREGIVING

By Sandra O'Connell

As seen in <http://www.caregiver.com>. Reprinted with permission.

“The only way for me to survive is for the two people I love the most to die.” When I wrote those words I was unable to foresee a future without the endless demands of caregiving. At the time, my beloved husband, Rev. Ralph Minker, and my mother were each suffering from a form of dementia. He was diagnosed with Alzheimer’s disease at age 69; Mom had vascular dementia, not uncommon for someone in her ninth decade. In the midst of the great balancing act that is the caregiver’s reality, another kind of life seems impossible. And when it is over (YES caregiving does end) there are new challenges in finding a life not consumed by your loved one’s illness.

The intense pain and anguish of those years is behind me now: a “new normal” has emerged from the days when caregiving ended. Now I find contentment if not joy, I laugh more than I cry and at last have recovered my health. The journey has not been a straight line; detours abound for depression, resentment, loneliness and grief. Finally there come moments, hours and then days, and at last there are weeks and months when the stress of those years does not dominate my life. Perhaps my experience will help those trying to find their way to a new normal after being a caregiver. There is no right or wrong way—each journey is individual—I only suggest a few guidelines to adapt as your own.

Find your own way to grieve. The overwhelming feeling of most caregivers in the initial stage of loss is not grief, but relief. When my husband died, the days of repeated questions, skirmishes over meals and getting dressed, the sadness of watching his growing confusion and the nights of interrupted sleep ended. For caregivers of someone with memory issues, relief will often trump grief. The person you once knew has been fading away for several years. With illnesses such as stroke or cancer, there is relief that the physical suffering is over mixed with your loss. Most approaches to grief counseling don’t cover the unique feelings that come after years of caregiving. I did not find it particularly useful, although a few of the books did offer helpful nuggets of advice.

The intense pain and anguish of those years is behind me now: a “new normal” has emerged from the days when caregiving ended.

But then, so was lying on the couch in a semi-catatonic state for hours on end, although after a while that did get boring. It helps to not add guilt over feelings of relief to the grieving process. Eventually the pain of grief abates. Here are my suggestions to help the process:

- write in a journal
- talk with friends
- go to a support group
- see a counselor
- find solace in your faith
- cry as you need to

Grief, however, does not vanish. Occasionally, without warning, like an errant wave, the pain of loss will tromp you. Each successive wave tends to subside more quickly and leave less damage.

Regain your health. Your body has most likely paid a price for your turn at caregiving: high blood pressure, incipient heart problems, rising sugar levels, weight gain (or loss), poor sleep and depression are among the calling cards it may leave behind. Now is the time to put YOU at the top of the priority list. Even if you sought support, went to yoga, took walks and had breaks, the stress of long-term caregiving wears away at your psyche and your body. No one with any real-world experience will deny what the researchers have well documented: long-term

caring for a person with serious illness is a source of chronic stress, which is not good for your health. No need to attack everything at once; I set small goals for weight loss and a moderate increase in exercise. After three years of effort, which included multiple ups and downs (and losing 30 pounds), I was able to stop the cholesterol medication and relinquish anti-depressants. Each success fueled my ability to be more active and take on a new challenge such as volunteering at a local museum. In turn, feeling healthier gave me enough energy to do what is truly healing: engage with my community, develop new interests and friends, and spend time with people who care about you.

Build a new normal. After the death of her

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BRIDGES

By Margaret Toman



Eight months after my mother's death, I seem to be doing surprisingly well if "surprisingly well" means no bouts of agonized sobbing, attacks of guilt or withdrawal from the world. My tears have been more an anointing than a drowning. Well-meaning people warn that an abyss may yet lie ahead but for now it seems that after 16 years of difficult and devoted caregiving, devastation has been eclipsed by relief.

From the time of her diagnosis with Alzheimer's disease to the time of her death last December at age 102, my mother and I lived in a small house that I bought just for that purpose. We faced daunting challenges over those years - my job loss, her disease progression, financial strain, crises that rolled in like waves. That these were also years of transcendent love and devotion that I would do again does not negate the fact that as her Alzheimer's disease progressed, caregiving became increasingly arduous. For the last six years of her life my mother was totally dependent on me, as my wrecked knees, shoulders and finances attest. Mine is the comforting clarity of knowing why I did it. I loved her deeply. I didn't want to relinquish her care to strangers, preferred that she enjoy the comforts of home, and didn't want her to die of neglect in a nursing home as my brother did. I lived in suspense over the caregiving years, wondering about the how and the when of her death, dreading it, and forestalling it with a fierce and determined love. I died to myself with each loss she suffered and knew that a large part of me would go with her at the end. Perhaps the abyss has already been plumbed.

Bridges that I began building years ago span the before and after of my caregiving years: community service, political advocacy, social activism, and writing. I still comfort myself in the same ways: visits to the Farmer's Market, reading books about space and time,

working challenging crossword puzzles, reveling in music and in Velcro, who still declares her love for me with vibrant purring.

I miss my mother. I began missing her while she was still living, as dementia gradually eroded her identity and tamped her vibrancy. The door to her room is closed against the commotion of belongings still being sorted, her ashes sit on the hearth awaiting my disposition, her smile graces me from photographs around the house, I still "see" her in her chair. Pressed in the pages of poetry books I found dozens of 4-leaf clovers she spotted and picked as easily as if they were dandelions. In the back of her drawer was a bird's nest we found together during a walk, reverently wrapped in tissue paper and protected in a box labeled with her distinctive script, "Architectural Masterpiece." My tears spill silently, like falling stars.

Lately there are long stretches of time during which I do not think about my mother at all. I am pragmatic about this. I was with her when she died. I closed her eyes and escorted her to the ambulance for our final farewell. When tears come suddenly and unbidden, I accept them as a tribute to our steel wool love, believing that sorrow has inherent dignity and pain its own wisdom. I have made friends with melancholy. Wistful, nostalgic and kind, melancholy allows sadness without the self-recrimination of depression or the rigor of grieving. Melancholy concedes the light and shadow of memories and the freedom to move on.

In legal nomenclature I am now an "elder orphan," defined as "aging, childless, single," in my case, a heterosexual female who didn't marry. Aside from irritable joints I am in good health but keenly aware that time is gaining. I fear incarceration in a nursing home someday with Bible study and Bingo the only offerings for my adventurous mind. I need a health

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AFTER CAREGIVING *(continued from page 6)*

*The experience of caregiving will always be a part of who you are,
but the experience needn't define your future.*

husband and daughter, Joan Didion wrote in *The Year of Magical Thinking*, “I wanted to scream. I wanted my husband back.” Magical thinking, indeed. We all want our life back, the life we had before cancer, before the stroke, before ALS, before Alzheimer’s. Building a life with meaning and relationships is the challenge faced by each person after caregiving. Accept that it will not be the life you enjoyed before the illness. If you are still working or have ongoing family responsibilities, your time will quickly be consumed by the rhythm of daily life. You are changed in some ways—and while not faced with reconstructing your life—should pay more attention to your own needs. For others, post-caregiving will involve major change, such as dealing with reduced finances, perhaps moving to a new home or new city. Take the time to make these decisions with care, focus on what you want and need, not others’ expectations. To re-engage with life ask yourself what would:

- Offer a new challenge?
- Make a contribution with the skills acquired over a lifetime?
- Not ask too much of me at the beginning?

- Help me to meet new people?
- Be fun?

Eventually, day-by-day and step-by-step, a new normal will emerge. The experience of caregiving will always be a part of who you are, but the experience needn’t define your future.

Resources:

AMA Caregiver Self-Assessment Questionnaire at www.Caregivers.Library.org.

Bereavement after Caregiving, by Schulz, Hebert, and Boerner. Pamphlet from National Institutes of Health, www.ncbi.nlm.nih.gov/pmc/articles/PMC2790185.

Alzheimer’s Association Caregiver Center www.alz.org/care

Sandra O’Connell was the caregiver for her husband for 13 years as well as co-caregiver, from a distance, for her mother. She has been a member of the Speaker’s Bureau of the National Capital Area Alzheimer’s Association for more than 12 years. She now enjoys an active life in Ashburn, VA. Sandra may be reached at SOCauthor@gmail.com.

BRIDGES *(continued from page 7)*

care proxy, a power of attorney, an advocate who knows me well enough to protect me from those who do not know me at all. This moment in time is paradoxically terrifying and freeing. There is no one to fill these roles, nor anyone to be hurt or disappointed by anything I do. I can be a lusty wench, a fiery eyed political radical, a thorn or a blessing. I am free.

I do deal with loneliness lately, a new and unaccustomed feeling that I try to assuage by inviting everybody in the world to lunch. Fortunately, not everybody accepts. Gingersnaps go up and down in my cookie jar as if on a vertical zip line. Velcro, who has no room to talk, agrees that I am gaining too much weight.

Laughter and witty repartee are reappearing gradually, like birds after a storm. I talk to everybody—to strangers, to Velcro, to myself and to the air, lamenting or laughing during the evening news and relishing fits

of temper over campaign ads and candidate debates. Issues affecting the elderly rivet my attention. Only social security supports me now. So far I have avoided homelessness through strict austerity, well-timed miracles and unexpected benevolence. I probably can’t forestall it much longer. Where will I go? What will happen to Velcro? Who will I be beyond this grieving?

Eight months after my mother’s death I seem to be doing surprisingly well. If there is an abyss ahead, I will cross it on strong bridges built years ago. I am strong, too.

I must call my mother and tell her so.

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

WHAT TO DO?

Finding meaningful activities for people with memory disorders

We recently asked care partners what activities their relatives with dementia find enjoyable and meaningful. Dog walking, helping with household chores, and listening to music seem to be popular pastimes. Some have taken to the recent craze of adult coloring books, while others, not so much. Many people continue with activities and interests they have always had, perhaps modified, while others have found meaning in new ways. We all need to feel a sense of purpose—and this doesn't change with dementia.

One thing that my husband has gotten into is “dancing.” He seems to enjoy that more than ever. I also have finally convinced him, along with his numerous doctors, to go to the pool three days a week. It took some coaching, but after the first time, he has been willing to go and enjoys it.



Mom enjoys her garden, raking leaves, visiting with family and she still has a sharp eye for fashion; she has always been a classy dresser and trendy at times. My niece calls my mom her “Glam-ma.” Mom is not interested in shopping much but she is always “people watching” and commenting on their attire.

At our reunion this past Labor Day, her granddaughter had on some sandals that mom wore back in her day. Mom loved them so much she requested to try them on. We all had a good laugh including mom... niece shoe size 5.5, mom size 9. Mom is smiling in this photo! We don't see her smile often. It was a really good day.



My husband likes:

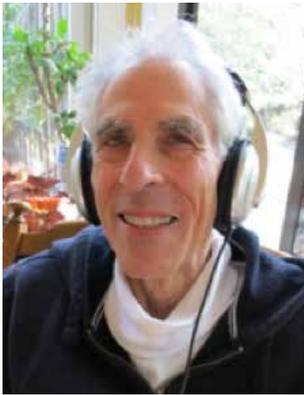
1. Taking the dog for a walk
2. Reading magazines,
3. Walking at the mall with me
4. Adult coloring books.

My husband and I polish silver together. I put the “stuff” on and do the rubbing to remove the tarnish, and he polishes. He is also very good at shredding papers.

When we moved here two years ago my husband spent hours and hours (and I mean hours!) sorting a big box of family pictures and our travels photos. He amazed me by knowing how to put them in order, better than I could. He really loved looking at them, but later as we made photo books he kept taking the pictures out of the books and became frustrated with them. He spent days studying these pictures on his hands and knees on the floor—didn't want them on a table. I would surely recommend sorting family pictures to a caregiver.

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ACTIVITIES *(continued from page 9)*



Perfect timing as my husband spent the morning and the rest of the day listening to music, at first, and then his book.

My friend made an attempt, though it was not successful, to engage my mom in art by purchasing her a coloring book for adults, with colored pencils and markers. Well, I found out my mom never liked coloring even as a kid, but for someone who enjoyed it growing up, it might work. All was not lost; at least I learned something new about her.

My husband likes to walk at the mall with me...often followed by lunch. Dries dishes, played puzzles and old maid with granddaughter. Vacuums on occasion. Plays cornhole game. Played pool.



My husband enjoys taking walks with me or others. He wants to walk 2 hours up these steep hills and work with weights every day. He says exercising is the only thing he could do. He also enjoys this and it keeps him physically fit with better core body stability. I believe his Lewy Body Dementia has progressed slower because of his excellent physical condition.

I read to my husband. He also enjoys listening to music.

My activities with my mom focus around chores she helps me with, and if I listed them out for others it would sound like I am treating her like the help.

Mother has really enjoyed her colored pencils and adult coloring books, especially ones of floral designs. It is helpful to me when I need to do something that she can't help with, that she can sometimes spend an hour or so entertaining herself by coloring. She only uses a few colors on her pictures, but it seems to be meaningful to her.

Since she likes to "help" so much, I try to do things that she can do some of the steps. When I bake bread, she can measure out the flour, grease the pan, and wash dishes as we go. The trick is not to have but one thing happening at a time. When I am making a whole meal, it gets confusing. Especially at suppertime, she is confused (sundowning) and wants to be near me. I set her up at one end of the counter and give her salad ingredients one at a time. She cuts everything up really small, so it takes her a long time. When she is done with the lettuce, I'll give her a few little carrots, then the peppers... If she finishes before me, I'll tell her she can sit down at the table and go ahead and get started on her salad. It makes preparing a meal go much smoother.

Mother also likes to walk out in her yard and pick flowers and make a little bouquet almost every day. I planted zinnias, dahlias and chrysanthemums in addition to the spring bulbs and camellias she already had so there is nearly always something to cut. She likes to watch the birds and we have several birdfeeders outside her dining room window.

Recently, I decided to try reading aloud to her. I had some biographies written on about a 5th grade level. Everytime I read a new chapter, I briefly summarize what we have read so far. We read a biography about Fanny Crosby and then looked up some of the hymns she wrote and sang them. Mother knew the words to the choruses by heart.

I think my wife's favorite "people" activity is seeing one relative and two or three old friends who stay in touch and visit occasionally. Her favorite activities are watercolor painting and listening to classical music.

A few weeks ago, we began going to an elementary school to tutor children. I found the opportunity for my wife to act as a "reading buddy" for children in the 5-7 year age group. My wife wanted to try it as she loves interacting with young children. She seems to be her old self (smiling and laughing) with young children.

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ACTIVITIES *(continued from page 10)*

My husband likes to ride in the car and hike in the woods.

My late husband had several things he liked to do, mostly on his own.

He loved to walk his dog. There is a road next to our house that leads to a farm (about 1/4 mile) and I can see him from the house, so he would wander down the road by himself with our dog who is older and didn't mind the slow pace. Then he would often come back with a small bouquet of wild flowers for me that he gathered from the area beside the road. Or perhaps a weed or two that was pretty, or a stone with a lovely pattern on it.

He liked to watch old time movies, especially with John Wayne. Also programs from years ago as he was growing up that he listened to on the radio, like Fibber McGee and Molly, Laurel and Hardy, Dragnet, etc.

He liked to sit in his office and look at photos he took of his carpets and those in his carpet books, and also photos from years gone by.

He loved to read, but lost that skill rather early, and would just read the same page over and over.

He also liked being in the kitchen helping with any task that involved preparing food. He was a great prep chef.

We have a dog so my husband enjoys walking Bo. He can still do this as his sense of direction has not been affected, which is amazing.

My mother enjoys engaging with my three-year-old son. Together they have fun:

- Building cars out of Play-Doh.
- Walking and playing "train" at Duke Gardens. Mom and my little boy switch between being the engine

and the caboose, essentially, who leads and who follows.

- Feeding the ducks at the pond.
- Coloring and drawing.



Other creative ideas we have heard about from care partners include:

One mother and daughter together make origami balls as gifts for support group members. They call them "memory keepers" because there's a way to open them up and drop inside a small note with a memory written on it.

A married couple delivers Meals On Wheels – the care partner does the driving and her husband takes in the meal and chats.

We have heard of several care partners who take their family member to a local assisted living facility to play piano for the residents. For many, music abilities remain long after other cognitive changes have started.

We hope these fresh ideas from North Carolina care partners inspire you as much as they inspire us!

MORE IDEAS FOR PEOPLE WITH DEMENTIA

Activities at Home: Planning the day for a person with moderate or severe dementia from the Alzheimer's Association - http://www.alz.org/national/documents/brochure_activities.pdf

Activities for Kids and a Person with Dementia: 101 Activities, from the Alzheimer's Association http://www.alz.org/living_with_alzheimers_101_activities.asp

A Caregiver's Guide to Dementia: Using Activities and Other Strategies to Prevent, Reduce and Manage Behavioral Symptoms, by Laura N. Gitlin and Catherine Verrier Piersol, 2014

Sixth Sense Caring: Stories of Creative Elder Care, by Maggi Ann Grace and Vicki Johnson <http://sixthsensecaring.com/>

The Best Friends Book of Alzheimer's Activities, by Virginia Bell and David Troxel, Vol. 1 2004, Vol. 2, 2007

4 MEDICATIONS TO TREAT ALZHEIMER'S & OTHER DEMENTIAS: HOW THEY WORK & FAQs

By Leslie Kernisan, MD MPH

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If someone in your family has been diagnosed with Alzheimer's or another dementia, chances are that they've been prescribed one of the "dementia medications."

But were they told what to expect, and how to judge if the medication is worth continuing?

I've noticed that patients and families often aren't told much about how well these medications generally work, and or how to determine if it's likely to help in your situation.

So in this post, I'll explain how these medications work. I'll also address some of the frequently asked questions that I hear from seniors and families.

If someone in your family is taking one of these medications or considering them, this will help you better understand the medication and what questions you might want to ask the doctors. **This is especially important if finances or medication costs are a concern.**

Note: This article is about those drugs that have been studied and approved to treat the cognitive decline related to dementia. This is not the same as treating behavioral symptoms (technically called "neuropsychiatric" symptoms) related to dementia, such as paranoia, agitation, hallucinations, aggression, sleep disturbances, wandering, and so forth. There are no drugs FDA-approved to treat the behavioral problems of dementia. I will address the off-label use of psychiatric medication for this purpose in a future article.

4 Medications FDA-Approved to Treat Dementia

FDA-approved medications to treat Alzheimer's and related dementias basically fall into two categories:

Cholinesterase inhibitors. These help increase the amount of the neurotransmitter acetylcholine in the brain. Acetylcholine helps neurons function well.

- Three such medications are FDA-approved to treat Alzheimer's in "mild to moderate" stages:
- Donepezil (brand name Aricept)
- Rivastigmine (brand name Exelon)

- Galantamine (brand name Razadyne)
- Tacrine is a fourth cholinesterase inhibitor which was FDA-approved but is no longer in use due to a much higher risk of side-effects.
- Donepezil and rivastigmine have also obtained FDA-approval for the treatment of more advanced dementia.

Memantine. This is the name of an actual drug rather than a class of drugs, but since it's the only one available of its type, experts consider it the second category of dementia treatment drug.

- Memantine (brand name Namenda) is FDA-approved to treat "moderate to severe" Alzheimer's disease.
- Memantine is an "N-methyl-D-aspartate (NMDA) receptor antagonist." It dampens the excitatory effect of the neurotransmitter glutamate in the brain.

Since over-excitation of the neurons has been associated with neurodegenerative disease, memantine is considered a "neuroprotective" drug. Hence it is potentially a "disease-modifying treatment."

In comparison, cholinesterase inhibitors are considered "symptomatic treatment," as they affect the function of neurons but not the underlying health of neurons.

In other words: memantine might slow down the underlying progression of Alzheimer's, even if it doesn't appear to be helping a person. Cholinesterase inhibitors don't change the underlying progression of Alzheimer's, but they can potentially help a damaged brain work a little better.

Frequently Asked Questions About Dementia Medications

How well do cholinesterase inhibitors work?

This is a topic that has been intensively studied and somewhat debated. Of note, most major studies of cholinesterase inhibitors are industry-funded; only the AD2000 trial was not industry-funded.

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MEDICATIONS *(continued from page 12)*

Overall, in mild to moderate Alzheimer's disease, the average benefit seems to be a small improvement in cognition and ability to manage activities of daily living. The effect has been sometimes compared to a few months delay in progression of symptoms. (It is not clear that treatment with cholinesterase inhibitors affects long-term outcomes such as the need for nursing home level of care.)

A 2008 review of the scientific evidence concluded that the effect of these drugs is statistically significant but "clinically marginal."

But there's a catch to consider: studies also suggest that although a fair number of people (30-50%) seem to experience no benefit at all, up to 20% may show greater than usual response. So there seems to be some individual variability in how these drugs work for people.

To date, we have not developed any good ways to tell ahead of time who will respond to these drugs.

So it's important to follow a person's cognitive symptoms, and side-effects, once they start taking a cholinesterase inhibitor. If it doesn't seem to be helping, it's reasonable to consider stopping the medication after a few months.

How well does memantine work?

In people with moderate to severe Alzheimer's, memantine seems to provide some benefits, in terms of slowing the deterioration of Alzheimer's. But again, the benefit overall seems to be fairly modest.

It's not at all clear that people with mild to moderate Alzheimer's benefit from memantine; a 2011 review concluded that the scientific evidence doesn't support this claim.

Do these medications work for dementias other than Alzheimer's disease?

These medications have been studied for other forms of dementia, including vascular dementia, Lewy Body dementia, Parkinson's dementia, and mixed dementia. (Bear in mind that the older people get, the more common it is to have mixed dementia, and the harder it is to make a specific determination of the underlying cause of dementia.)

Studies generally find that cholinesterase inhibitors are associated with modest improvements in symptoms in these other forms of dementia.

For memantine, some research suggests it can help with vascular dementia, although the benefits again seem

to be quite modest.

The effect of memantine on Lewy-Body dementia and Parkinson's dementia is less clear, with some research suggesting a small benefit but also reports that some people experience worsening hallucinations and delusions with memantine.

Do these medications work for mild cognitive impairment?

Not as far as we know. The research evidence so far indicates that dementia medications do not improve outcomes for mild cognitive impairment.

However, it remains very common for patients with mild cognitive impairment to be prescribed donepezil (brand name Aricept) or another cholinesterase inhibitor. In principle, this should be done as a trial, meaning that the patient and clinician decide to "try" the medication, see if it's helping with memory or other thinking difficulties, and stop if it doesn't appear to be helping.

In practice, many people with mild cognitive impairment end up taking the cholinesterase inhibitor indefinitely. They may be reluctant to stop, but in other cases, it may be that the prescribing doctor doesn't get around to checking on whether the medication is helping or not.

What are the side-effects of these medications?

Doctors — including geriatricians — consider these medications to be "well-tolerated." This means that most people don't experience more than mild side-effects, and serious adverse events are rare.

For cholinesterase inhibitors:

- The most common side-effects are gastrointestinal and include nausea, diarrhea, and sometimes vomiting. These affect an estimated 20% of people.
- People tend to adjust to gastrointestinal side-effects with time. It helps to start with a small dose and gradually increase. Rivastigmine is also available in a patch formulation, which tends to cause less stomach upset.
- In the oral formulations, donepezil tends to cause fewer side-effects than rivastigmine and galantamine.
- Some people also experience dizziness, a slowed heart rate, headaches, or sleep changes.

For memantine:

- Dizziness is probably the most common side-effect.
- Some people seem to experience worsened confusion or hallucinations.

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MEDICATIONS *(continued from page 13)*

- Memantine generally seems to cause fewer side-effects than cholinesterase inhibitors do.

Is it common to take more than one medication for dementia at the same time?

It's quite common for patients to be prescribed a cholinesterase inhibitor plus memantine.

This "combination therapy" has been studied in people with moderate-to-severe Alzheimer's, and some research suggests a small benefit compared to treatment with just one medication. However, the benefit again appears to be modest at best.

A study of combination therapy in people with mild-to-moderate Alzheimer's did not show benefit. There is no good research evidence indicating that combination therapy is beneficial in mild Alzheimer's.

There is no reason to take more than one cholinesterase inhibitor at the same time.

At what point do you stop dementia medications? We're not sure it's making a difference.

Many patients and families feel these medications don't have much effect. This isn't surprising, since the research results usually find that the effect in most people is small to non-existent.

As cholinesterase inhibitors are "symptomatic" treatment and not disease-modifying, if there's no sign of improvement after a few months on the maximum dose, many experts agree that it's reasonable to stop the medication.

That said, as these medications are well-tolerated by most patients and are unlikely to cause harm to anything more than one's wallet, it's common for people to remain on cholinesterase inhibitors indefinitely.

As for memantine, this drug is potentially "disease-modifying." So it may make sense to continue memantine for a few years, even if no improvement is noted by the clinician or family.

Experts generally agree that there's not much value in continuing either category of medication once a person has reached the stage of advanced dementia, at which point a person is bedbound, unable to speak, and shows little sign of recognizing familiar people.

Do people get worse when they stop dementia medications?

Research suggests that some patients do appear to get worse after stopping cholinesterase inhibitors.

If this appears to be the case, it's reasonable to resume the cholinesterase inhibitor.

The discontinuation of memantine hasn't yet been rigorously studied. An observational study of nursing home residents suggested some worsening after stopping memantine.

Do any vitamins help treat dementia?

Vitamin E — which works as an anti-oxidant in the body — has been studied for the treatment of Alzheimer's, and may be beneficial.

In 2014, a large study of patients with moderate-to-severe Alzheimer's disease found that daily treatment with 2000 IU/day of Vitamin E resulted in less functional decline than treatment with placebo, memantine, or a combination of memantine and vitamin E.

Of note, since the study was conducted in the VA (Veteran's Affairs) health system, most participants were men. And again, the benefit seen was modest.

It is not clear that vitamin E helps for milder Alzheimer's, or mild cognitive impairment. Always talk to a doctor before trying vitamin E for brain health, as vitamin E can increase bleeding risk in some people.

No other vitamins have been shown to slow cognitive decline in Alzheimer's or other dementias. In particular, although low vitamin D levels have been associated with a risk of developing dementia, no clinical research has shown that treatment with vitamin D helps people maintain cognitive function.

A study of vitamin B supplementation in the treatment of people with mild to moderate Alzheimer's disease did not show any benefit. Note that participants in this study had normal vitamin B12 levels at baseline; the very common problem of vitamin B12 deficiency in older adults can cause or worsen cognitive problems.

A practical approach to dementia medications

It's easy to get a bit lost in the weeds, when it comes to medications to treat the cognitive decline of Alzheimer's and other dementias.

Overall, these are medications that seem to offer only a little — if any — benefit to most people.

They are indeed widely prescribed, because patients are usually anxious to do everything possible to preserve their mental abilities, and because doctors want to be able to offer *something*. And most of the time, they don't seem to harm patients or cause significant side-effects.

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MEDICATIONS *(continued from page 14)*

I think it's reasonable for people to take or try these medications, as long as they are aware of the evidence regarding the usually modest benefit.

So what should you do about medications, if you or your older relative has been diagnosed with Alzheimer's or another dementia?

If you have already been on dementia medications for a while:

If you aren't experiencing side-effects, you may want to continue on the medications indefinitely.

But if you are concerned about medication expenses and pill burden, consider a trial of stopping the medication.

After all, the overall benefit of these medications is small. And you can always restart dementia medications if you think the dementia symptoms got worse off the medication.

If you are just starting the dementia journey:

If you are debating whether to start medications for dementia, keep in mind the following points:

- Only cholinesterase inhibitors are FDA-approved for mild to moderate dementia. You should definitely ask questions if a clinician proposes starting memantine during the early stages.
- Cholinesterase inhibitors are for symptomatic treatment and do not alter the underlying neurodegeneration. They provide a modest benefit to some people but many people don't seem to benefit. We are not yet able to tell ahead of time whose symptoms will improve with these medications.
- A reasonable and careful approach is to work with the doctor on a "trial" of a cholinesterase inhibitor. This means:
 - Carefully documenting cognitive symptoms before starting the medication.
 - Starting the medication at a low dose, and increasing to a full dose over time.
 - Monitoring for side-effects, such as nausea, vomiting, or diarrhea. These do usually get better with time. Consider lowering the dose or switching to a patch formulation if the side-effects are difficult to handle.
 - Working with the clinician to reassess cognitive symptoms after 2-3 months. If no improvement has been noted by the patient, family, or clinician,

consider stopping the cholinesterase inhibitor.

Other ways to preserve cognition and brain function in dementia

Here's the most important thing to keep in mind, when it comes to managing the cognitive decline of Alzheimer's and other dementias:

Medications are only a small part of the solution.

In fact, there are many **non-drug** ways to optimize brain function. They work for people who don't have dementia too, so I've listed them in this post: *How to Promote Brain Health: The Healthy Aging Checklist Part 1*.

If you're concerned about preserving brain function and delaying cognitive decline, you'll want to review the ten approaches I cover in the brain health article.

For instance, people often don't realize that many commonly used medications are "anticholinergic," meaning they interfere with acetylcholine in the brain and worsen thinking. In other words, these medications essentially have the opposite effect of the cholinesterase inhibitors, which is not so good for the brain.

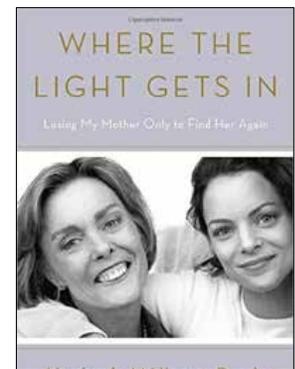
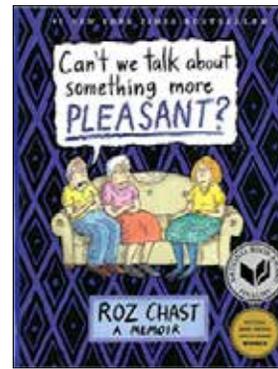
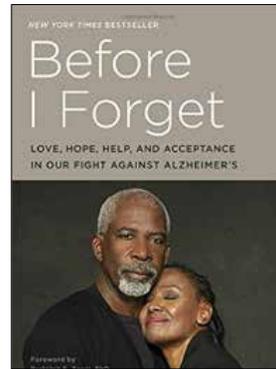
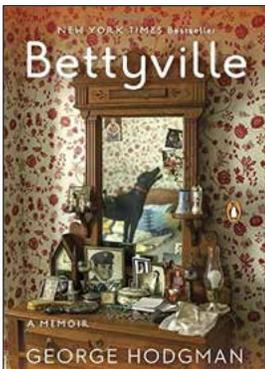
In a perfect world your doctors and pharmacists would notice this problem and stop the anticholinergic medications, or at least discuss the pros and cons with you. But as our healthcare system is still highly imperfect, this may not happen unless you ask for a medication review.

Delirium is another common problem that can worsen dementia and often accelerates cognitive decline. So to manage dementia and delay cognitive decline, it makes sense to learn about delirium prevention.

The bottom line on medications to treat dementia
In short: the medications we currently have available to treat Alzheimer's disease and other medications may help a little. The main harm people experience will be to their wallets. Don't expect these drugs to work miracles and consider stopping them if you are concerned about drug costs or pill burden.

And above all, don't forget to think beyond medications, when it comes to optimizing brain function and delaying cognitive decline in dementia.

Dr. Leslie Kernisan is a board-certified geriatrician. Her website <http://betterhealthwhileaging.net/> offers practical information to address problems that often keep aging adults from enjoying better health, well-being, and independence.



BOOKSHELF

AARP Meditations for Caregivers: Practical, Emotional, and Spiritual Support for You and Your Family, 2016, by Barry J. Jacobs and Julia L. Mayer, offers insights and experiences in dealing with the challenges of caregiving. This book contains over 150 meditations concerning common emotional themes associated with caregiving, such as guilt, shame, anger and anxiety. Supportive and reflective.

Alzheimer's and Dementia for Dummies by Consumer Dummies (with The American Geriatrics Society and The Health in Aging Foundation), 2016. An easy-to-read guide to help families understand the diagnosis, cope with symptoms and make informed decisions about care. Concise and credible.

Before I Forget: Love, Hope, Help, and Acceptance in Our Fight Against Alzheimer's, 2016 by B. Smith and Dan Gasby. Chef, restaurateur and lifestyle guru B. Smith was shocked to find herself diagnosed with Alzheimer's in her mid-60s. Smith and her husband share their story of coping with the physical and emotional challenges of the disease while retaining their strong romantic bond. Just released in paperback.

Bettyville: A Memoir, 2015, by George Hodgman, tells of Hodgman leaving his New York lifestyle to return to his hometown of Paris, Missouri to care for his aging mother. Betty is a force of nature, a strong-willed 90-something who loves her son but has never come to terms with his homosexuality. Together, he and his mother learn to make peace with their past and enjoy their present. Hilarious and poignant.

Can't We Talk About Something More Pleasant? A Memoir, 2016, is a humorous and heartfelt memoir by cartoonist Roz Chast, now available in paperback. This *New York Times* bestseller highlights issues relating to aging parents and loss with lighthearted humor, cartoons and meaningful insights.

Caring for a Loved One with Dementia: A Mindfulness-Based Guide for Reducing Stress and Making the Best of Your Journey Together, 2016 by Marguerite Manteau-Rao. This social worker and long-distance caregiver illustrates how mindfulness practices can ease interactions with the person with dementia and provide long-lasting benefits, even stress reduction for the caregiver. Consoling and assuaging.

How to Care for Aging Parents, 3rd Edition: A One-Stop for All Your Medical, Financial, Housing, and Emotional Issues, 2014, by Virginia Morris offers practical and comforting advice to those who are caring for aging parents. Morris provides a clear, all-inclusive and concise guide on caring for aging parents. A helpful basic reference.

Keeping Love Alive As Memories Fade: The 5 Love Languages and the Alzheimer's Journey, 2016, is a new take on the classic love language series by Gary Chapman. Chapman teams with fellow North Carolinians, Deborah Barr and Edward Shaw, to deliver a book on the 5 love languages that is specifically directed towards couples living with Alzheimer's. Creative and insightful.

When Someone You Know Is Living in a Dementia Care Community: Words to Say and Things to Do, 2016, by Rachael Wonderlin is a compassionate book about making decisions regarding residential care for people with dementia. Wonderlin offers insights based on her own experience and research in the field.

Where the Light Gets In: Losing My Mother Only to Find Her Again, 2016 by Kimberly Williams-Paisley. Actress Kimberly Williams-Paisley writes about how her family dealt with her mother's diagnosis of primary progressive aphasia at age 62. As her once-articulate mother gradually lost her powers of speech, Williams-Paisley had to figure out how to forge a relationship with the person her mother had become. Revealing and engaging.

Online Help



Late-Breaking News

Dementia rates have fallen Listen to Diane Rehm's podcast, or read the transcript, "Why Dementia Rates Among Older Americans Have Fallen."

Decline in dementia seen among older adults A brief overview of exciting news, "Dramatic decline in dementia seen among older adults in the US." See the data and read what you can do to lower your risk of developing Alzheimer's

Alzheimer's Disease and Related Disorders

Could Alzheimer's stem from infections? New research from Harvard University suggests that Alzheimer's could be caused by a reaction to an infection that leaves debris behind in the brain.

Gun ownership and memory disorders In the New York Times article, "Another Delicate Topic with Aging: When Is It Time to Give Up Guns?" author Julie Turkewitz describes how memory disorders and guns may become a lethal combination.

Alzheimer's or depression: Could it be both?? Those with Alzheimer's disease frequently struggle with depression as well. To enjoy better quality of life, it is important to treat both the depression and the Alzheimer's.

High blood pressure is linked to cognitive decline? The National Institute on Aging recently published research linking cognitive decline with high blood pressure. There is new evidence that controlling cardiovascular conditions such as high blood pressure can help delay or reduce cognitive impairment.

Alzheimer's disease in people with Down syndrome A recent study has shown there is a common connection with the brain plaques found in people with Down syndrome and those with Alzheimer's.

Learn You Have Alzheimer's, Then Invite a Reporter to Tail You? Really? In this New York Times follow-up piece, author N. R. Kleinfield discusses the background and challenges of researching and writing "Fraying at the Edges: Her Fight to Live with Alzheimer's," as well as the author's personal interest in Alzheimer's disease.

Brain scans offer insights into loss of money skills Those living with memory disorders are often the most vulnerable to financial abuse. A recent study has shown that MRIs may be able to identify brain areas associated with a reduced ability to handle financial affairs.

Shouldn't we try to keep this a secret? Read here for tips on sharing the diagnosis with others as well as ways to overcome the stigma associated with Alzheimer's disease.

Why pain can go untreated in people with Alzheimer's New research has shown that it is difficult to detect pain in someone with Alzheimer's. However, there is no evidence that people with Alzheimer's are less distressed by the pain they experience. **Know Your Family History** Many people have questions concerning the hereditary factors of Alzheimer's disease. This new booklet from NIH, *Understanding Alzheimer's Genes*, provides helpful insights into the genetics of the disease.

Caregiving

Should I have the conversation with my family member? The Conversation Project offers a "kit" with tips on how to start conversations about an Alzheimer's diagnosis or related decisions. The kit gives sample questions to guide the conversation and advice on what to do in difficult situations, such as when a person insists there's nothing wrong.

Alzheimer's and dementia care videos UCLA's Alzheimer's and Dementia Care Program has a series of videos on caring for people with dementia. The videos can help caregivers understand and respond to the behaviors of those with dementia, such as sundowning, wandering and asking repetitive questions, offering practical tools for use in a variety of settings.

Real-Life Strategies for Dementia Caregiving This article offers practical tips for dementia caregiving. These are 10 brief tips for families struggling with knowing the "right" way to handle common, difficult situations that arise with dementia care.

Online Help *(continued from page 16)*



Travel tips for people living with dementia This helpful article offers travel tips for people living with dementia as well as their caregivers.

How To Be Good Enough A few helpful tips for daughters on managing caregiver stress and keeping up with demanding schedules

Home safety for people with Alzheimer's Prevent accidents in the home by avoiding common home hazards. This information may help improve home safety for those with dementia.

5 lessons in setting boundaries that every caregiver must learn Caring for others often makes it difficult to find the time to care for one's self. Setting boundaries is a difficult but necessary part of caregiving.

The terrorist inside my husband's brain Susan Schneider Williams, wife of comedian Robin Williams, writes a meaningful and heartfelt editorial for the journal, *Neurology*, about their journey through Lewy Body Dementia.

Love and Burnout: Caregivers, Too, Need Care This New York Times article covers the story of Mark Donham, a man who quit his job in order to care full-time for his wife with Alzheimer's. After his wife's death, Donham had to face the emotional and financial aftermath, a challenge common to many caregivers.

Medications

Alzheimer's Disease Medications This 2016 Alzheimer's Disease Medications Fact Sheet discusses medications used to treat the symptoms of Alzheimer's and describes common side effects. An easy-to-read chart of medications is included.

Alcohol use and older adults Older adults are often more sensitive to alcohol's effects and most medications are not intended for use with alcohol. Alcohol is especially problematic for those with memory disorders due to alcohol's tendency to worsen memory problems.

Managing Multiple Health Problems Juggling multiple medications can be challenging and potentially dangerous. Here is a helpful article on managing multiple health problems. This article is also helpful in identifying inappropriate medications for older adults.

Planning, Insurance & Long-Term Care

A daughter faces challenges in getting her father in and out of the hospital safely In her "Daughterhood" blog, elder advocate Ann Tumlinson offers a video about a common, difficult issue: helping a parent manage his or her complex health care needs in the face of a chaotic healthcare system.

Palliative Care with Alzheimer's Caregiver.com offers some information on what palliative care is and isn't.

Palliative care for people with dementia in long-term care CaringKind, a New York-based Alzheimer's organization, has developed palliative care guidelines for people living with dementia in nursing homes.

Safe and smooth transitions between care settings This website provides guidance for families and health care professionals to help chronically or seriously ill patients transition safely between care settings.

What's in your parent's wallet? This article offers practical tips on ways to manage finances for others.

End of Life: Helping with Comfort and Care End-of-life is a subject which is often avoided in families facing dementia care. This NIA guide for end of life planning and care includes a special section on Alzheimer's and dementia.

Caregiving at Home: A Guide to Community Resources This Fact Sheet explains a wide range of resources for caregivers and individuals with cognitive disorders. The fact sheet provides community care options ranging from informal support networks to hospice care.

Technology

The internet: A new challenge for caregivers

The internet presents a new challenge to people caring for those with dementia. Faculty from Northwestern University offer tips on how to manage online behavior without infantilizing the impaired person.

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