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The Official Magazine of the Alzheimer's Foundation of America



MAUREEN MCGOVERN  
CREATING HOPE IN LIFE WITH DEMENTIA

VOLUME 18, NUMBER 1



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# THE HEALING POWER OF A PET

**S**uzy Plaskey was walking her dog, Dusty, in her familiar Michigan neighborhood when suddenly it was no longer familiar. She called her husband, Mike, who was on the road for business and told him, “I’m lost.” He asked if she recognized anything and she said no. He then asked if Dusty was with her. When she said that he was, Mike told her to let Dusty go and the little shih tzu would run right home, leading the way. As much as she wanted to get home, Suzy would not release Dusty.

The two had always been close, but after Suzy was diagnosed with early onset Alzheimer’s, also called young-onset, in her mid-50s, their bond deepened to the point where they were practically inseparable. Mike understood this.

***“Dusty was her safety,” he said. “She was only a block away. Dusty could have taken her home. That reinforced to me the power of a pet. There was no way she would let go.”***

Suzy and Mike were married for more than 30 years and have three children. After Suzy died in January 2020, having lived with Alzheimer’s for eight years, Plaskey wanted to find a way to put that power of a pet to work for more people. Two months later, he sat in the basement of his nephew Jimmie to brainstorm. Out of that came the Team Suzy Companion Pet Program. Over the next year he worked to secure nonprofit status and met with Michigan Humane to partner in creating a way to connect pets in need of a home with people experiencing memory loss.

“This can help people on a daily basis,” he says.

Team Suzy will issue a grant to the family to cover expenses of daily care such as food, toys, leashes and

help with some veterinary care for the life of the person or pet. Plaskey expects the cost will be about \$2,500 a year for each dog or cat. Eligibility requires that the person with dementia must live at home or with a caregiver and the adoption process must be completed exclusively with Michigan Humane.

Matthew Pepper, Michigan Humane’s president and CEO, was brought onboard through a mutual connection, Gary May, a producer of its annual telethon on Detroit’s WXYZ-TV, who had studied the impact pets have on people’s lives and was enthusiastic about Plaskey’s plans. He arranged a lunch between the two men.

*Continued on following page*



Suzy and Dusty

## THE HEALING POWER OF A PET *cont'd from p. 3*

“It made perfect sense to me knowing the role animals can play in mental health,” Pepper said. “Mike is fully into it. I think we shook hands that day and the rest is history. Those are the kind of people we want to partner with.”



Mike and Suzy

Pepper sees the benefits to all involved. The pet goes to a loving home and the person living with memory loss can experience improved health, such as lower blood pressure and elevated mood and awareness, through the animal's presence. The caregiver also benefits, Pepper says.

“While the person is with the dog, they get a break to take some time for themselves and allow the dog to fill the role of caregiver for a time. This is necessary for someone giving everything to help someone with Alzheimer's and dementia.”

Michigan Humane will spay or neuter the animal and ensure that it is medically and emotionally ready, as it does with all adoptions. For people going through Team Suzy, the adoption fee will be waived and veterinarian services will be provided in the time following the placement. Because of the nationwide vet shortage, Michigan Humane will help find vet care for Team Suzy adopters after the initial care.

Pepper says his organization is now working on connections with autism and Parkinson's nonprofits “to elevate our narrative so we're not just supporting the animal; we're here to create safer and healthier communities....What the animal brings mirrors what pharmas do.”

Two families are in the application process, and Plaskey is exploring the possibility of forming a connection with a local care facility that has an independent living residence and a

memory care unit in the same building. He envisions having people in the independent living residence adopt a dog or cat with the agreement that they will take the pet visiting in the memory care unit once a week in exchange for the waived adoption fee, veterinary care and annual support from Team Suzy.

“All the studies out there, and there are so many, show the power of pets for emotional health,” he said, adding that he reached out to mental health professionals at the University of Michigan and Toledo University to tell them about Team Suzy and offered to share his experiences. A requirement of the adoption application is that families will fill out a monthly evaluation form.

“I'm not a scientist, but if you tell me what to look for I can.”

The strong possibility of replication is one of the reasons AFA awarded Team Suzy its \$25,000 Anne & Irving Brodsky Innovation Grant in 2022. The grant, created by AFA founder and board chairman Bert E. Brodsky, is awarded annually to help fund creative programs that improve the lives of individuals living with Alzheimer's or related illnesses and their families.

“The Brodsky grant for me was very emotional, that other people believed in what we're doing,” said Plaskey who is now retired and devotes full time to Team Suzy. “We know it will be replicable. The collaboration with Michigan Humane is what makes it work. Once it gets rolling it's almost a no-brainer.”

Pepper agrees.

“If anyone reads this and has possible plans, reach out to us. There's no question, this is going to work and change people's lives.”

Photos courtesy of Mike Plaskey

**For more information, visit [www.teamsuzy.org](http://www.teamsuzy.org).**



Suzy and Dusty



Photo courtesy of Lonna Whiting

• From •

# DINING AT THE DEMENTIA CAFÉ

AN ESSAY *By Lonna Whiting*

Admittedly, I had strong emotions and unhealthy attachments to Mom The Person, my most devoted companion, my favorite eating buddy, and my greatest teacher. At first and for many years, I took on every single part of her she lost to The Dementia and made it a part of me instead. Just after diagnosis on October 4, 2013, I secured power of attorney, and from then on I made all her decisions. I legally and emotionally became her. Put another way, when The Dementia managed to swallow her autonomy seemingly overnight, I reached into its mouth and snatched what I could right back.

*Mother, I am now you. How am I doing?*

When The Dementia came for what was left of her independence, I found her a place to live at an assisted living facility.

*Mother, you're safe and clean. There is nothing else to be done.*

And when it took her personal history, I held onto the people she loved the most.

*Mother, your dad's name was Bob. He was a good man.*

When The Dementia devoured my name from her tongue, I spit it out for her again and again and again.

*Mother, I am your daughter. My name is Lonna.*

When The Dementia chewed up her own name, I fed that right back to her.

*Mother, your name is Beth. You are beautiful.*

When The Dementia inhaled her ability to walk, I wheeled her around.

*Mother, the world is still going by. You are still a part of it.*

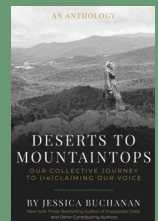
When The Dementia sucked up her laugh, I laughed for her.

*Hahahahahaha.*

When The Dementia ate her smile, I smiled for the both of us.

*Mother, do you know how much I love you?*

“Dining at the Dementia Café,” an essay by Lonna Whiting, excerpted from *Deserts to Mountaintops: Our Collective Journey to (re) Claiming Our Voice* (Merack, January 2023) by Jessica Buchanan



## ABOUT THE AUTHOR

**Lonna Whiting** is the owner of lonna.co, a growth strategy and communications consultation agency located in Fargo, ND. Whiting writes frequently about her experiences as a care partner to her mother, Beth. You can read more of her work at [www.Lonna.co/writing-samples](http://www.Lonna.co/writing-samples).



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# ASK THE AFA MEDICAL ADVISORY BOARD

**ALLISON REISS, MD**

**Q: I keep hearing that some people who have had COVID have a lasting experience with brain fog. Could this end up leading to Alzheimer's or dementia?**

**A:** It is highly unlikely that COVID-19 infection is causing Alzheimer's disease. Rather, the infection may magnify neurologic symptoms in someone who already has cognitive impairment and reveal underlying Alzheimer's. More severe COVID-19 with accompanying neurologic symptoms is more likely in the older population as they are more vulnerable to coronavirus. People who were under the radar and not getting medical attention may have sought care for COVID and then, once seen by healthcare professionals, received an Alzheimer's diagnosis. It is not COVID causing Alzheimer's but rather that the undiagnosed symptoms are now being diagnosed.

COVID-19 may be a second insult to a brain that has already accumulated a lot of damage and it may exacerbate some of the damage-inducing pathways and thus make Alzheimer's symptoms worse. Also, COVID may cause problems with the oxygen level in the brain that would contribute to worsening cognition.

The effect of COVID-19 on the brain is being widely studied and researchers are looking at both short- and long-term issues. Brain fog is a debilitating long-term symptom. There are no specific treatments other than supportive care and this needs to change.

Modifiable factors that may be important in delaying or preventing Alzheimer's include a balanced diet, controlling blood sugar and blood pressure, physical activity, refraining from excess alcohol consumption and avoiding head injuries. A healthy brain requires a healthy heart and circulation, so take care of your cardiovascular system. Many people avoid too much sun exposure for health reasons and the COVID-19 pandemic kept people isolated indoors for long periods. This led to vitamin D deficiency, which is often unnoticed but easy to remedy with vitamin D rich foods or supplements. I generally believe it is better to get vitamins from food rather than pills, but vitamin D is the one possible exception. Staying engaged socially and in one's community and lifelong learning also build reserves of brain function and flexibility.

*AFA Medical, Scientific, & Memory Screening Advisory Board member Allison Reiss, MD, is an associate professor of medicine at NYU Long Island School of Medicine and head, Inflammatory Laboratory, Biomedical Research Institute, NYU Langone Hospital-Long Island.*



# Is it Sexual or Something Else?

## Perceived Sexual Behaviors in Persons Living with Dementia

**O**ne woman in the assisted living residence had to be watched closely so she didn't take off her clothes—all of them. AFA social worker Melpo Voulieris, LMSW, who worked there at the time, said she had to educate the staff about what was behind the woman's actions.

"Taking off clothes is not necessarily sexual," she said. "As dementia progresses, impulse control may be impaired, and disrobing may occur when a person is no longer able to communicate certain needs—clothes may feel scratchy or uncomfortable, or the person may be hot or cold, tired, or even in pain. In the assisted living facility, care partners and staff were careful to select more comfortable and less restrictive clothing for the resident and paid close attention to body language for any triggers that prompted her to take off her clothes."

Sexual desires are normal for everyone, says Danuta Lipinska, MA, Reg.MBACP, a senior facilitator at a support program for care home managers in the U.K., but people with memory loss may have forgotten how to handle them.

"As dementia progresses, for some people there is less awareness of what constitutes private information and behavior. A lot of things trigger feelings of sexuality or lust. There's not a lot of other stuff going on in their life. They may not feel they have much control over other things."

Rather than trying to forbid habits like sexual gratification or looking at erotic material, Lipinska says to direct the person to a private place.

***"It's going to be difficult to shut that down. Things that were private are now in the public domain. It makes it really tricky, but there are things you can do."***

Keep in mind, often what seems to be sexual may be merely a need for companionship. "Behaviors that appear to be sexually motivated, in fact, may be something else but equally necessary for well-being," Lipinska says.

If you are a caregiver who feels uncomfortable or threatened by some of this behavior, AFA suggests the following responses:

- Address the behavior when it happens.
- Avoid arguing. Tell the person in a calm and firm voice that the behavior is inappropriate, matching your body language to your words by frowning and shaking your head, but don't shame the person.
- Wear clothes that indicate you are a professional, such as scrubs.
- Call the person by name or use Sir or Ma'am, not endearments like honey or sweetie.
- Keep a journal to help identify triggers and keep at a safe distance when possible.
- Provide alternative cuddling, such as a soft blanket, stuffed animal or doll.

# Creating Person-Centered Bathing

Surveys show that about half of residents in care facilities get disturbed during bathing. Understanding why can turn bath time from a task-centered struggle to person-centered care.

Unfortunately, for people with memory loss, this once familiar task can now be disorienting. It is also one of the most intimate. Your person may feel embarrassed, frustrated by loss of independence and dignity, or think they have already showered. They often don't realize they need help and resent the caregiver's attempts.

Start by letting your person do as much as they can, such as pulling down their pants. You might need to help them a little, but allow them to think they're doing the most so they feel they are still in control.



Address one section of the body at a time, using calming words and tone, and try to include the person in the process. These proven tips may help:

- Establish a routine and follow the same bathing schedule the individual had before diagnosis (time of day, frequency, etc.)
- Make sure the bathroom is safe, with shower chair and bars.
- Provide as much privacy as possible.
- Let them pick out their towel and after-shower clothes.
- Ensure proper room temperature before disrobing.
- Prepare in advance. Make sure soap, towels and other items are within reach. Use bathing items that are soft to minimize skin irritation.
- Always test the water temperature.
- Limit the number of showers each week. Try for three, if possible.
- Make showers as quick as possible. Wash the most important parts first.
- Offer a bath with assistance, instead of a shower.
- Sponge bathing might be an option.
- Model the behavior on how to wash the body. Some people might need direction.
- Ask a family member to assist. Your person might be more comfortable with someone of the same sex assisting, such as a son helping a father.
- Play soothing music or light candles to relax the person.
- Use fragrances that are enticing.
- Offer a snack after shower time.

# To Test or Not to Test?

The global genetic testing market was valued at \$8 billion in 2021, according to Precedence Research. Ancestry tracing sites have spurred the growth of personal-information seeking so significantly that genealogy has become the second most popular hobby in the United States, *Science News* reports.

Nathaniel A. Chin, MD, an assistant professor (CHS) at the University of Wisconsin-Madison, department of medicine, geriatric division, says “probably the most important question” involving this interest is what people should consider before getting tested. The recent controversy surrounding Australian actor Chris Hemsworth’s decision to go public with the results that his test revealed a high risk for Alzheimer’s highlight the importance of careful consideration.

“It’s not just a test that affects one person, just as Alzheimer’s is not a disease that affects one person,” Chin says. “The key things to consider are: Why are they getting it? What are they hoping from the outcome? What is their motive?”

Secondly, people need to consider what they will do with the information if they prove to be at risk. Will they behave differently and make changes? Will they see themselves differently or worry that others do? What are the psychological consequences of knowing this information?

“Are there specific treatments based on your genetic risk? The answer is no,” Chin says. But while no therapeutic interventions exist now, great support groups do and joining a research study is also possible.

***“Who are you going to talk to? Will you tell family and friends. Will your insurance company learn about it? Will it change your medical care? These are some of the questions that come up. One test leads to so many other questions. It’s a ripple effect.”***

Because of all these considerations, Chin advises against home tests, which don’t specifically test for Alzheimer’s but “can tell you a lot of interesting and emotionally charged things about yourself, including if you are at an increased risk through the gene APOE.”

## **What is the APOE gene and how does it affect risk?**

APOE is apolipoprotein-E, a “susceptibility” gene for late-onset Alzheimer’s disease. It is designated into three risk levels—APOE 2, APOE 3 and APOE 4. APOE 3 is considered neutral and is the

most common, with a 2 to 5 percent risk for Alzheimer’s. APOE 2 has a one to two percent risk. APOE 4 holds a 10 to 15 percent increase. Chin emphasizes that a person can have the high-risk gene without ever developing Alzheimer’s and, conversely, may not have the gene and still develop the disease.

“It’s a risk, not a guarantee.”

What is most important for someone wishing to know their Alzheimer’s risk, Chin says, is that they find a healthcare provider who can discuss results and what they mean for that person. He said it is best to see a neurologist, psychiatrist, geriatrician or medical geneticist. In the seven years he has been in practice at an academic institution, he has never ordered a genetic test. He refers patients to a medical genetic clinic.

***“I would advocate that people need to consider how they will handle the information. That is the value of good counseling, to know what is involved. Counseling plays a huge role and should be mandatory.” It is not currently mandatory.***

For initial exploration, Chin recommends the website [genetestornot.org](http://genetestornot.org), which helps people think through the whole process of getting tested.

Chin said counseling about risks, particularly genetic risks, should be part of medical education. Medical providers play a critical role in terms of explaining risk, helping the patient consider the psychological effect the information could have and what the consequences of telling family and friends could be.

A trained genetic counselor can spend between 45 minutes to two hours going over this with a patient, he said. Unfortunately, busy primary care doctors do not have that kind of time. That is why some may decline to do genetic testing. “They’re not prepared to handle what comes with it.”

People shouldn’t have to worry that a test showing high risk will affect their health insurance because GINA, the Genetic Information Nondiscrimination Act, protects them, Chin says, but life and disability insurance are different. He advises that people get these types of insurance set up before they are tested.

Possible discrimination in employment for people testing at high risk is “tricky,” Chin says, because while laws prevent discrimination, “there is a lot of bias and stigma around Alzheimer’s.”

If an employer were to learn of an employee’s risk factor, the employer might watch that person more closely, looking for mistakes that would lead to dismissal or demotion.

“Information is readily accessible these days and one must be really careful.”

Chin points to the outcome of the 39-year-old Hemsworth’s discovery and subsequent disclosure after a DNA test he took for his six-part docuseries, *Limitless*, on the streaming service Disney+, revealed he has two copies of the APOE4 gene. He was supposed to learn the results on the show, but the producers told him privately because of what was revealed. He chose to be open to educating people about the importance of a healthy lifestyle in preventing or slowing Alzheimer’s and was criticized for going public with information his family didn’t ask for.

“It’s sad to see them kicking a person while he’s down,” Chin said. “There’s always value when a person in the spotlight headlights the power of prevention and emphasizes the importance of quality of life.”

He reserves his concerns for the people who did the blood testing without potentially counseling Hemsworth about the consequences of knowing the results. “If he was blindsided then that is completely unacceptable. It’s high risk to drop something like that on a person who is not prepared. I’m impressed with the way he’s handling it. He’s letting people know this is serious information and must be treated as such. He’s having an impact.”

*In addition to Dr. Nathaniel A. Chin’s professorship, he is the associate director of the Geriatric Memory Program at the University of Wisconsin Hospitals and Clinics, the medical director and clinical core co-leader at the Wisconsin Alzheimer’s Disease Research Center (ADRC) and the medical director of the Wisconsin Registry for Alzheimer’s Prevention (WRAP) study. He is also a member of AFA’s Medical, Scientific & Memory Screening Advisory Board.*



# SPREADING A MESSAGE *of* HOPE: Q&A WITH SINGER MAUREEN MCGOVERN



Photo Courtesy: Maureen McGovern & Family

**M**aureen McGovern was a 23-year-old folk singer in 1972 when she was chosen to record “The Morning After” for *The Poseidon Adventure*. The song and movie became megahits and launched her five-decade career as a concert performer, recording artist and Broadway musical theatre actress. All of that changed several years ago when she was diagnosed with posterior cortical atrophy (PCA), a degenerative brain and nervous system disorder, with symptoms of Alzheimer’s. She spoke to *Alzheimer’s TODAY* about her life back home in Ohio and the projects she has planned.

### ***How did your diagnosis come about?***

Five or six years ago I started to have trouble remembering little things. I found myself saying, “I know this song. Why did I forget the words?” I made a joke out of it in shows but it kept building. I started having to keep lyrics or a music stand in front of me while I was performing. I saw my doctor for tests and originally everything was “normal.” Eventually, though, my tests began to show changes in my brain and I was diagnosed with PCA and mild dementia. Words are becoming harder and harder to find. It can be very challenging.

### ***Have you adjusted to the diagnosis?***

I have travelled the globe for 40 years and was completely independent. Since my diagnosis I have moved to an independent senior residence for the convenience, safety and support. I had to downsize with the move and had to let go of many treasured items. It was hard and frustrating to leave the place where I had been for the last 20 years.

I am grateful for where I am now. I live on the fifth floor with an amazing view. I see the sunrise and am enjoying the changing landscape of each season. It was hard to adjust to the changes at first, but I’m more comfortable now. I now know my diagnosis and understand what is happening. I know many people are going through this, too. I want them to know they are not alone. I plan to write a book about my life experiences.

### ***We read that you can no longer travel or perform in concerts. Can you sing and do you?***

I sing a lot in my apartment to keep “the pipes” in order. The neighbors are very happy. There is a fellow resident here who is 90 years old. He plays the piano and loves to perform. We get together every couple of months to perform for the community. It’s a lot of fun and our fellow residents seem to really enjoy the shows.

### ***What is your biggest challenge?***

Not knowing exactly what is in the future. I try to see every day as a gift and keep moving on and trying to help other people.

### ***What else are you working on now?***

Throughout my career as I have travelled to different cities to perform, I would stop to visit hospices, hospitals and prisons. This was my effort to bring hope and healing through music. That’s always been a part of my heart. I remember one visit to a hospice with my friend, Dr. Deforia Lane, a music therapist. We visited a grandmother who was in her last moments. I thought, “Oh, my God, what can I do to help her and her family?” You could feel the sadness in the room. Her family said that she liked country music, so we sang a familiar country song for her. (“Country Roads” written by John Denver). I got to a certain point in the song and we heard a soft “who, who, who” sound. She was “singing” along with us. There was such beauty in that. Her children and family were crying tears of joy. Sharing a simple gift like that is wonderful. Music is healing.

Through the years I have also supported charities by performing concerts and telethons. That work has meant the world to me. I am currently working with music conductor Jeff Harris to do a recording of inspirational music, songs that bring hope.

### ***You said you will be working to bring more attention to music therapy.***

When people are feeling low, music lifts up their souls.

In 1972, I had just finished a concert when I was asked to visit a hospital the next morning, on Christmas Day. There were babies in cribs and children in beds. The babies didn’t know anything about me or my music but the parents needed to hear a hopeful message. After I sang, they came and hugged me. Something as small as a song can change how someone feels, even if just for a moment.

I want to be helpful any way I can. That’s what I’m looking forward to. I may not be able to perform concerts with symphonies or act in live theatre any longer, but I am still singing. I am dealing with this disease as best I can. I am happiest when I can make someone else happy.

### ***You said you slowly realized that your inner life has not changed, that dementia is not going to stop you from living your life.***

What we keep inside, in our heart, is our inner life. I try to remember things that were very important to me and I’m always trying to help somebody else in their dilemma. Every day is a chance to help someone else. I know that all of that is still inside me.



## They're Our Medical Records, Why is it so Hard to Track Them All Down?

Getting your loved one's entire medical history all in one place is a challenge, but there are a few reasons why it's important to do so for those impacted by Alzheimer's:

- **Be prepared** if financial benefits change and need to be renewed or reassessed.
- Have everything **ready and organized** in case of a move, change in providers, or a medical emergency.
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# Do You Have to Choose Between Work and Caregiving?

by Pam Ostrowski



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**Y**ou went into the office early, spent a day in meetings, and now it's 5:30 p.m. You still have to stop by your parents' house with dinner, make sure they've taken their medications, and then get home to fix dinner and catch up with your family, spend a couple of hours doing "real" work before you hit the bed, exhausted and overwhelmed, knowing tomorrow will be the same. The thought "maybe I can't do it all" crosses your mind as you drift off to a restless sleep.

You are not alone.

According to The National Council on Aging, 70% of caregivers who provide care for an aging loved one suffer work-related difficulties due to their dual roles—they take time off, forgo promotions and sometimes leave the workforce altogether. Employees lose up to \$3 trillion in wages and benefits while employers lose \$17-33 billion due to absenteeism and turnover. Dementia caregiving can affect employees 24/7, due to worry, middle of the night calls, and physical care for their loved one.

Most caregivers for aging loved ones are the most experienced employees, possibly in management or executive roles.

Caregiving employees also may be the sole breadwinners of the household. They want to be successful in their work but businesses are forcing them to choose between work and their aging loved one.

Employers have the opportunity to help their employees who are caring for aging loved ones be successful at work. Let's look at some options that support the employee caregiver.

## Communicate with Your Employer

A Harvard Business School report, "The Caring Company," stated that in the absence of a supportive "care culture," employees worry that admitting to caregiving responsibilities will impact their career growth, compensation, and fulfillment at work.

**Advice for employee caregivers:** Talk with your manager and the Human Resources (HR) department at your work. Share your commitment to your job as well as your need to be supportive of your family. Ask how you can work together to make this happen so that you can be at your best at work and not burn out due to trying to do it all. A few ideas to discuss include job sharing, flexible hours, working remotely, working a different shift, and adjusting job responsibilities.

*Continued on following page*

## Performance at Work

Presenteeism (lack of focus, more errors, less productivity when an employee is not fully functioning) and absenteeism (not coming to work at all) are the first signs of quiet quitting, the term used when employees do the bare minimum to get by in their work. You may feel so overwhelmed you may even want to leave your job for something else.

**Advice for employee caregivers:** Moving to another job is not likely to solve the problem of trying to provide care to an aging loved one while working. Instead, try to learn some task-management skills to support your performance, such as focused time blocking (read and respond to emails at fixed times of day), complete the task you dread the most first, and prioritize, e.g., identifying the three tasks you must get done that day.

Often, it's the inability to focus that paralyzes caregivers into not being able to make progress in any area of their lives. Establish work, family, and caregiving boundaries so that you also have time for you. It's too easy to just say "I've got this" when, in your heart, you know it's not sustainable.

Some great reads that are short and you can start using their advice immediately are Brian Tracy's *Eat That Frog* and David Allen's *Getting Things Done*.

## Finances

Financial strain can affect work performance. It is not uncommon for dementia caregivers to spend their own money to pay for their loved one's expenses (everything from medications to food). This means the money earned at work goes to additional

expenses incurred by caregiving. According to AARP, eight out of 10 caregivers report having routine out-of-pocket expenses, with those caring for a love one with dementia spending twice as much as other caregivers. (See p. 17, "Did You Know?" for additional information about this issue.)

**Advice for employee caregivers:** Speak to a money manager to review your budget and assets. Avoid using any of your retirement savings to help pay your aging loved one's expenses. Sit down with an estate attorney and a certified financial adviser to get their ideas on how to best pay bills. Most will provide a complimentary first meeting to address your questions. Check out the National Elder Law Foundation (NELF) and the National Association of Personal Financial Advisors (NAPFA) for a professional in your area.

## Respite and Self-care

Respite or self-care is usually the last priority of an employee caring for an aging loved one, especially if that individual has dementia. Not getting "down time" creates both mental and physical health issues. These issues negatively affect the employee's ability to successfully contribute at work and impacts their feelings of success and happiness.

**Advice for employee caregivers:** Make it a priority to make quiet time for yourself, even if it's just 10 minutes in the morning and afternoon. In order for you to perform best at work, you need seven to eight hours of sleep and restorative time for your mind and body. Build supportive relationships while at work and get professional caregiver help so you're able to focus on your work and enjoy it more.

# DO YOU NEED MORE SUPPORT?

- **Employee Assistance Program (EAP):** This work-based program assists employees with personal or work-related problems that may impact job performance, health, and mental and emotional well-being. Services for employee caregivers may include video-based counseling, online chats, e-mail interactions and face-to-face consultations.
- **Family and Medical Leave Act (FMLA):** The FMLA entitles eligible employees of covered employers (with 50 or more employees) to take unpaid, job-protected leave for specified family and medical reasons. Learn more here: [www.dol.gov/agencies/whd/fmla](http://www.dol.gov/agencies/whd/fmla)

- **Paid Family Leave (PFL):** PFL policies are state-paid regulations that vary from state to state and supersede federal law when the benefits are more generous than the national regulation under FMLA. Learn more here: <https://www.ncsl.org/labor-and-employment/paid-family-leave-resources>

### ABOUT THE AUTHOR

**Pam Ostrowski** is the CEO of Alzheimer's Family Consulting ([AlzheimersFamilyConsulting.com](http://AlzheimersFamilyConsulting.com)) and the author of *It's Not That Simple: Helping Families Navigate the Alzheimer's Journey*.



Tabjana Gladskikh | Dreamstime

# DID YOU KNOW?

## Family Members May Be Compensated for Caregiving



Noriko Cooper | Dreamstime

If you are a family member who feels the need to cut back on work or even quit to take care of a loved one, you may be able to get paid for your services. “It’s a very discreet issue,” says Matthew S. Raphan, Esq., a partner at Raphan Law Partners, LLP. “It’s not something that comes up regularly, but there are a few options when family members look to be paid.”

The most common way to do this is through a Power of Attorney document. In New York State the POA is a statutory form drafted by the state legislature. In other states people may draft their own. A person does not need a lawyer to complete the POA, he said, although most people prefer the expertise.

For those who qualify financially for Medicaid, the Consumer Directed Personal Assistance Program (CDPAP) allows the recipient to hire a family member or friend rather than a stranger from an agency. The person must meet certain eligibility requirements, such as being an American citizen or have legal working status and be at least 18. They will be paid by Medicaid.

“Sometimes family members are in the best position to care for the person and culturally this is an advantage that really works well. If a person is hiring a caregiver through an agency they don’t always get to pick and choose who it is. Many people are more comfortable with the flexibility and security that a family member can provide.”

Raphan said another possibility is that the person needing care and their chosen caregiver could have a lawyer draft an agreement between them that would guarantee payment, although he thinks this is rare.

Raphan said compensating a family caregiver is not common because most people consider caring for a family member to be their personal responsibility to a loved one and not something for which they should ask for compensation. However, it is possible.



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# Physician Heal Thyself:

## A Neurologist with Alzheimer's Disease

*By Daniel Gibbs, M.D., Ph.D.*



My dog Jack and I getting our 10,000 daily steps. Photo by Alisha Jucevic©

An email with a black box warning! That's what I got 10 years ago after my wife, Lois, and I submitted saliva samples to a DNA testing service. Lois is the family genealogist, and she thought that DNA testing would be helpful in filling in some of the missing branches of our ancestral trees. In addition to lists of DNA relatives, the report included many risk genes for a variety of medical conditions, none of which were present for either of us. However, this locked black box contained two genes of neurological interest: a mutation in the LRRK-2 gene, the most common cause of hereditary Parkinson's disease, and the APOE-4 allele, the most significant genetic risk factor for late-onset Alzheimer's disease.

I am a general neurologist, and I knew about these neurological risk genes. About six years before this, I had started to lose my sense of smell. I thought this was most likely due to normal aging, but within five years I could not smell anything. About 80% of people with Parkinson's disease lose their sense of smell, usually some years before the tremor and gait problems develop. I wondered if I might be on the path to Parkinson's, so I unlocked the black box to see if I had the LRRK-2 mutation. I didn't have that.

What I did have was two copies of the APOE-4 allele giving me a 50% chance of having a diagnosis of Alzheimer's dementia by age 70 and making it almost certain that I would have it by age 80. It turns out that virtually all people with Alzheimer's disease have at least some loss of smell, but most are not aware of it until tested. My loss of smell had been my canary in the coal mine, but I had been unaware of its significance. Before getting my APOE-4 results, Alzheimer's was just not on my radar screen. Both of my parents had died early from cancer, but looking back a generation or two, there clearly was a family history of dementia.

I was stunned by this news. I was 61 years old and still active teaching neurology to residents and medical students and providing care for a variety of patients with neurological problems, including dementia. I traveled to Tanzania every year to teach neurology there as well. Cognitively, I thought I was still doing fine, but I had a friend who is a dementia specialist do some testing on me. Everything was normal, but there were some caveats. In all cognitive domains but one I scored in the 95th percentile. However, in verbal memory I was in the 50th percentile, still normal, but it was a sign that there might already be some subtle damage to the part of my brain that deals with language.

A year later, when I was 62, I retired. I wanted to make sure that I didn't wait until I made a mistake in the care of my patients. I plunged into the neurological literature to find out what was known about slowing the progression of Alzheimer's disease. I found that there was consistent evidence that regular aerobic

exercise can slow progression of the disease by as much as 50%. Plant-based diets like the Mediterranean diet or a variant called the MIND diet with a greater emphasis on berries and nuts have been shown to slow progression by 30–50%. Other lifestyle modifications that appear to be beneficial include staying intellectually and socially active, getting at least seven hours of sleep a night, and controlling cardiovascular risk factors like diabetes, high blood pressure, increased cholesterol, and smoking. I follow these guidelines religiously, and I think it is making a difference.

I also want to do everything I can to help move the science about Alzheimer's forward. I have participated in six research studies so far. These include three clinical trials of medications, two technology-based studies, and a longitudinal neuroimaging study using amyloid and tau PET scans to follow the progression of Alzheimer's in my brain. I don't expect that any of these studies will cure me, but I hope by my participation we can come a little bit closer to finding solutions to prevent, slow or even reverse this disease.

I feel strongly that people with Alzheimer's disease and their families should feel comfortable talking about their journeys with family members, friends and neighbors, and, if possible, with the general public. Stigma and misconceptions must be addressed. The pathological changes in the brain, the amyloid plaques and tau-containing neurofibrillary tangles, appear early, as much as 20 years before any cognitive issues arise. These 20 years before cognitive decline begins may well turn out to be the most effective time to stop or at least slow disease progression. Several current studies are looking at the efficacy of treatment in this pre-symptomatic period.

Although I was uneasy at first, I have come to enjoy talking to people about Alzheimer's disease. I have written a book about my experiences for the general public. I have given over 35 interviews and talks for radio, television, podcasts, newspapers, magazines, medical students and Alzheimer support groups.

My Alzheimer's disease is slowly progressing. My most recent cognitive tests put me at the border between mild cognitive impairment (MCI) and early Alzheimer's dementia. There is more amyloid and tau on my recent PET scans. But I am adapting to changes with the support of my wife, family and friends. Life is still good, and I expect it to continue being good for many years to come.

#### ABOUT THE AUTHOR

**Neurologist Daniel Gibbs, M.D., Ph.D.**, is the author of *A Tattoo on My Brain: A Neurologist's Personal Battle Against Alzheimer's Disease*, now available in paperback. It details his journey from treating Alzheimer's patients for 25 years to managing his own diagnosis. A documentary under the same title is being filmed about his story.

# RAMEN VEGGIE SOUP

## NUTRITION FACTS

Serving: 215 calories  
1 g fat, 46 mg carbs  
5.6 g dietary fiber  
10.5 g protein  
25% daily value iron  
648% daily value vitamin D  
12% daily value potassium

Sodium varies depending on brands used. If you are on a sodium-restricted diet, omit the soy sauce.

\*If you are on a gluten-free diet, make sure all ingredients are gluten-free.

*This deliciously warming soup can be made in a variety of ways depending on the season and availability of vegetables. Add frozen vegetables, like peas or corn, for added color, texture and nutrition. Try different proteins like diced tofu, peas, shrimp, edamame beans or cooked chicken. For a \*gluten-free variation, choose brown rice or buckwheat noodles. Serves 4.*

### CHOOSE ORGANIC INGREDIENTS WHEN AVAILABLE:

32 ounces low sodium vegetable broth  
(or chicken broth)

1/2 medium onion

8 ounces baby bella mushrooms, sliced

6 baby carrots, chopped

1 cup Brussels sprouts, trimmed & cut in half

1 cup frozen corn

1 cup frozen peas

2 cups baby spinach

2 tablespoons reduced-sodium soy sauce  
(choose gluten-free brand if needed)

1 teaspoon honey

1 teaspoon hot sauce (yuzu hot sauce), optional

4 ounces dried soba noodles, preferably made from  
brown rice or buckwheat

### DIRECTIONS

1. In a large saucepan, on medium heat, sweat onions and mushrooms for 5 to 7 minutes.
2. Add Brussels sprouts and carrots. Continue to cook for 5 to 7 minutes, adding a bit of broth if liquid is needed.
3. Add corn and peas until defrosted.
4. Add the rest of the broth, soy sauce, honey and optional hot sauce.
5. Bring to a boil, add noodles. Separate noodles gently with a fork and reduce heat to a simmer. Follow package directions for cooking time.
6. Add spinach and allow to wilt in the soup.
7. Stir and serve.



Recipe by Layne Lieberman, MS, RD, CDN, culinary nutritionist and award-winning author of *Beyond the Mediterranean Diet: European Secrets of the Super-Healthy*. For more information and recipes, visit [WorldRD.com](http://WorldRD.com).



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# Planning Early for Care

**S**enior living has changed greatly over the years in terms of home care, senior communities and skilled nursing facilities (SNF). In the past, being “put in a home” was something people feared and their loved ones, often out of guilt, tried to avoid. But the options have broadened and improved to the point that senior care is now a thriving industry.

“It comes from a place of love,” says Diane Trunecek, senior care advisor of CarePatrol of New York and Connecticut. “This is not a one size fits all situation. We now have options to meet each individual’s care needs and budgets, now and long term, as well as any other nuance that may be important.

“Your loved one may not be the person today that you think of them as being in the past. That does not mean that part of them is completely lost. It may just mean that you learn to find new ways to connect to those parts. Planning does not always mean that the journey will be perfect, but it could mean that you may be more equipped to handle the bumps in the road with the tools you need.”

Home care is most common, Trunecek says. This provides one-to-one care but can lack socialization or stimulating programming with peers who are in similar stages. Not all home caregivers have knowledge of different medical concerns, such as urinary tract infections. Additionally, reliability can be a problem, especially for those who work and need a dependable caregiver.



Ravi Pixel | Dreamstime

“People often try to keep their loved one home longer than they maybe should,” she says. “This can take a toll on their own physical and mental health and begs the question, would your loved one want that for you?”

In contrast, Trunecek says, a senior living community or SNF offers a team of trained experts, although residents often share

***Continued on following page***

## PLANNING EARLY FOR CARE *cont'd from p. 21*

rooms in a hospital-like environment that does not typically have a proper memory care section. Staff may not be trained in working with those who have cognitive concerns or offer programming, so ask what support they offer.

Senior living communities with proper memory care “neighborhoods” are often a home-like environment, Trunecek says. Residents have their own apartment or share one. These communities offer specialized programs, nutritious meals and the staff is often trained to work with memory concerns.

Deciding what type of care is best for your loved one is one step. Paying is another. “Most people are surprised at how little their insurance covers, if anything at all,” Trunecek says. “Be knowledgeable about your plans and what they cover.”



## When is the right time to think about transitioning a loved one to a higher care level?

“Most professionals say that the time is before we recognize they need it, earlier in their journey than you may think—yesterday, now,” Trunecek says. “This allows them to acclimate to the space with more ease, as whatever capabilities they have now are likely the most they will have moving forward. It is important to keep in mind that some memory care communities have a waitlist, so it is better to approach them before you need them. Take the stress out of caregiving by educating yourself on options earlier rather than later.”

## What to Consider Concerning Cost

Most care options are private pay—savings, assets, others supplementing to help pay. Some people qualify for Medicaid, a federal policy that is different in each state. “Learn about your state’s Medicaid laws, speak with an elder law attorney, local government offices, or other professionals.”

### Other avenues to help pay for care.

Long-term care policy, veteran benefits, state funding (check your state’s website to see about vouchers or subsidized care).

### Other resources for more economical care options.

Day programs (small fee may apply), the Program of All-Inclusive Care for Elderly (PACE) office (for transportation vouchers and sometimes professional teams), local organizations (church/temple, volunteer organizations), the Alzheimer’s Foundation of America, Meals on Wheels and your local Department of Aging.

Trunecek says a price/cost analysis comparing living at home versus a senior living community can help. “Oftentimes people see the price and have sticker shock. Once they compare expenses at home with care, many people are surprised to find that the senior living communities can be more economical.”

Working with a senior care advisor can help narrow options and get you connected with professionals. If your area has Medicaid options, you may want to leave “a nest egg” to work with in case periods of private pay are required.

*Adapted from the AFA Care Connection webinar “What They Wish They Would Have Known Earlier: ‘Getting Your Ducks in a Row’ for Memory Care Options.” Diane Trunecek is a senior care advisor in the New York City area. She assists people in narrowing their options based on care needs and budget, both now and long term.*



# Caregiver Creativity: Connecting Through Legos

Loretta Veney was five when her mother gave her Legos to play with. Little did either know then that those colorful plastic bricks would be part of a lifelong bond between them and would eventually send Veney into a career path she never could have foreseen.

The bricks, given without any instructions, were meant to make the child creative but they became therapeutic for the mother, who often suffered from depression.

“If she had a bad day at work, we got the Legos out. We talked through things with the Legos.”

In the decades ahead, when dementia made talking difficult for her mother, Doris Woodward, sitting together with those bricks unleashed memories and words Woodward had been unable to access.

***“I tried never to finish her sentences. I really believe those Lego bricks helped her find her words. They solved so many problems for us.”***

It was Legos that helped Woodward deal with the shock of her dementia diagnosis.

“She was really shaken up and borderline in tears. I got out my Legos in the car and said, ‘Build how you feel.’”

Veney kept Legos in the car because her mother was a nervous passenger and working with them distracted her. On that day her mother couldn’t concentrate on building. She reached for a Lego person, snapped off its head and told her daughter, “I feel like in a couple of years from now I’ll lose my head.”



Seeing the effectiveness with her mother, Veney retired in January 2021 from a 40-year career in security management and training in the Washington, D.C. area to devote her time to educating others in how to use Legos to reach people living with dementia. She does this through social media, her website ([lorettaveney.com](http://lorettaveney.com)), leading workshops, writing and speaking.

When she announced in January 2022 that her mother had died, she received condolences from people in 18 countries around the world who shared stories of how they had been inspired by her to use Legos with their loved ones.

“If you find something that works you share it. I used my mother sort of as a test case. I didn’t think it would become as big as it has. My mother would be thrilled.”

# Caregiver Matchmaking



Choosing a caregiver for a loved one with memory loss should be about creating a relationship between the two, one that is built not just on skills but ideally will involve creativity, flexibility and mutual interests.

“What’s most challenging is finding people who really have a genuine passion for the work,” says Joe Fisher, founder and CEO of Renewal Memory Partners who has 15 years of experience matching caregivers and receivers. “Many people are just looking for a paycheck. You want to find people who view this work as a calling. That brings a totally different energy to the work that is felt by the clients.”

Finding caregivers who are good communicators is crucial, he said.

“Most communication is nonverbal with people with dementia who are still good at picking up on nonverbal cues.”

Corey Bliss, Renewal’s senior care director, advises looking for someone with experience caring for memory loss individuals or who has had a “lived connection,” such as a family member with the issue. “That’s the best teacher.”

Both Fisher and Bliss say the connection between caregiver and receiver should be based on a solid relationship.

“The relationship part is not all that different than it is with any two people,” Bliss said. “It’s about being a good listener, being patient and meeting people where they are. A relationship works best when two likeminded individuals come together and have shared experiences. The care provider is learning from the client and the client is learning from the care provider. This is what makes the best mutual relationship.”

What causes relationships to fail, she said, is personal preferences, such as when a talkative person is paired with someone who is reserved and prefers to be quiet.

The pairing process takes time, she says, explaining that the caregiver needs to take their cues from the person with memory loss. “You start with observing what the client is attuned to.”

Fisher says the caregiver must attune to the person with memory loss to see how they react to the volume at which you speak, whether they need more time to process the information they are receiving and how the complexity of a task can be broken down into parts.

***“In general, care providers who are successful are attuning constantly. Let the [care receiver] be the star of the show. For every minute of talking have three minutes of listening.”***

Out of respect for their person, Bliss said family members should look for a caregiver who will allow the care receiver to have as much independence as possible, especially in the early stages of cognitive change.

Fisher elaborated, “Do things with the client rather than for the client rather than for the client. This is not intuitive to everybody. Some work hard to do everything. They are well-intentioned but they could be taking away things that are important to a person’s self-esteem. This preserves independence and self-worth.”

He describes his agency’s process as “part art and part science.” The science part involves matching care receivers with someone who shares their interests, such as a love of history, architecture or opera. The art part is based on intuition in observing when the two meet.

“You have gut feelings these two people are going to enjoy each other’s company. It’s the intangible part of the process and taps into emotional intelligence.”

Families looking for a caregiver should take time with this exploration.

“A mindful introductory process leads to a lot of success,” Bliss says.

Another part of success involves the safety of the care receiver. Family members want to know their loved one will not be abused or neglected. They also want to know the provider is dependable, especially if they work and need to count on that person showing up on time. For these reasons Fisher says it’s important to work with a licensed agency that will have screened the potential caregiver thoroughly.

One measure of judging the success of the relationship, he says, is to look for the “halo effect.” The family should observe whether the person “remains upbeat, talkative and engaged for the remainder of the day. That’s a good sign the visit was a success, and the client had a high level of cognitive engagement. If the visit didn’t have a lot of engagement, you’re not going to see that effect.”

Caregivers wanting to have a good relationship with someone with memory loss should find out as much as they can about who that person has been in terms of career and interests, as well as their scheduling needs, what their symptoms of cognitive change are and how much insight into the condition they have.

“It’s really getting to know who this person is as a person,” Fisher says. “It’s not defining them as their disease but as a person with the illness. Consider the level of insight the person has into their disease. If they are in denial, they’re not going to want anything involved with the word ‘care.’ Knowing the level of resistance enables you to recalibrate the work with the family to use terminology that resonates with the person. If they are a retired executive, you can use ‘executive assistant.’ If they were an artist, you can use ‘studio assistant.’ Language matters.”

Some of the best caregivers are people from the performing arts world and other creative fields, Bliss said, because “they will be constantly recalibrating during the day what’s going to work for their client. They instinctively know how to pivot.”



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## Did You Know?

Each year, **MORE THAN 16 MILLION** Americans provide more than 17 billion hours of unpaid care for family and friends with dementia.

**OVER HALF** of all dementia family caregivers provide care for four years or more.

The number of people in the U.S. living with Alzheimer's is projected to more than double to **14 MILLION BY 2060.**

*Source: Centers for Disease Control and Prevention*



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