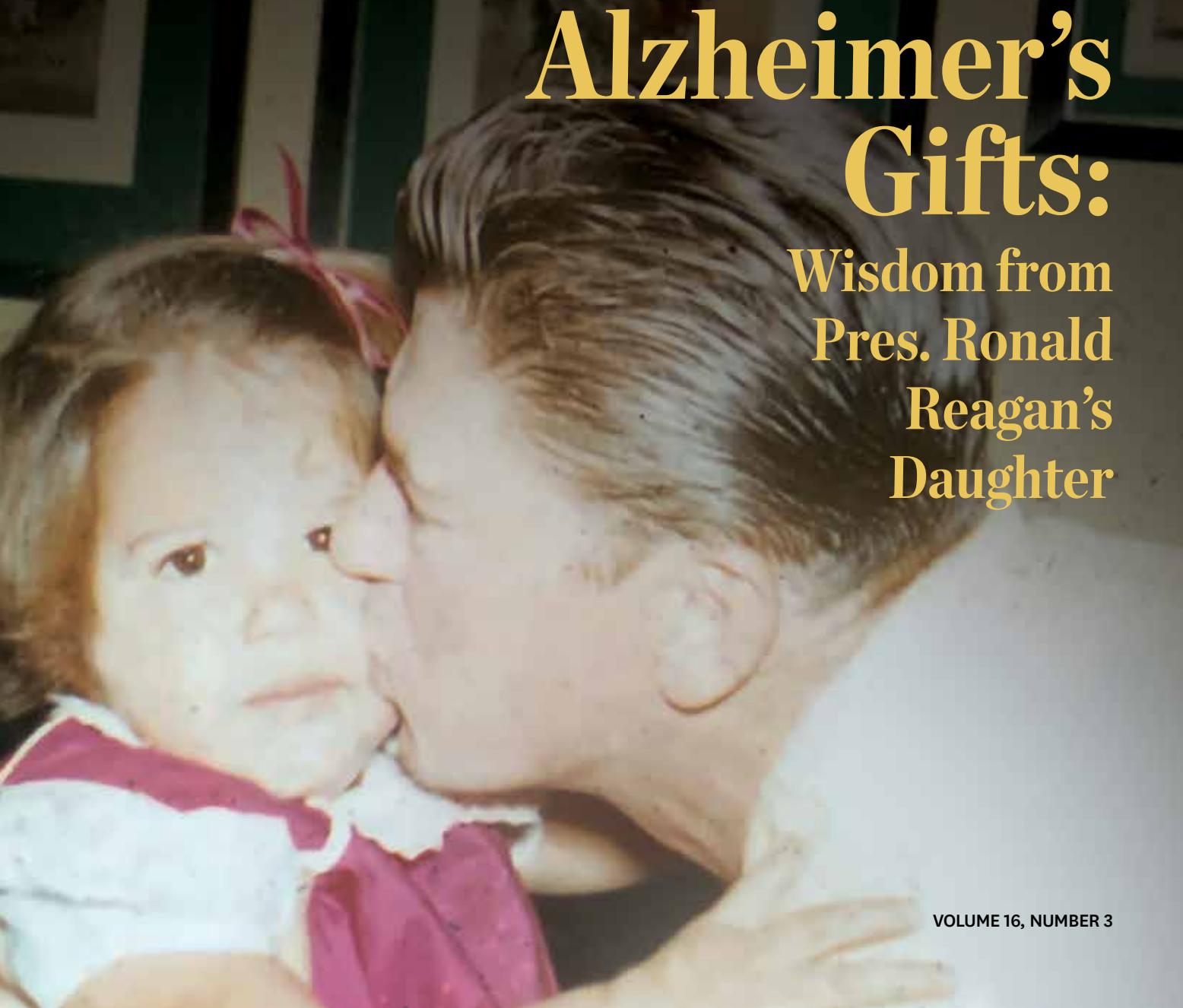


Alzheimer's TODAY®

The Official Magazine of the Alzheimer's Foundation of America

Alzheimer's Gifts:

Wisdom from
Pres. Ronald
Reagan's
Daughter



VOLUME 16, NUMBER 3

Do you know a high school senior who has been impacted by Alzheimer's?

NOW Accepting Entries!



AFA's Teen Alzheimer's Awareness Scholarship

2022



AFA's Teen Alzheimer's Awareness Scholarship provides educational funding to college-bound high school seniors who have been impacted by Alzheimer's disease.

Applicants are asked to write an essay (1,500 word maximum) describing the impact of Alzheimer's disease or another dementia-related illness on themselves, their families or their communities, and what they have learned from it.

The grand prize winner receives \$5,000, with additional prizes awarded for runners-up. More than \$350,000 in college scholarships have been awarded since the program's inception.

Deadline for submission: March 1, 2022

Learn more at alzfdn.org/scholarship



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Weathering the Shortage Storm

Americans are grappling with supply shortages right now. Visit your local grocery store or retail establishment and you're likely to see large gaps on some shelves because the demand is outpacing the supply. Certain employment sectors also have staffing shortages because employers cannot find enough people to fill open jobs. This includes professional caregiver support, such as home health aides.

Continued progress in the fight against COVID-19 made families affected by Alzheimer's more willing and able to bring outside support workers into the home, but some families are experiencing difficulties. There simply are not enough workers.

So what can you do to weather the storm if you're having trouble finding professional caregiver support?

Contact your local Area Agency on Aging (AAA). Oftentimes, professional caregivers who are self-employed and do not work for an agency will notify an AAA when they are available for hire. An AAA is a government-designated organization that addresses the needs and concerns of older individuals and their caregivers. Letting the AAA know you are looking for help can help make a match!

Some areas also have a volunteer or caring companion program which can be helpful. While these individuals do not provide hands-on care, they can deliver respite for the caregiver by socializing with the individual living with dementia, supervising them, and helping with household chores.

AFA's social workers can help connect you with your local Area Agency on Aging. Contact them through the AFA Helpline, seven days a week by phone (866-232-8484), webchat (www.alzfdn.org), or text message (646-586-5283).

Check with local colleges. Often, students seeking degrees in fields such as nursing or social work are encouraged (or required) to do volunteer work to gain experience in their field. Many colleges have internship programs or matching programs which pair these students with families in need of services. If there's a college in your area, reach out and see if they have this type of program.

Utilize the RSVP program. The Retired and Senior Volunteer Program (RSVP) is the largest older adult volunteer program in the country. It recruits, trains, and places older adult volunteers (ages 55+) in service opportunities, including helping vulnerable adults through home visitation. To find an agency offering the RSVP program in your area, visit www.benefits.gov and type "RSVP program" in the search bar or contact the AFA Helpline.

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Before I Forget... Let Me Tell You That I Do Forget

For the past three years I've been living with a diagnosis of Alzheimer's disease; and during this time, here is what I've learned about the disease and about myself:

I was diagnosed with Alzheimer's disease in 2018. But from the very first day I decided to stay positive.

Continued on following page

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BY EUGENIA ZUKERMAN

Before I Forget cont'd from p. 3

Indeed, on that first day, I went back to my apartment, sat down and stared at the wall, and then for some reason I started writing a book called *Like Falling Through a*

Cloud: A Lyrical Memoir of Coping with Forgetfulness, Confusion, and a Dreaded Diagnosis.

It is very important to remember that Alzheimer's has three phases. The longest phase is the first. In phase one, you are able to perform most functions quite normally; and I have found the key is to continue living life to the fullest, as best you can, and for long as you can after being diagnosed. Unlike many fatal diseases there is no physical pain, so enjoying life, and being productive, doesn't stop the day you are diagnosed.

I may have an advantage because I've been playing the flute from the age of ten and am enjoying a vibrant career as a flute soloist. The good news is that doctors are now saying there is a relationship between playing a musical instrument and memory retention.

I'm also currently the Artistic Director of Clarion Concerts in Columbia County, New York State. In that role, I invite top classical artists to perform in our concerts in superb venues in our area. I'm also doing book readings to organizations serving individuals living with Alzheimer's disease, which lead to lively discussions with others who are living in phase one.

From these discussions, I've discovered how people are dealing with their diagnoses. Many of them have, unfortunately, lost their friends because they are embarrassed to talk about their diagnoses. Many avoid social encounters and situations. I try to show them the opposite side of the coin. For example, when I meet new people, I immediately tell them that I have Alzheimer's. Lots of times I will say, "Before I forget, let me tell you that I do forget, because I have Alzheimer's."

Their reactions vary, but, most times, because the disease is so widespread, the response is that they have a parent or family member with the disease; and they immediately feel more comfortable.

I said above that in phase one of Alzheimer's, one can perform most functions "quite normally." So here is the downside for

me. I have stopped driving my car. Not because I became lost while driving, but because I have lost my confidence about my ability to drive. When I told my husband about my concerns about telling the difference between the gas and the brake pedal, we knew instantly it was time to stop. And I no longer have the ability to read the newspaper every day, and reading a book is getting harder and harder. And, yes, truth be told, I am repeating the same questions more frequently, as my short-term memory begins to fade.

But my resolve to stay positive remains strong!

One has a major decision to make once diagnosed: You can either crawl into bed and cry or make the very most out of the rest of your life by staying positive and seizing every day.

The last lines of the final poem in my book, *Like Falling Through a Cloud*, say it all:

I do not embrace my inevitable decline, but I am determined to find a way to make the rest of my stay on this problematic planet filled with light and love and music.

*I have a strategy to keep on keeping on
which is simple
wake up
fetch the flute
summon up Syrinx
give thanks for
another day
and then
play on!
play on!
play on!*

Photo courtesy of Angela Jimenez

Eugenia Zukerman is a musician, writer, and journalist who covered the arts for CBS Sunday Morning for more than 25 years. An internationally acclaimed flutist, she has performed with major orchestras and music festivals around the world. She is also the author of *Like Falling Through a Cloud: A Lyrical Memoir of Coping with Forgetfulness, Confusion, and a Dreaded Diagnosis*.

Helping Someone Accept Their Diagnosis

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PROBLEM SOLVE HOT-BUTTON TOPICS TOGETHER.

Issues relating to a loss of self-sufficiency (i.e., driving, living alone) may make the person defensive and resistant. Address them through a dialogue, not by dictating or arguing. "Roll" with any resistance—be open to expressed concerns and keep the discussion collaborative. Addressing these issues often takes multiple attempts, so let the conversation "sink in," be ready to continue it at any time, and test the waters again as needed.

BE EMPATHETIC, NOT SYMPATHETIC.

Sympathy is caring about and feeling sorry about someone else's trouble, grief, or misfortune. While well-intentioned and meant as a form of compassion, it often leads to disparity and drives disconnection. Empathy is understanding someone's experiences from their perspective and sharing their emotions (i.e., "putting yourself in their shoes"). Being empathetic facilitates fuller relationships.

Exploring these topics together can be tough.

Sometimes the goal is helping the person feel you are on their side before getting into serious concerns. This can take several conversations—that's ok, as long as the conversations start early and your loved one is safe during the process.

Have questions? Contact AFA's Helpline seven days a week by phone (866-232-8484), webchat (www.alzfdn.org) or text message 646-586-5283.

THEY SAY...

You didn't tell me about that.

YOU SAY...

I'm sorry. I thought I did. Let's write it down so both of us remember.

THEY SAY...

The bus is late.

YOU SAY...

*Darn bus!
Let me check the schedule for you.*

THEY SAY...

Someone else's name instead of yours.

YOU SAY...

I love you, {loved one's first name}. I'm your son/daughter/spouse/friend {your first name}. {Name they used} is doing well.

THEY SAY,

YOU SAY.

BY
PAM OSTROWSKI

THEY SAY...

Someone stole my purse/keys/etc.

YOU SAY...

Let's check around one last time.

I might have missed it the first time I looked.

When your loved one with cognitive impairment and memory loss is struggling and says something to you that doesn't make sense or hurts your feelings, try out these suggested responses.

Meet them where they are today. Introducing your reality will only shut them down.

THEY SAY...

I want to go home.

YOU SAY...

*Home is a wonderful place, isn't it?
What's the best part of being home?*

Let's go look in your apartment at some of our favorite things.

ABOUT THE AUTHOR

Pam Ostrowski is author of *It's Not That Simple: Helping Families Navigate the Alzheimer's Journey* and Founder of AlzheimersFamilyConsulting.com.

THEY SAY... YOU SAY...

THEY SAY...
When are we leaving?

YOU SAY...
*Not quite yet.
We have a couple of more things to do.*

THEY SAY...

"I'm fine" when you know something's amiss.

YOU SAY...

Do you hurt somewhere? {ask these one at a time and point to the area as you ask}. Is your leg OK? Is your arm OK? Is your hand OK? Is your stomach OK? Is your head OK? Are you sad?



Do you have a loved one with agitation associated with Alzheimer's dementia? Is their agitation becoming overwhelming?

Is someone you care for with Alzheimer's dementia exhibiting excessive motor activity, verbal and/or physical aggression?

If so, they may qualify for the **ASPECT™** clinical research study. The purpose of this study is to evaluate the safety and effectiveness of an investigational drug for agitation associated with Alzheimer's dementia.

To be eligible for this study, a potential participant must:

- ✓ Be between the ages of 50 and 90
- ✓ Have a diagnosis of probable Alzheimer's dementia
- ✓ Have moderate-to-severe agitation that interferes with their daily life
- ✓ Have a reliable caregiver who spends a minimum of 2 hours per day, 4 days per week with them and is willing and able to comply with all study procedures

Other eligibility criteria may apply.

The image depicted contains models and is being used for illustrative purposes only.

Those who qualify will receive study-required medical care and study drug at no cost.
Health insurance is not required.

**For more information visit: aspect306.com
or call 1-877-592-2574.**



MLB-786-US-0602-0221

Breaking the Stalemate

Persuading a loved one to do something they don't want to do—go on a diet, exercise, or give up smoking or alcohol—is often challenging under normal circumstances. When the person is living with dementia and the issues in question relate to things which impact independence, quality of life or dignity, it can be even more challenging and emotionally trying.

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Tough conversations can be made easier when involving a care professional—a third-party expert offering an objective, independent, evidence-based recommendation, rather than a loved one who may be perceived differently by the individual. Involving a care professional (i.e., physician, nurse, social worker, etc.) in the decision-making process can help “break the stalemate” and alleviate feelings of pressure and/or guilt the family member may be having about making these types of decisions.

Relinquishing driving privileges, for example, is often a difficult conversation to have with a loved one. Many are resistant or unwilling to give it up voluntarily. A situation such as this is a prime example of when asking a care professional to be part of the discussion can be helpful.

“When I worked as a geriatric nurse practitioner providing primary care in an internal medicine clinic, if a patient scored poorly in executive thinking, which determines their ability to make safe decisions, and short-term memory, I was required to recommend to the state motor vehicle department that they can no longer drive,” said Marge Dean, RN, CS-BC, GNP-BC,

NP-C, MSN, FAANP, a member of AFA’s Medical, Scientific, and Memory Screening Advisory Board. “I let them know I would be making that recommendation, explain that the final determination would be made by the motor vehicle department, and tell them how they could request a hearing to state their case if they so choose.”

“I had one patient who owned a car lot, selling cars his whole adult life, present all types of reasons at each visit as to why he should be able to continue driving. For example, he promised to only take lightly trafficked back alleys,” Dean said. “We discussed the fact that if a child chased a ball into the alley, he could hurt that child, and that such a tragedy would always be with him. He finally understood and gave up the keys after that.”

Living arrangements can be another sensitive topic. Some loved ones may want to remain at home, on their own, without help—even after an incident where they got hurt and required a trip to the hospital. When something like this happens, a family member can ask

Continued on following page

the hospital social worker to conduct a risk assessment as part of the individual's discharge planning—a process which determines what type of care someone will need after they leave the facility. Discharge plans are aimed at preventing readmissions and making a move from the hospital as safe as possible.

During this process, the social worker will evaluate the individual's condition and living situation, looking at factors such as:

- **Can this person safely live alone?**
- **Are they able to comply with their discharge instructions?**
- **Do they require in-home care, such as a home health aide?**
- **Do they need services, such as meal delivery?**
- **Are safety improvements needed in the home?**
- **Should the person return home or go to another care facility?**

Both the individual and their family members will be part of the discussion. Then the social worker will work to create

a discharge plan based on the findings of the assessment and afford everyone the opportunity to give feedback. Any concerns would be voiced at this time. The hospital will not discharge the individual until the plan has been finalized and is able to be implemented.

"Risk assessments are a great opportunity for families," said Jennifer Reeder, LCSW, AFA's Director of Educational and Social Services. "Not only will an expert review their loved one's needs to maximize safety and quality of care; they will actually help the caregiver carry out whatever recommendations are made."

"If the person needs in-home care, the social worker will provide a list of options," Reeder continued. "When the person requires services, such as meal preparation or transportation, the social worker will connect the family with them. The social worker can also let you know how much will be covered by your insurance as well as Medicare and/or Medicaid."

No one knows your loved one better than you. Sharing your concerns with a care professional and getting them involved to help "make the case" for choices that are in the best interest of their health, safety, and well-being is a tool that caregivers should keep at their disposal.



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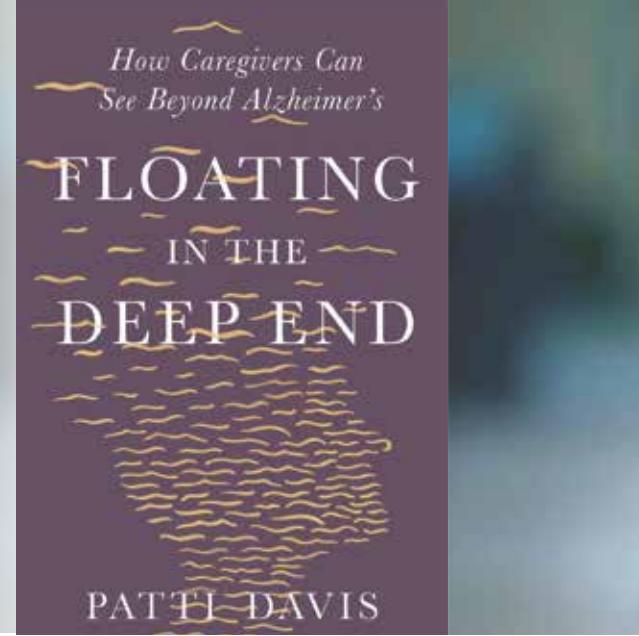
Alzheimer's Gifts: Wisdom from President Ronald Reagan's Daughter

When U.S. President Ronald Reagan died June 5, 2004, after living a decade with Alzheimer's disease, daughter Patti Davis thought for a brief time that she was "finished" with Alzheimer's. She quickly realized, "How could I possibly be?" Soon after, she wrote *The Long Goodbye*; then she founded her caregiver support group, "Beyond Alzheimer's," which she ran from 2011-2017 and is currently licensed at Geisinger Medical Center in Pennsylvania and Cleveland Clinic in Las Vegas. This year, she published a new book, *Floating in the Deep End: How Caregivers Can See Beyond Alzheimer's*. The Alzheimer's Foundation of America spent some time with Davis contemplating what she's learned and wants others to know, nearly 20 years later.

Continued on following page



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Alzheimer's Gifts cont'd from p. 11

WHAT WAS YOUR REACTION TO LEARNING OF YOUR FATHER'S ALZHEIMER'S DIAGNOSIS?

It was a very, very dark time in my life. Everything had gone wrong. I really didn't know if I still wanted to be here. I was tired down to my soul; and I thought, "No one is going to miss me." I didn't see any reason to go on. Then I found out that my father had been diagnosed with Alzheimer's. It could have been the last straw. But, instead, it was the opposite.

It took me out of my despair enough to say, you know what, this is bigger than me. This is bigger than the pain that I'm going through. And I want to be here for this. I want to show up for this. I want to be as positive a force in this journey as I can.

When I was writing this book, I thought very hard about whether I wanted to include this fact. Then I thought there might be somebody reading who is in a really dark time in their life. I wanted to impart the idea that there is something bigger than your own pain. There is some situation out there that needs you. It gives you a bigger lens through which to look at life.

YOU TALK ABOUT THE GIFTS OF ALZHEIMER'S THROUGHOUT THE BOOK. CAN YOU EXPLAIN WHAT YOU MEAN BY THAT?

With Alzheimer's, or really with any version of dementia, there is a stripping away of everything. It's a stripping away of everything for the person who has the disease; and it's also a stripping away for the caregivers, the loved ones, the family members.

I've often said that Alzheimer's brings up everything. It brings up everything in families. It brings up everything in you. So it gives you an opportunity to work on the things that you need to work on...because *there they are*. They are just raw and uncovered.

I remember someone in my support group having an issue with control. I said, "You are trying to control something that you can't control," and they said, "It's just the way I am." I said, "Well, there's the way that we are; and there's the way that we are meant to be. Can we look at the way we were meant to be?"

I don't think God put anyone on this earth and went, "You, I think you're going to be the control freak." We are supposed to work our way out of that stuff.

YOU MENTION THAT THE SOUL OF THE PERSON IS THERE.

Yes, that was my other grounding for the ten years of my journey through this. I didn't believe my father's soul could have Alzheimer's, so that kept me looking past the disease to find glimmers of his soul in there.

I'm very aware when I say that to people that there are those who go, "I'm an agnostic or I'm an atheist, that doesn't jibe with my beliefs."

Fine....Just consider that it might be possible. Just consider it. Because it will change how you deal with that person.

ANY ADVICE TO DEAL WITH THE ONGOING GRIEF?

You have to go with it, because it will catch up with you if you don't.

I've always said, Alzheimer's is a death before dying. The grieving process needs to start at the beginning. If you allow yourself to go with it, you will learn a lot from moving through that grief, especially if it's someone with whom you have sweet relationship or sweet memories. There is a sweetness to that grief.

It's more difficult if it's a person you didn't get along with. That's a very hard situation. If you had a parent who was mean or abusive and then they get dementia—that's a tough one. You have to look past what was done to you and hopefully choose compassion in yourself.

SWEET MEMORIES IN THE GRIEF. YOU HAD SOME OF YOUR OWN THAT YOU NOTE IN THE BOOK?

My father was a very magical father when we were little kids. He knew how to talk about leprechauns, and he certainly knew how to teach us how to swim. That was a big one.

My memories of him when I was younger was riding horses with him, following him out into the ocean and learning to body surf. He was very big on teaching his children to swim as soon as possible. He was a lifeguard when he was younger. He'd say to my mother, "My children are never going to drown!"

[Davis chuckling.]

When he had Alzheimer's, we would take him down to the beach in Venice sometimes and walk on the boardwalk, so he could be close to the ocean. Water was very important to him.

WHAT ADVICE DO YOU HAVE FOR CAREGIVER STRESS?

You have to take time for yourself. You have to. Particularly if it's a family member, because you have the emotional stress also.

I think a lot of what comes into play when people don't take time for themselves is an avoidance of grief.

We don't want to give ourselves over to grief. It hurts. And we'll do anything to avoid it. Dementia gives you ample opportunity to avoid grief. You can just stay really busy with the person you are caring for and say, "I don't have time to sit there silently with myself or to meditate or anything

like that....I don't have time." Really what's driving that is, "I don't want to take the time."

DO YOU THINK THE PUBLIC'S PERCEPTION OF ALZHEIMER'S HAS CHANGED SINCE YOUR FATHER'S DIAGNOSIS?

Well, I do in the sense that we are more open about it, and willing to talk about it. People like Glen Campbell and Tony Bennett helped out with that. I think we are much better about talking about the disease.

I don't think we are much better at caring for the caregivers and recognizing what they go through though.

I don't think in the 10 years that my father was ill I can remember anyone asking me how I was doing.

And I know when I was running my support group, almost every time when someone new came in and either I or my co-facilitators said, "How are you doing?"

They would be startled. Like "Oh, no one has ever asked me that before."

WHAT THINGS DID YOU LEARN THAT YOU WOULD LIKE OTHER CAREGIVERS TO KNOW?

There is always another way of looking at things. That applies to any aspect of life, and it certainly can to this disease.

You can look at what is in front of you, which is the loss of cognition, the loss of memory, someone becoming unfamiliar to you. You can stop right there, if you want. Or you can look deeper and remember that there is still a human being. There is still someone with emotions, desires, and needs.

I'm not advocating denial. I'm not advocating turning away from what's in front of you. I'm saying that our physical senses don't tell the whole story. We know that. People used to look at boats out in the ocean and think the earth was flat, because the boats just disappeared. Our eyes, our ears, what we are witnessing is not always the whole story.

Family photos (including cover), courtesy of Patti Davis.



We fight disease, so more
you shines through.

Protecting what makes you, uniquely you, drives us every day.

We are Acadia, fiercely committed to elevating life through science for people impacted by CNS disorders every day. By collaborating with each other, inviting new ideas within and beyond our walls, we're dedicated to protecting everything that makes you, uniquely you — enabling brighter moments for patients and their loved ones.

Learn more about our trailblazing breakthroughs in neuroscience at
www.acadia-pharm.com



Guide to Government Resources

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Government exists to serve people; and fortunately for families affected by Alzheimer's disease, a multitude of governmental programs exist that are designed to help you. Understanding the differences and intersections of federal, state, and local programs can be tricky though, but it becomes easier with some background knowledge.

Following is information about some of these programs, the services they provide, and how to connect with them.

Eldercare Locator. This nationwide public service of the Administration on Aging connects older Americans and their caregivers with trustworthy local support resources. The Eldercare Locator can provide information about government insurance and benefit programs, transportation resources, housing, and elder rights.

- **Visit eldercare.acl.gov or call 1-800-677-1116 (available 9 am to 8 pm ET, Monday-Friday).**

MedlinePlus. MedlinePlus is a free, online health informational resource service of the National Library of Medicine (NLM), the world's largest medical library, and a part of the National Institutes of Health (NIH). The MedlinePlus mission is to present high-quality, relevant health and wellness information that is trusted and easy to understand, in both English and Spanish. Users can learn about health conditions, medical tests, medications and supplements, and healthy recipes, as well as find health professionals, services, and facilities.

- **Visit www.medlineplus.gov.**

Medicare. Medicare is health insurance for individuals ages 65+, and also offers tools for finding nursing homes, physicians, and certified home health care agencies, along with information on insurance plans and coverage. Medicare can also help you search for, and compare, nursing homes.

- **Connect through www.medicare.gov (live chat available 24/7 excluding certain federal holidays) or 1-800-MEDICARE.**

Medicaid. Medicaid delivers health coverage to millions of Americans, including income-eligible adults, elderly adults, and individuals with disabilities. It can include benefits as well, such as nursing home care, personal care services, and assistance paying for Medicare premiums and other costs. Medicaid is administered by states according to federal requirements. Eligibility criteria varies by state, as some have expanded coverage beyond the federal requirements.

- **Find information about your state's Medicaid program at www.medicaid.gov.**

Area Agencies on Aging (AAA). These government-designated agencies address the needs and concerns of older individuals and their caregivers in a specific region (i.e., city, county, or multi-county area). AAAs assist with services such as caregiver support, respite care, mobility assistance programs, home care, and meals on wheels.

- **Locate your local Area Agency on Aging through the Eldercare Locator or the AFA Helpline at 866-232-8484.**

GUARDIANSHIP & CONSERVATORSHIPS

By Matthew S. Raphan, Esq.

Guardianships have been a trending topic in the news lately. Pop singer Britney Spears is the latest high-profile example, but many other people across the country are subjected to guardianship proceedings. So, how does this happen?

Guardianships (sometimes referred to as conservatorships) are established to protect people who are unable to manage their financial or health-related affairs. Guardians are appointed by a court to make decisions for individuals with a mental incapacity (such as Alzheimer's disease) that prevents them from handling their own basic needs. Without the oversight of a guardian, these individuals are often in danger of suffering physical or financial harm. Important to note, people who become subjected to guardianship proceedings typically have not planned for their own incapacity. This means they have not legally authorized anyone to act on their behalf, and a guardianship is necessary to fill that void.



Andrey Popov | Dreamstime.com

Guardianships, like many court proceedings, can be lengthy and intrusive. Indeed, these proceedings sometimes result in a court deciding to take away someone's legal ability to make their own decisions, and appointing a third party to act on their behalf—potentially someone they do not want, like, or even know. Furthermore, the guardianship process can be extremely expensive, both for yourself and your loved ones. Fortunately, there's an alternative.

The law allows us to plan for our own incapacity, which can be an extremely powerful tool. There are two primary methods of incapacity planning: a durable power of attorney and a health care proxy. Conceptually, these documents are similar in that they both appoint someone to act on our behalf if we lose capacity. The power of attorney allows us to select someone to manage our financial affairs, while a health care proxy spells out who should make medical decisions for us if we cannot make them ourselves.

Laws with respect to these documents vary by state, so be sure to speak with counsel in your location for further details.

Guardianship comes into play when an incapacitated person does not have these safeguards in place. A guardianship proceeding can generally be commenced by any person or entity who has an interest in the subject person's well-being, typically a care facility (i.e., hospital or nursing home), family member, or friend. These proceedings can take months, or sometimes years, to conclude.

Each state has its own laws with respect to guardianships. During the proceeding, the court may appoint an attorney for the person alleged to be incapacitated, as well as an investigator (sometimes known as a court evaluator) to examine the matter. The court evaluator may interview your doctors, social worker, family, and friends, and review your financial materials, your home, and personal effects. Once

the investigation concludes, the court evaluator typically issues a written report and makes a recommendation to the court.

Ultimately, the court conducts a hearing with testimony before the judge, who will then determine if the subject of the proceeding is incapacitated. The judge may select and appoint a guardian to manage the individual's financial and medical affairs, who is then empowered to make decisions about how they live. The guardian may be a family member or friend but could also be a third party who you do not know and have no relationship with.

What a guardianship often lacks is guidance and input from the person it impacts the most. Taking care of you or your loved one's affairs in advance by engaging in proper incapacity planning can save enormous heartache, headache, and financial expense.

For instance, if someone loses the ability to handle their financial affairs and is perhaps facing eviction, it may be vital for a court to assist if there is nobody else legally capable of helping.

However, what a guardianship often lacks is guidance and input from the person it impacts the most. Taking care of you or your loved one's affairs in advance by engaging in proper incapacity planning can save enormous heartache, headache, and financial expense.

Matthew S. Raphan, Esq., is a Partner at the New York-based Raphan Law Partners, LLC, whose practice areas include guardianships, elder law, estate planning and administration, wills, trusts, and Alzheimer's planning. He is admitted to practice law in New York and New Jersey.

RECIPE FOR YOUR HEALTH



Lentil Soup

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Lentils are chock full of nutrients, including potassium, calcium, zinc, niacin and vitamin K. One of the oldest consumed legumes in history, lentils are particularly rich in dietary fiber, lean protein, folate and iron. From the cook's perspective, lentils are easy to prepare since they don't require soaking or lengthy cooking times. This simple lentil soup recipe is plant-based, vegan, heart-healthy, delicious and nutritious!

INGREDIENTS

Choose organic ingredients when available.

- 1 tbsp. extra virgin olive oil
- 1 medium white onion (about 1 cup), finely chopped
- 1/2 cup carrot or 6 baby carrots, finely chopped
- 2 celery stalks, finely chopped
- 1/2 tsp. sea salt (optional)
- 1 lb. dry lentils, picked and rinsed
- 1 cup peeled and chopped tomatoes (no added salt)
- 2 qts. low-sodium vegetable broth
- 1/2 tsp. ground ginger
- 1/2 tsp. ground cumin
- 1/4 tsp. freshly ground pepper

DIRECTIONS

1. Place the olive oil into a large pot and set over medium heat.
2. Once hot, add the onion, carrot, celery and salt.
3. Sweat until the onions are translucent, approximately 6 to 8 minutes.
4. Add the lentils, tomatoes, broth and seasoning and stir to combine. Increase the heat to bring to a boil.
5. Then reduce heat to a low simmer, cover and cook until the lentils are tender, approximately 30 to 40 minutes.
6. Using a stick blender, puree to your preferred consistency.



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](#).

NUTRITION FACTS

SERVES 6,
PER SERVING:
328 CALORIES

TOTAL FAT 3 GRAMS
POTASSIUM 808 MG
CARBS 50 GRAMS
FIBER 24 GRAMS
PROTEIN 23 GRAMS
CALCIUM 4% DV

Excellent source of vitamins A, C, & iron.

Sodium varies depending upon brands of broth and tomatoes.



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For many, the holiday season is a joyful one spent together with loved ones—including families affected by dementia. Being adaptable and building an inclusive environment are key to creating dementia-friendly holidays and celebrations.

Adapt past favorite traditions or create new ones.

Build on old traditions where you can, such as enjoying favorite music or movies. Start new ones around things the person can, and likes to do, such as touring neighborhood holiday lights, and do it together. Whenever possible, involve the person by asking what traditions are important to them (this will help you prioritize and plan).

Avoid overdecoration.

Excess stimuli may be challenging for someone with dementia. Too many flickering lights or an abundance of decorations can be overstimulating and disorienting.

Create a safe and calm space.

Avoid fragile decorations (which can shatter and create sharp fragments) and ones that could be mistaken for edible treats (which can create a choking hazard or broken teeth). Reduce clutter to avoid potential tripping hazards. Securely hook Christmas trees to the wall to avoid falls and utilize menorahs or kinaras with electric candles to reduce fire hazards.

Creating DEMENTIA-FRIENDLY Holidays

HOLIDAY CELEBRATIONS

Like with traditions, adapting celebrations is key for a dementia-friendly holiday.

BEFORE THE CELEBRATION

Prepare the person.

Help build familiarity and comfort by showing them photos of the guests or arrange a phone call/Facetime chat with the visitors beforehand.

Be open with guests.

Consider sharing beneficial information with guests beforehand, such as ways they can communicate with the person, what they respond well to, and what

may upset them—especially visitors who don't regularly interact with the individual. This will guide them on how they can be helpful and supportive.

DURING THE CELEBRATION

Preserve normal routine.

Changes in daily routine can be challenging for someone living with dementia. If the person usually takes an afternoon walk, build in time for that. If they go to bed early, hold the celebration earlier in the day so that everyone can participate.

Connect with loved ones through technology.

Videoconference technology (i.e., Facetime, Zoom, Skype) can include others who can't attend in person.

Take a strengths-based, person-centered approach.

Focus on what the person is still able to do and what they choose to do now, rather than dwelling on what they used to do.

Learn more about these and other dementia-friendly holiday tips by visiting www.alzfdn.org or call the AFA Helpline at 866-232-8484.



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CAREGIVING TRENDS

Millennials As Caregivers

Now an Integral Part of the Care Community



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The vast majority of individuals living with Alzheimer's disease and related dementias are receiving in-home care—nearly 80 percent, according to the U.S. Centers for Disease Control and Prevention (CDC). What might be surprising is just how many millennials are engaged in the caregiving.

While Baby Boomers (defined as people born between the years 1946 and 1964) still make up the largest portion of family caregivers by generation (34 percent), according to a 2020 report by AARP and the National Alliance for Caregiving (NAC), millennials are not far behind—accounting for nearly a quarter of all family caregivers

in the United States (23 percent). Typically, they are caring for a parent or grandparent with a long-term physical condition (such as a dementia-related illness) in a “moderate-to-high intensity care situation,” providing approximately 25 hours a week of unpaid care to their loved one.

An aging population, combined with the fact that dementia-related illnesses are projected to further grow in prevalence, means that millennials will play an increasing role in family caregiving.

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Why millennials are well suited

Millennials have many qualities that make them effective caregivers:

They're comfortable using technology.

Millennials grew up as technology was doing the same—they're old enough to remember life without smartphones, apps, social media, and the internet, but young enough to be early adopters of these technological advances. Since technology has been integral in their lives from an early age (they were among the first to grow up with computers in the home), they are extremely comfortable with it.

That's incredibly important in an increasingly virtual world. They are able to take advantage of a variety of caregiver support resources through technology: monitoring tools for safety (app-controlled home cameras and door alarms), ride-sharing apps (such as Uber or Lyft) to facilitate travel for medical appointments, online ordering for household items such as food and clothing, telemedicine, and tech-enabled pharmacy services.

Even if they are not the primary caregiver and live elsewhere, millennials' technological comfort allows them to provide support by doing internet research, arranging for services such as grocery delivery, and setting up automatic bill payments or paying bills online. All of this can ease the challenges of caregiving.

They're adaptable.

Because they've lived with and without modern technology, millennials can adapt quickly to different situations (and help their elders adapt as well).

They're emotionally invested.

Despite the responsibilities, challenges, and nuances of caregiving, millennials were the most likely group to say caregiving was rewarding, according to a February 2021 *Forbes* article—91 percent of millennials in the U.S. and 88 percent internationally found caregiving fulfilling. The aforementioned AARP/NAC study also found most millennials got a sense of purpose from their caregiving role.

Challenges faced by millennial caregivers

Like any caregivers, millennials have their strengths, but also face challenges that are less common among their older contemporaries—many related to money, according to the AARP/NAC study.

Less financial means.

Because they are younger (on average 30 years old), at the beginning of their careers, and had shorter earning time



as compared to older caregivers, millennial caregivers have lower household incomes and more often report high levels of financial strain because of their caregiving responsibilities, such as increased debt, delaying/forgoing bill payments, borrowing money from family or friends, and being unable to afford basic expenses such as food. Although they are typically working while



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providing care, they are usually in an hourly position.

Additionally, millennials are more often single (having never been married), leaving them as sole-income earners.

Weaker support structure.

These income challenges leave millennials with a weaker support structure as compared to older-generation caregivers. They are less likely to have paid caregiving help, least likely to report having health insurance, and more frequently report being in fair or poor health. Finding affordable services in their recipient's community is more difficult for millennial caregivers.

Rising to meet the challenge

Millennials are not the future caregivers in the fight against Alzheimer's—they are on the front lines, in the trenches, right now. Fortunately, they are well equipped—they are passionate, hard-working caregivers who find great reward in their labor of love and are rising to meet the many challenges they face head-on. Like all caregivers, they need help. Strengthening their support infrastructure is vital to help make them an even stronger caregiving generation.

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FACING EVICTION FROM A CARE SETTING

Dementia-related illnesses often bring with them different types of difficult behaviors; and the expectation is that facilities will be able to care for loved ones through the end of their lives, despite this. Though the reasons given for eviction from assisted living facilities and nursing homes vary, receiving an eviction notice is often shocking and difficult for families.

"When these types of issues arise, loved ones should ask the facility what steps have been taken to determine the cause of this change or increase in behavior. Facilities have the responsibility to work with a resident to ensure that they are receiving person-centered care, which can assist in lessening these types of challenges," said New York State Ombudsman Claudette Royal. The Ombudsman Program helps residents of long term care facilities understand their rights. It also advocates for residents by receiving, investigating, and working to resolve complaints made by or on behalf of residents. "If these interventions are not effective, another level of care may need to be considered. Facilities should work with the resident and their loved ones to pursue other appropriate options."

Understanding the distinction between assisted living facilities and nursing homes, both in terms of care and services provided and procedures taken if your loved one develops challenging behaviors, is important. Assisted living facilities primarily provide personal care in a home-like, social setting. Their goal is to maximize the quality of life and provide a more independent lifestyle. Nursing homes, on the other hand, deliver medical and personal care in a clinical setting.

Both memory care in assisted living facilities and nursing homes provide 24-hour care, supervision, and meals. However, memory care specializes in care for those with memory loss and focuses on enhancing the quality of life in a secure environment. The majority of nursing home care is covered through Medicaid, if your loved one qualifies. While some assisted living facilities and services may be covered by Medicaid, many are private pay.

Legal responsibilities for memory care units in assisted living facilities and nursing homes differ as well when it comes to evictions. Assisted living facilities, governed by states, are

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allowed to evict patients if the facility cannot meet the resident's needs. Evictions are completely legal as long as the facility doesn't violate its admission and retention policy and state laws.

Nursing homes, on the other hand, under the Nursing Home Reform Act, are legally required to document that they attempted to meet the needs of patients or show why they cannot. They must give 30 days' notice (required by the Centers for Medicare and Medicaid Services) when asking someone to leave. In addition, the resident has the right to appeal the eviction. Also, nursing homes, under federal law, must ensure their residents are discharged to another residence for a safe discharge. Assisted living facilities should also have a safe discharge; however, the requirements are state-specific.

If you receive an eviction notice for your loved one, try working with the care facility—especially with the help of an ombudsman. Evictions are frequently the result of persistent, aggressive behavior that is a symptom of dementia and almost always triggered by something that your loved one cannot communicate, such as pain, discomfort or fear. Ask if these issues can be resolved without having to leave. If unsuccessful, ask for an extension (90 or even 120 days, for example). Procure an independent doctor's evaluation to see if staying in the facility is the right move or even if the residence can fulfill your loved one's medical needs.

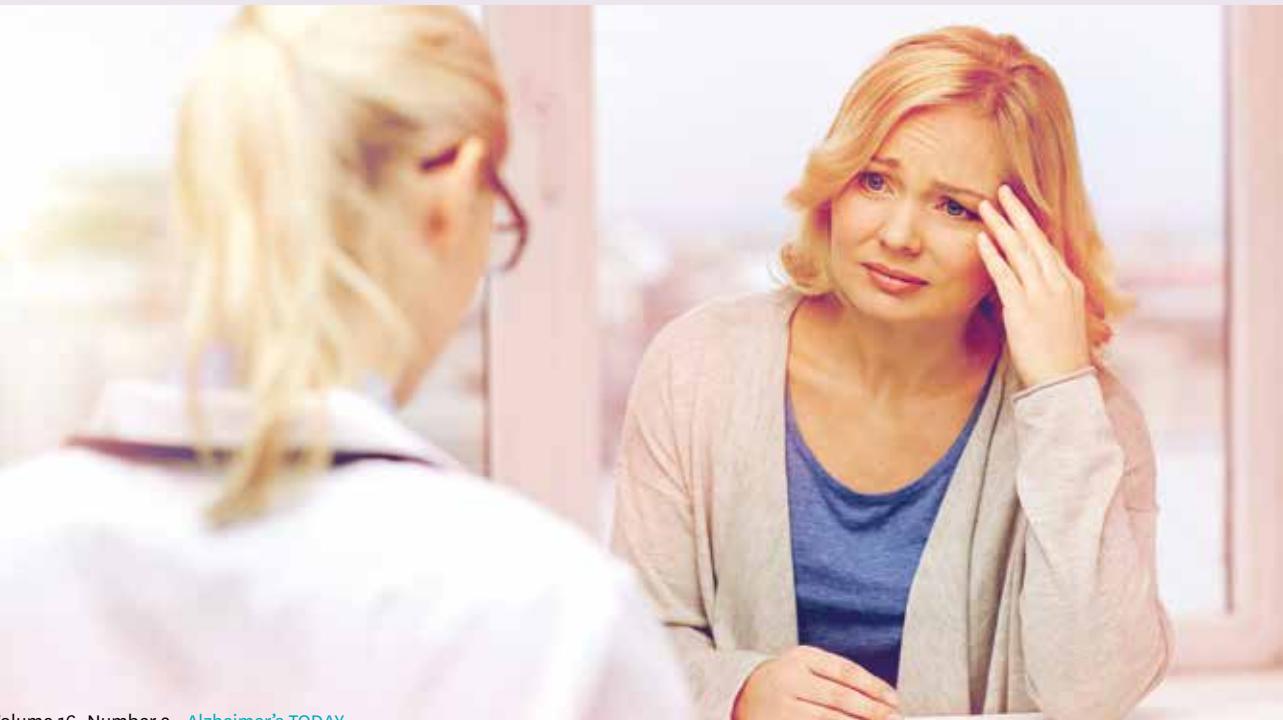
Normally, one would do exhaustive research before making the decision on when and where to move, so slow down the eviction process. Give yourself more time. If your loved one has to move to a new facility, you want it to be the right one, not just any one.

STEPS YOU CAN TAKE

1. Contact your local long term care ombudsman's office (every state has one). Unlawful evictions are one of the more common complaints an ombudsman receives. An ombudsman will then meet with the resident, advise them of their rights, including the right to appeal, as appropriate. Upon the resident's request, the ombudsman will also advocate and conduct a confidential investigation.
2. Ask for a reasonable accommodation under the Federal Fair Housing Act.
3. Hire an attorney (they can help with reviewing your loved one's contract with the facility as well as language and provisions regarding involuntary transfers and endangering behavior.)

Remember that sometimes a facility is looking out for your loved one's best interest by asking them to leave because a new care facility might be a better fit. As an example, if your loved one resides in assisted living and their daily care needs exceed what the facility can provide, a move to a nursing home or memory care may be beneficial. Remember, if your loved one *must* leave, the facility has an obligation to share your loved one's records and care plan with the new one to help ease their transition.

As with any situation, knowledge and information are tools of empowerment. Knowing your rights and the resources available to you can help ensure you are able to effectively advocate for your loved one.



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