WHAT TO DO AFTER A DEMENTIA DIAGNOSIS

PRESENTED BY

We Are Dementia Strong

WEAREDEMENTIASTRONG.COM

CAREGIVER SUPPORT
AND RESOURCES

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We all deserve a life worth living.

A responsible and considerate planning and preparation process for elder care, done well, should include:

- **Patient Advocacy**
- **End-of-Life Care**
- **Medicaid & VA Planning (with Asset Protection)**
- **Care Partner Team Building & Planning**
- **Caregiver Support & Referrals**

For more information, visit CaregiverSupportandResources.com or email info@caregiversupportandresources.com

Is a Board-Certified Patient Advocate Right For You?

MEDICAL CARE Patient advocacy clients must understand all treatment options for various conditions, whether they are terminal illnesses like Alzheimer's disease and cancer or less-stressful needs that simply come with aging. Treatment options are just that: options. Sometimes seeking second and third opinions is necessary to deliver the best possible care. We empower care-partner teams to ask tough questions of the right professionals involved in all aspects of care.

Health care systems can be quite complex. Some individuals may see a network of doctors, clinicians, specialists, and other providers to address specific needs. Confusion is common. We work alongside clients to secure care options in a variety of settings. We will even coordinate and attend medical appointments, if appropriate. We also help care-partner teams to organize health care, financial and legal documents, as well as prescriptions and recommendations by health professionals.

MEDICAID & VA PLANNING A skilled nursing facility in Florida costs on average $9,171 per month. Elders can save their entire lives and think that they'll have adequate funds for whatever happens only to suffer a stroke, major heart attack, or get an Alzheimer's or Parkinson's diagnosis. Literally overnight, they no longer have the means to afford health care they need. Incurring this type of expense would cause most people to lose everything - and many do. To receive Medicaid and VA benefits, clients must first be financially eligible.

A patient advocate helps clients to understand financial eligibility ins and outs to protect assets for now and the future. Medicaid, unlike Medicare, will cover all long-term care costs. Once we obtain Medicaid eligibility for an individual, if they remain within the Medicaid guidelines, they will be eligible for the rest of their lives.

LIFE TRANSITIONS Life circumstances change. The end goal is to age comfortably at home, and sometimes that's possible. But conditions and diagnoses come that at times bring elders and their families to decide it may be time to transition to a more optimal living situation. Transitioning to an assisted living facility or nursing home, or sometimes hospice end-of-life care, is difficult for everyone involved.

A patient advocate assists care-partner teams and empowers them with strong transition strategies. In addition to financial eligibility requirements, elders and their care partners deal with moving logistics including real estate and continuity of care. Some moves are temporary. When a client is discharged to a rehab facility (or hopefully home), the patient advocate plans and coordinates similar resources for the next step.

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We Walk this Dementia Path Together

Hello. My name is Maureen Rulison, President of the 501(c)(3) nonprofit #WeAreDementiaStrong and the company Caregiver Support and Resources, LLC serving the Tampa Bay, FL area, and this is my life partner/care partner, Brian LeBlanc. If you're reading this, you likely just received some unsettling news. You or a loved one are diagnosed with Alzheimer's disease or another form of dementia.

The journey to this point may have been long and arduous, replete with confusion and uncertainty: "Why does Mom keep forgetting my name?" "I don't remember this way home." "Did he remember to turn off the stove?" Or it may have been short and unexpected with few obvious indicators beyond family history. However you got here, you and yours now face an overwhelming number of decisions and challenges. Don't worry. We walk this dementia path together.

Brian lives with Alzheimer's and vascular dementia. After his diagnosis in 2014, he immediately set to work as a national advocate for dementia awareness and education. Today, with #WeAreDementiaStrong and Caregiver Support and Resources, LLC, we've helped thousands of individuals just like you to navigate the complex realities of dementia care. Experience, both professional and lived, is our guide.

This is your guide. We hope this free magazine sets you on the right path toward effective life-care planning, care-partner team building, patient advocacy, financial security and end-of-life preparations. Keep it handy to light the way when that path is most dim.

Of course, we're always here to chat. Contact us at maureen@caregiversupportandresources.com and thebrianleblanc@gmail.com.

Warmest regards,

Maureen

Maureen Rulison, BCPA, CMP, CDMCP
President and Founder
#WeAreDementiaStrong
Caregiver Support and Resources, LLC

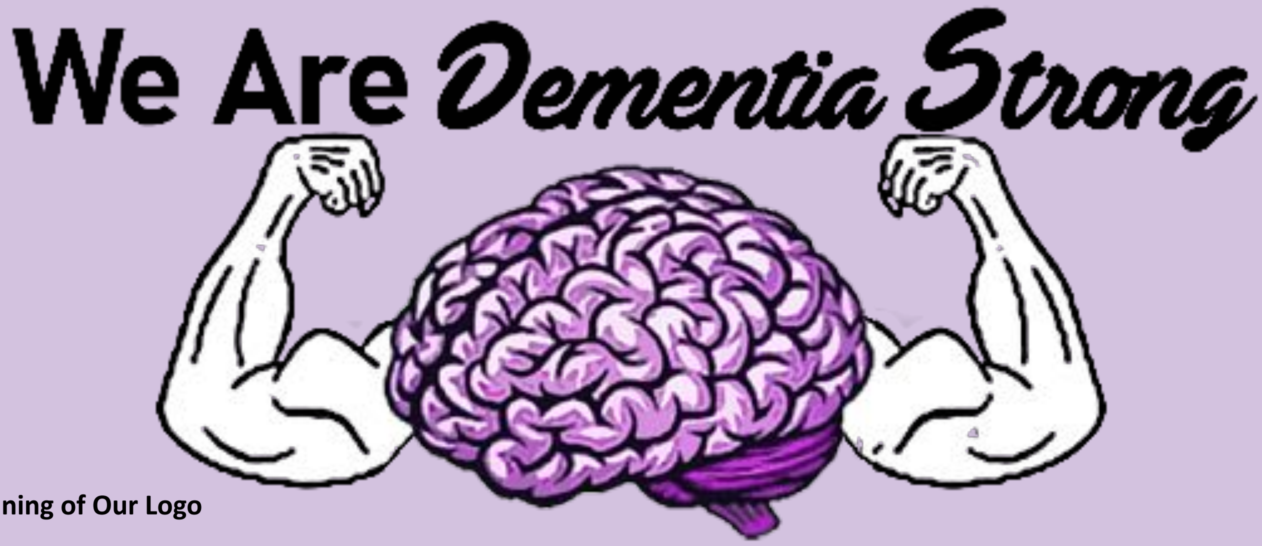
#WeAreDementiaStrong

Our Mission

#WeAreDementiaStrong is a 501(c)(3) educational non-profit that guides persons living with dementia and their care partners to a healthy *life worth living* after diagnosis. We achieve this, in part, by providing:

- Educational opportunities
- Live presentations for persons living with dementia and their care partners (family and professional)
- Interviews with Brian LeBlanc and Maureen Rulison, as well as leaders in the fields of dementia, person-focused care, aging in place, and all other issues that interest and affect the people that are walking our same journey
- Webinars

Our goal is to provide tools for each person to identify what a *life worth living* means to them. Everyone is unique because of their life's experiences, race, color, religion (creed), gender, gender expression, age, national origin (ancestry), disability, marital status and sexual orientation.



The Meaning of Our Logo

- Purple represents the color of Alzheimer's disease (dementia) awareness.

- "Strong" because society, as a whole, thinks of persons living with dementia as weak, needy and incapable. We fight to dispel this myth and stigma.

- "Strong" because, whether you are a person living with dementia or family or a professional/nonprofessional care partner, you have more strength than you know and need a consistent refilling of that strength.

- "We" means all of us-working together, toward a common goal: a world that understands and embraces people of all abilities.

You've Just Received a Dementia Diagnosis. What's Next?

What are the first things you should do after you or a loved one receives a dementia diagnosis? In this section we'll take a first look at these eight steps. Later, we'll take a deeper dive into what to expect:

1. Breathe

You WILL get through this – with help, support and a foundation of knowledge that will allow you to know what to expect and how to address it. Think of patience as a muscle – and start building it today. You are going to need plenty of it, first and foremost for yourself. It may be hard to envision right now, but persons living with dementia can and do live happy and fulfilling lives. They may live many wonderful years, enjoying time with family and friends, long before advanced stages. Our partners at Caregiver Support & Resources, LLC are dedicated to the proposition that everyone is entitled to *a life worth living*.

2. Take It One Step at a Time

Remember, there is no right way to respond. For now, handle what is on your plate, one day at a time. Your life is taking a big turn in a different direction. Flexibility and the ability to adjust to changing realities are your new best assets. Yes, you should soon begin building an overall life-care plan that factors the logical progression of dementia-based conditions and the support systems you will need along this journey. For now, keep your eyes and ears open and don't fall apart!

3. Educate Yourself

Right now, today, how much do you know about Alzheimer's and other forms of dementia? Most people have a smattering of wisdom from movies, television, commercials, and perhaps the experiences of relatives, friends, and neighbors. As with any challenging life situation, the best defense is to become an expert on the issue.

Begin with trusted sources. The Alzheimer's Association and AARP are some very credible national and international information wells to begin your study. We then recommend refining your search to include in-depth content about regional and local agencies providing senior care, dementia-related support, respite care, residential assistance, etc. Learning more about available *services and resources fitting your individual needs*.

The Caregiver Support and Resources, LLC blog and social media are updated regularly with helpful content to educate and guide a variety of important care decisions.

4. Build a Plan for Your Unique Circumstances

Cobbling together a one-size-fits-all life-care plan is not going to help you, your loved one or anyone else involved in care. Your best plan should grow from *your distinct needs*. Ask yourself some basic questions as you build your own plan.

- How old are you?
- How advanced is your dementia currently?
- What is your general health status?
- How is your current financial health?
- Does your current living environment suit progressing needs?
- Do you live in a community with plenty of amenities?
- How can your network of family and friends serve important care roles?
- Will your health insurance cover medical needs?
- Are all legal, financial and property matters covered?
- Are you prepared for end-of-life care (and beyond)?

The answers to these questions will inform your planning. Your plan should account for such variables as: medical care and therapy; socialization; independent living; potential transitions to an assisted-living, memory care or nursing facility; how you can pay for all this; and assets that should be protected.

5. Assemble Your Care-Partner Team

No one goes down the path of Alzheimer's or dementia alone, nor should anyone have to. Your care-partner team may comprise:

- Close family and friends
- Clinicians including a primary care provider and specialists
- Physical and behavioral therapists
- End-of-life care providers and planners
- Elder-care legal experts
- Financial and asset planners
- & Anyone else desired or necessary for specific life situations

Of all these, family and other loved ones are vital to the team's success. The family is the wheel that keeps life turning -- and *worth living*. Intimate family members, other close relatives, friends, neighbors and even work colleagues can provide support at critical times.

Everyone plays a critical role on the care-partner team. **No role is too big or too small.** A brother may handle cooking and cleaning, while a niece may organize financial and legal matters, while a grandchild may visit regularly for emotional support.

6. Explore Your Financial Options

Short- and long-term residential health care costs are astronomical. Elders in Florida aged between 70 and 90 generally own their home and have net assets between $25,000 and $750,000. Even on the upper end of that scale, an unexpected medical emergency can cause savings to dwindle quickly. And on the lower end, even a short-term stay at a rehab facility can completely empty the bank account. In many cases, without protection, it does. This can be a terrifying prospect for families.

Nationally, the average monthly cost of long-term care needs for seniors and disabled individuals is $4,000-$7,000 per month. **The average cost of a skilled-nursing facility in Florida is $9,171 per month. For memory care units add $1,000 a month.** Many people do not realize Medicare and most other insurances do not cover beyond the first 100 days in a nursing home. The remaining costs are up to the family, individual, or family estate.

Don't make the mistake of thinking that caring individuals will cut you breaks. You may very well meet compassionate individuals at institutions you work with, but keep in mind, the system itself has no sympathy. Facilities will pursue your loved one's assets after death to cover unpaid costs. Plan ahead, protect assets and take advantage of every assistance opportunity so your family doesn't have to endure financial hardship (or bankruptcy) on top of everything else.

7. Mind Your Own Mental Health (and Your Family's)

It may seem premature to talk about this now, but it's not really. There are strong feelings that accompany the dementia diagnosis. They are uncomfortable, at best. You may feel angry. You may even grieve the parts of yourself you see slipping away. Do not chastise yourself for having these feelings! They are not an unreasonable reaction to a devastating life event. Explore the possibilities of getting some talk therapy. Talk to a counselor, a loved one, a friend, a neighbor, a clergy member or support group. This will do two things: it will take your mind temporarily away from what can be an unbelievably stressful situation, and it is a form of self-care that you probably need.

8. Focus on *Quality* of Life

All of these supports are there to get you beyond just surviving, so you can concentrate once again on *quality of life*. And our partners at Caregiver Support & Resources, LLC help persons living with Alzheimer's and other forms of dementia and their families to live fulfilling and rewarding lives.

Peebles & Gracy:
A Legal Ally for Life Care Planning

By Kelsey Boudin
Southern Tier Communications Strategies, LLC

It's one of the greatest fears of aging. You're in a nursing home or even at home, approaching end of life, and the loved ones around you are in turmoil.

You're incapacitated. For millions of Americans, the steady march of Alzheimer's disease or another type of dementia plays the culprit, eroding mental, emotional and physical capacities in the mid-to-late stages.

And worse: without preparation, your last wishes for comfort care haven't been formally established. Perhaps it's uncertain how you're going to pay for that nearly $10,000-per-month room in a long-term nursing home. The last thing you want is to place a greater burden on those you love most. It's never too early to begin planning to avoid confusion later.

Peebles & Gracy, P.A. -- *a law firm with over 90 years of experience serving the Tampa Bay, FL area* -- expertly navigates the legal and financial aspects of life-care planning.

Second-generation partner Andrew Gracy has a passion for guiding individuals and families with some of the most complex decisions of their lives.

"My father always described his job as 'problem solver,'" says Gracy, who became managing partner in 2002 following his father, Greg Gracy's, retirement. "I quickly realized he was right. That is what attracted me to the practice of law. I like to help people. And now I get to help people to solve some pretty difficult problems."

The Many Angles of Life-Care Planning

Life is complicated enough. End of life shouldn't be, Gracy says. Having a planning partner for all of its circumstances -- in good health and bad, financial security or struggles -- clarifies all the possibilities and necessities.

A well-rounded life-care plan directs health care you want and don't want if you're incapacitated and unable to choose. Someone named as your health care surrogate can make choices about comfort care or difficult end-of-life scenarios.

A strong estate plan protects your legal wishes, assets, and anything else of financial or sentimental value. It may establish power of attorney for a trusted agent to oversee your legal, financial and business decisions. It also may, through a last will and testament, distribute wealth and property to loved ones and other appropriate beneficiaries.

"Most people are afraid to appoint someone to act as their agent for financial matters. No one wants to give up control of their own affairs," says Gracy, who earned his law degree from Nova Southeastern University. "We tend to think, 'That will never happen to me. I would never be in a vegetative state.'

Peebles & Gracy (Continued)

“Accidents can happen to anyone at any age. In your younger years, you may have children you need to support and make sure everyone gets educated and started in life the right way. In later years, though, we need someone who can help us out to get our bills paid on time and make sure we are getting the proper personal and medical care.”

Experts in Medicaid Eligibility Planning & Asset Protection

The financial stakes are high. Medicare and most other major insurances will cover only the first 100 days of a long-term stay in a nursing home or assisted-living facility. The rest? Well, that’s on the individual -- and sometimes the estate. Average long-term care costs in Florida can break the bank quickly and dwindle life savings for things like adult daycare ($1,907 per month), home health care ($3,718 per month) and private nursing home rooms ($9,643 per month).

Nineteen percent of all Florida residents receive health care coverage under Medicaid -- including 57 percent of nursing home residents and 29 percent of elders and persons with disabilities (including dementia and related illnesses). The needs-based entitlement program covers individuals and families with limited income and assets.

To benefit, they must meet eligibility requirements. Most require professional guidance to get there. Medicaid planning can be simple -- sometimes requiring only assistance with the collection and preparation of documents. It may be complicated -- perhaps a complete restructuring of one’s financial assets. Sometimes qualifying for Medicaid may involve transferring assets from the applicant within established timeframes or, if possible, changing eligible assets into non-countable assets.

“We have been very successful in preparing families for the worst-case scenario,” Gracy says. “We have been able to preserve assets that can be made available to give your loved one the best possible care.

Certain things are not covered by Medicaid, and by preserving the assets your loved one can get better hearing aids or better dentures for their overall well being.”

Gracy continues his father’s legacy in a strategic partnership to help local families and caregivers in need. *Peebles & Gracy, P.A.* works alongside Maureen Rulision of *Caregiver Support and Resources, LLC*, in Medicaid and VA planning with asset protection.

"Dad always loved working with Maureen. When I took over the practice, working with Maureen from the start, I knew she was super knowledgeable about the Medicaid system and elder care in general," Gracy says. "Through the years, I have had to work with other Medicaid planners, and none of them come even close to Maureen's abilities and professionalism. At this point, I will not work with anyone else on a Medicaid case except for Maureen. We have worked together for so long now, we have an understanding of how each of us makes decisions and how we advise the client."

Life Care & Estate Planning Delivers Peace of Mind

Through the decades, Peebles & Gracy, P.A. professionals have successfully handled life-care and estate-planning cases for thousands of individuals and families. Much like securing quality insurance, the process brings peace of mind, Gracy says.

"You hope you never need it, but it is crucial if you do. The estate plan is created around the client," Gracy says. "We are basically putting together a team that will assist the client in their time of need. My goal is to get your estate in order so that if something bad happens you are prepared to deal with it, and you will have the people you trust in place to help you out."

Effective estate planning can help to avoid hefty tax bills and prepare for the astronomical costs of long-term care. These are legal aspects of life-care planning that can affect anyone at any stage of life, Gracy says. The consequences if not prepared, he adds, could be severe.

"If you don't create a power of attorney or designate a health care surrogate and you become incapacitated, the decision of who will take care of you could be left up to a judge," he notes. "If your children live out of state, there's no guarantee they will be named as your guardian. A professional guardian will be appointed, who will end up controlling all aspects of your life for you. Don't let that happen."

A Decades-Long History of Local Success

Frederick T. Peebles established the firm in 1926. It has served the Tampa, Clearwater and Dunedin areas ever since. Nearly a century later, the lifelong local Gracy is proud to help his hometown community. He is active in the local community through organizations such as the Clearwater Bar Association, Dunedin Chamber of Commerce, Rotary Club of Dunedin North, and the Dunedin Youth Sailing Association.

The Clearwater Central Catholic High School and Florida State University alum left the corporate world to pursue law and continue the firm's legacy.

"I've never been more proud to help my friends and neighbors," he says.

Contact Andrew Gracy at info@peeblesandgracy.com or (727) 736-1411. Visit www.peeblesandgracy.com.

Let’s Change the Dementia Narrative

By Brian LeBlanc abitofbriansbrilliance.com

Each day, I scour the news sources looking for the “next big thing” in the dementia and Alzheimer’s world. Some days there are very interesting stories full of hope and promise. Then there are days when the headlines lead you to believe the next “big thing” has been found, only to find the words, “hopefully” or “in the future” or “in the next 10 years” in the body of the article.

You see where I’m going.

The thing I continually see are people like me who are living with Alzheimer’s and other dementia-related Illnesses being referred to as “patients” and/or “sufferers.”

I’m not sure about you, but I am NOT a PATIENT of any newspaper, magazine, documentary, news channel or TV host. I also don’t SUFFER from my Alzheimer’s.

I struggle. But I’m also not a STRUGGLER.

Part of what I do when I’m advocating is to remind everyone that, although I have a disease that will one day contribute to my death, I am NOT (and you are NOT) anyone’s patient except for my (your) doctor. “XXX” is my doctor and I am his/her patient.

That’s it. No one else has the right to claim me as a patient. I find that to be highly insulting, and it gets on my very last nerve.

When I, and others, are referred to as “SUFFERERS,” it also strikes a nerve. I will speak only for myself on this, for I’m not sure if others feel like they are suffering. I don’t feel that way. Suffering means “the state of undergoing pain, distress or hardship.” I can understand the hardship part from a financial point of view, and on the days when I am in my fog, but I still don’t consider myself “suffering.”

If I offend anyone by saying this, I don’t mean to. But this is reality. There may be some folks out there who feel as if they are suffering. The only thing I can say to that is each of us are individuals and life is going to affect us in individual ways.

The focus right now on those of us living with Alzheimer’s or other dementias is “SEE ME, NOT MY DISEASE.” Better said, we need a “PERSON-CENTERED FOCUS.”

The person-centred approach is about ensuring someone with a disability is at the center of decisions which relate to their life. It boils down to: “Who knows us better than US?” Instead of making decisions FOR US or ABOUT US, why not include US in the conversation? Ask US what we think. Discuss options with US. Just treat US for who we are, and that is human beings.

I know, in the later stages, I will be unable to communicate my wishes as to what I would like or dislike. With that said, I already have an advanced healthcare directive and appointment of agent, as well as a durable power of attorney. It was important to me to make sure I was making the decisions for my life. I did not want to put that responsibility on anyone else. (As a side note, as long as I can still eat, there will be peanut butter, chocolate and of course there will be music.)

Let's Change the Dementia Narrative (Continued)

My advice to anyone and everyone is to have these documents prepared. My advice is free and you, as an individual, can do with it what you like.

I've said many times, "This is NOT how I expected to spend my retirement but, it is what it is." I try to be productive every day, BUT . . .

Sometimes I am, sometimes I'm not.
Sometimes I write, sometimes I watch Netflix.
Sometimes I just sit, look at photographs and listen to music.
Sometimes I go to Starbucks.
Sometimes I just sit and think.
Sometimes I just sit and cry, but not for long.
I'll admit, it's a hard life. But I know there are others who have it worse, so I don't dwell in the darkness for long. I have loved ones who I can call day or night. I have friends -- a lot fewer than what I once had -- but those I can still lean on when needed.

Lastly, I have myself.

In my Alzheimer's mind, I'm still me. I can still drive, I can still work, I can still fix technological things, I can still balance a checkbook. OK, I can't physically do ANY of these things anymore, but that's OK. I know what my limits are . . . most of the time.

At the end of the day when I lay my head on my pillow, I know I'm still me. I'm not everyone's patient, I'm not suffering and I'm not the me I used to be, but that's OK. You see, I don't worry about the things I wasn't able to do today, for when I wake up tomorrow morning, I won't remember. I'll just re-invent myself all over again, until the next day, and that's OK with me.

Editor's Note: Abitofbriansbrilliance.com is written and managed by Brian LeBlanc, who lives with Alzheimer's and vascular dementia.

Your Support is Greatly Appreciated!

#WeAreDementiaStrong was granted 501(c)(3) nonprofit status in 2021. **We need your help** to propel our successful international mission of advocacy and education from the lived perspective of a person living with dementia and his care partner. Our organization, along with our friends and allies, helps persons living with dementia and their care partners with valuable education, insights, and guidance on community services and resources. **Our advocacy and outreach aims to improve quality of life and care outcomes** for everyone: the individual living with dementia and everyone who supports them personally and professionally. We strive to help individuals and families create a purposeful and healthy *life worth living* after receiving a dementia diagnosis.

As a nonprofit, #WeAreDementiaStrong is 100% dependent on community donations, sponsorships and grants to accomplish our mission. **Please consider a tax-deductible donation to support our cause today. Donors will be publicly thanked in future events and editions of this magazine.** Fill out the form below and enclose a check to:

#WeAreDementiaStrong
19029 US HWY 19 N. 32 F
Clearwater, FL 33764

Where Your Donation Goes

Give the gift of dementia advocacy and support. Your donation will help us to produce educational content (like this magazine), as well as:

- Live presentations, webinars and Podcasts on dementia-related topics and news.
- Lobbying lawmakers for more Alzheimer's research funding.
- Interviews with world-renowned dementia experts in fields like home care and living transitions, person-focused care, spirituality, and community resources.
- Direct referrals to helpful agencies serving important roles in the continuum of dementia care.

Yes, I'd Like to Make a Donation Today!

Select your level of partnership:

- ☐ Platinum ($5,000 and up) - Includes a full-page ad in the magazine and a monthly ad during the #WeAreDementiaStrong Podcast, as well as your name and/or logo at all speaking engagements and webinars.
- ☐ Gold ($1,000 and up) Full-page magazine ad.
- ☐ Silver ($500 and up) Half-page magazine ad.
- ☐ Bronze (name your gift) Your name listed on a thank you page.

Name (First, Last)____DOB______________

Email address____

Hometown____

Name one thing you'd like to learn about dementia____

Building Your Care-Partner Team

Okay, you've had a little time to come to terms with your loved one's dementia or Alzheimer's diagnosis, and you feel ready to get to work. Where do you begin? Let's start with your care-partner team. The individuals gathered around your loved one will support all necessary steps.

When considering the people who will be a part of your care-partner team, we encourage family members to think about a series of concentric circles around the loved one who has just received the diagnosis. Think about the family as the *first circle of support*. Immediate family members, relatives, friends of the family, friends of your loved one and immediate neighbors all can play roles in caring for your loved one.

The common vernacular uses the term "caregivers." We prefer the person-focused term "care partners." It immediately empowers the person living with dementia to plan care **in accordance with *their own* needs and wishes**. It's not a one-way street. Everyone works together to plan and execute *a life worth living*.

(For more information, visit www.caringbridge.com)

Start with Immediate Family

Who is closest to the loved one with the diagnosis? Let's say your mother received a dementia diagnosis. Perhaps you could begin with your father, stepfather or whomever her life partner may be. Ask yourself some basic questions: What is his or her health status (including mental/emotional health)? How is he or she handling the diagnosis? Do they tend to "catastrophize," to lean into the negatives, the challenges, the downsides? Take this into account, because it can affect everyone on your care team -- most importantly, your mother. It's OK to say, "Dad, I realize this is very hard for you, so I have talked to _______ (another close family member), and they have made it clear we can rely heavily on their help."

You don't want issues from care partners to negatively affect Mom's treatment and daily well-being. She will need all the positive energy and optimism she can rally.

Quite often, those closest to the loved one with dementia are *ideal care partners* at the center of the team. Their love, support and familiarity with the individual are key to meeting everyone's needs. They may serve the leading role in directing appropriate elements of the care plan. They may have the most in-depth perspective on their loved one's needs and wishes. They may also step back and assume a secondary or supporting role in other elements, so those with greater expertise or unbiased views can take charge.

Appoint a Family Lead Person (FLP)

Identify the one family member who has the most checkmarks on the list of *ideal care partner*. Who has physical proximity to your loved one? Their sister, who lives 3,000 miles away, is not a logical first choice for this role. Who has a positive, warm personal relationship with the individual? Who has the resources that are most needed. These come in many forms: TIME is one of the most important ones. If possible, choose someone who is not working a full-time job. A retired person may be a strong choice.

An FLP with strong personal finances is another important resource. There may be unexpected or last-minute out-of-pocket expenses that need to be paid. Having an FLP who's living paycheck-to-paycheck will not be so helpful in this regard. And remember, having a family member who is able and willing to handle these occasional surprise expenses is a good thing, *BUT* your family *should not* assume they will shoulder a larger share of the costs than anyone else, unless they have agreed to do so.

The Second Circle of Support

You will almost certainly need to rely on a variety of professionals for help, especially in the later stages of severe health conditions and terminal illnesses. They may not be required for years, but start looking at your options early. This is among the most important decisions your family will make. In addition to patient advocacy and life-care planning, Caregiver Support and Resources, LLC offers guidance and referrals to an array of agencies serving needs including:

- Elder law
- Hospice & palliative care
- Finance
- Medical
- Real estate
- Respite care and other community resources
- Counseling

Your care-partner team may include both traditional and non-traditional care methods. Some families prefer support in accordance with religion and faith. A clergy member, lay leader or other religious/spiritual adviser may serve a central role in meeting such needs. Likewise, professional death doulas (essentially on-call attendants to the loved one and their families) can offer a variety of services including counseling, faith healing, medical care, respite care, and even cooking and cleaning to alleviate burdens on stressed families.

11 Common Alzheimer’s and Dementia Behaviors

By Maureen Rulison

It’s just after dinner. The sun is going down, and your father rests in his favorite recliner as you pick up the dinner table. He calls out from the living room, “When are we having dinner?” You glance up at the clock.

“But we already had dinner, Pop,” you call back calmly. “You finished most of your chicken this time.”

You hear a groan, and the recliner clicks in. He shuffles out to the kitchen. “What are you talking about?” he asks crossly. “I haven’t eaten since breakfast.”

You gesture to the table, where more than half of the dishes and a few scraps of Mom’s chicken marsala remain. “See, Dad?” you plead. “There’s your plate. Wasn’t it good?”

He shoves his plate. His silverware clanks loudly against the wall. He stands hunched over the head of the table, teeth clenched, fists balled against the placemat. “You’re just saying that so I go to bed early!”

It’s going to be another rough night.

The Care Partner’s Struggle: Alzheimer’s and Dementia Behaviors

You may recognize our hypothetical scenario. Perhaps you and your mother have actually looked at each other in despair at another outburst your father can’t control. Maybe your own spouse, brother, aunt or niece struggles with **common Alzheimer’s and dementia behaviors like confusion, emotional outbursts, hallucinations, disorientation and so many more**.

Alzheimer’s disease and other forms of dementia each have their own styles that affect people in different stages, well, differently. But, in general, there are certain behaviors and characteristics that affect many individuals. Here are some of the most common:

1. Repetition

You’re likely familiar with repetition. You’ll hear the same story countless times -- sometimes with different endings. You’ll hear the same questions time and again.

While dementia is so much more than memory loss, **this is often a memory thing.** Especially in the early stages of dementia, short-term memory is among the first things to go. Your loved one likely doesn’t remember from one moment to the next what has and hasn’t already been said in the conversation or done in their daily routine.

They may **repeat certain phrases and activities** -- like “When are we going home?” when they’re already home or refolding clothes that have already been folded. Repetition can also signal anxiety, uncertainty or boredom with current places and situations.

2. Wandering

Persons living with dementia may appear to wander aimlessly around the home or wherever they may be. **But make no mistake, wandering is not aimless to them.** Especially in later stages, they’re just trying to get where they feel they need to go.

Those feeling disoriented, not recognizing their current surroundings, may be “searching” for home. They may feel uncomfortable or anxious, trying to find a place that feels calm and safe, even if it’s just the other side of the room for a brief moment. They may be looking for something meaningful to them -- a keepsake, special picture or someone they love -- although they may not remember what that something is.

3. Sleep Changes

You may notice your loved one no longer sleeps through the night or spends increasing amounts of time napping during the day.

11 Common Alzheimer's and Dementia Behaviors (Continued)

Humans function with **a natural circadian rhythm**, which compels us to sleep and wake at "normal hours." In most healthy individuals, such brain activity is influenced by external stimuli -- namely perceptions of light and dark that accompany the rise and set of the Sun. Those living with dementia, which systematically destroys brain cells (including those governing circadian rhythm), may gradually lose this vital function.

They may also experience sleep disturbances. A brain at rest is anything but "at rest." It cycles through stages, from light sleep through deep and dream (REM) sleep. Damaged brain cells misfire and upset those stages, causing restlessness, sleep interruptions and night terrors.

4. Sundowning

Relatedly, "sundowning" may cause increased agitation, confusion and restlessness as evening sets in. Dementia regressions affecting a person's internal clock can be upsetting for reasons your loved one likely can't understand or verbalize. They may feel they should be getting sleepy or that they actually are tired, but are too uneasy to comfortably settle into a "normal" evening routine.

Sundowning may also result from mental exhaustion. Remember: your loved one has just completed another day navigating life in a perpetual state of confusion. Wouldn't you be cranky?

5. Losing Appetite

Appetite loss is common with dementia. Sometimes it may not be true appetite loss, but rather simply forgetting to eat. But quite often, as with many secondary conditions and symptoms of dementia, the brain's wiring that tells us to eat is disrupted.

Your loved one **may lose interest in food and drink altogether**. Expect weight loss and weakness as later stages set in. Stopping eating is often a significant factor in what makes dementia a terminal illness.

6. Collecting & Hiding Objects

Individuals with dementia may hide away common objects like silverware -- or even food. This could at first seem relatively harmless. It's easy enough to play off a drawer full of forks or pens as harmless, or as a confused manifestation of a lifelong collection hobby (like Mom's stamp collection or Dad's display of sports autographs).

But in advanced stages, this common dementia behavior **could be unsafe and unhealthy** (think fire hazards and rotten food). It may become severe as hoarding. Hiding objects can arise from a strong desire to control losses of memory and cognition. It may also stem from a delusion that someone is stealing from them or a self-preservation instinct to ensure there will be enough food and drink later.

7. Manipulation

Your loved one **may distort reality** to get the things they want or need. You might go so far as to call it manipulation. Whether they know they're being manipulative is subjective -- depending on their type(s) of dementia, level of awareness and personal characteristics.

Those with more awareness may use confusion to feign unawareness: *"You never told me that."* Or as a bargaining chip: *"You told me I could drive to the store if I took my medicine."* It's hard to reconcile your loved one's desires with what's rational and safe.

8. Poor Judgment

Similarly, poor reasoning and judgment is a common cognitive regression associated with Alzheimer's and dementia. Through no fault of their own, persons living with dementia may have a diminished ability to think through things that are important or dangerous.

Much more than memory alone, cognition dictates our ability to reason. It drives decision-making from whether a financial choice is prudent to whether it's safe to pull out onto a busy street.

11 Common Alzheimer's and Dementia Behaviors (Continued)

9. Communication Difficulties

Imagine always losing your train of thought. Or struggling to remember what something is called. Or worse yet, temporarily (or permanently) losing the ability to communicate verbally.

Persons living with dementia may have difficulty communicating, in one way or many. But they can most certainly **express emotions and meaning through nonverbal cues** like facial expressions, eye movements, gesturing, grunting and humming.

10. Anxiety, Aggression & Anger

Common dementia behaviors like anger and aggression -- as in our fictional dinner example earlier -- can stem from any number of feelings and experiences noted here. Your loved one may feel anxious and disoriented in their own home. They may be frustrated over not being able to communicate (above). They may feel paranoid from hallucinations and delusions (below).

In some cases, aggression may turn violent, often lashing out physically or verbally at family and friends they can't recognize or trust. The loss of control and meaning in their world is understandably upsetting.

11. Hallucinations, Delusions & Suspicions

Misfiring neurons can cause our loved ones to sense things that aren't there: mysterious figures in dark corners, creepy-crawly critters, phantom sounds, etc. It's scary, suspicious, enough to make anyone uneasy. *(Helpful hint: Arguing that something isn't there doesn't help to quell the dementia-related delusions that are **very real** to your loved one. Acknowledge their feelings, and change the environment. Sometimes switching on a light or changing rooms can calm the nerves.)*

A Great Life-Care Plan Should Address Common Alzheimer's and Dementia Behaviors

You may not know what lies in store for your loved one after a dementia diagnosis. They may progress slowly or rapidly through stages. They may experience different symptoms in different ways. But you *do know* there are common Alzheimer's and dementia behaviors that can be addressed in due time with a strong plan.

#WeAreDementiaStrong. If you need help, Caregiver Support and Resources, LLC has over 25 years of experience with all aspects of life-care planning including dementia care. We're happy to guide the process in a caring and compassionate way.

Early Onset Dementia: Mom Keeps Forgetting My Name

By Maureen Rulison

Your mother readies for the day one morning. You've just enjoyed a delicious breakfast. The comforting smell of maple syrup and pancakes lingers in the air, welcome as a family friend.

You're both excited for a day of, let's say, perusing yard sales. Your annual spring outing, rooted in tradition and love, is more about spending quality time together than finding little treasures.

Then something happens that's not so familiar. Mom calls you in the room. "Sarah," she says, "have you seen my gold bracelet?"

You walk to her room, confused. Your name's Rebecca, and she's wearing the bracelet. You're visibly taken aback as you explain what it seems she should already know. Your mother may even laugh it off. "Oh, silly me," she says, noticing the bracelet and gesturing toward a few strands of graying hair, as if to justify a "senior moment."

She's only in her late 40s. Isn't it too early for dementia? Forgetfulness happens sometimes to even the healthiest, most cognizant people advancing in years. But Sarah? The bracelet? Something in your mother's memory slipped, if only for a moment.

The simple answer is, no, it's not too early. Early onset dementia symptoms may begin in a person's 40s -- or younger. It affects approximately 200,000 of the 6 million Americans living with Alzheimer's or dementia today.

You See Symptoms of Early Onset Dementia. What's Next?

With time, instances like these may grow more frequent. Your loved one misplaces your name. His or her day-to-day and minute-to-minute memories begin to draw back with time. Your natural instinct may be to worry, to correct, to fight against the progression of regression in hopes their memories regain their once-strong foothold.

But a great care plan should allow some personal space, perspective and understanding. Here are some strong first steps:

Begin With a Comprehensive Medical Evaluation

Self-diagnosis, or a diagnosis by close family and friends, often works contrary to care goals. There are more than 400 different types of dementia. Each has its own definitive characteristics and speed. What's more, dementia affects each individual differently. Each requires its own special style of care.

You know your loved one well. Memory lapses, slips in reasoning and judgment, and other behavioral and physical changes -- especially early in life -- may be uncharacteristic. You should first seek the professional opinion of a primary care physician or neurologist. Comprehensive tests can understandably be scary or overwhelming. They typically include a medical exam, cognitive tests, brain imaging and other diagnostics. From these, a doctor has a clearer picture of symptoms and potential causes.

Early Onset Dementia: Mom Keeps Forgetting My Name (Continued)

You may learn there’s no medical reason for forgetfulness. A busy mind filled with shuffling stressors of work, family and everyday life can be forgiven for missing a beat occasionally. After all, many of those in the average 40-to-55 age range for early onset dementia are at a life stage when work and family responsibilities are most demanding. They’re often reaching the pinnacle of careers, while some also balance being care partners for elders themselves while guiding children through high school and college.

If tests do, however, uncover signs of dementia, you’ll be informed to address those specific symptoms and plan for the future.

Build a Person-Focused Life Care Plan

Early onset dementia still merits a *life worth living*. Changes in memory over time should have little impact on a person doing the things they love. For many years to come, they may enjoy family meals, hobbies, attending the kids’ concerts and sports events, and everything of the sort.

A life-care plan simply spells out how important details will be addressed, as needed. It’s a living, breathing document. Once in writing, it can be updated to include new wishes or care directives. It defines, organizes, prioritizes and mobilizes every aspect of an elder’s care from life through death. These elements may include:

- Medical care coordination
- Financial decision-making
- Care partner education
- Care advocacy
- Support services
- & More

My life partner/care partner, Brian, who lives with Alzheimer’s and vascular dementia, has a wonderful life care plan. It includes everything from enjoying music to donating his brain to science and vital organs for others to live on. It’s about enjoying life’s simple pleasures and helping others after he’s gone.

A life-care plan should be person focused. Brian often discusses losing 30 pounds post-diagnosis -- only because he would sometimes forget to eat. That’s a pain point, and it may require only a gentle reminder from a care partner about meal times. But a good plan is not only about preparing for and reacting to crises. It should emphasize the development of ongoing relationships with loved ones.

Remember, you’re caring for (and alongside) the person, not the illness.

Build Your Care Partner Team

We prefer the term “care partner.” The term “caregiver” or “care provider” implies a one-way transaction -- a person providing the care. Words matter. Even linguistically, the perception of this one-way street disempowers the individual, empowering only the medical professionals and family/friends “seeing to” their care.

Their voice matters!

Early Onset Dementia: Mom Keeps Forgetting My Name (Continued)

It's a partnership between two (or more) people and characterized by mutual cooperation and joint responsibilities. An elder may choose their son, daughter, nephew, neighbor, best friend, doctor, third-cousin-twice-removed, or any other combination for a journey that requires support for everyone involved.

Just as your elder may require help drawing a bath or cooking meals, their care partners may need resources in coordinating activities. A great team has well-defined roles. Perhaps a husband or wife does mealtime, while one of the children does laundry, and a sibling organizes a fun group activity for *everyone* to enjoy.

Or maybe someone does it all!

There are no strict rules for what a care-partner team does or should do. Everyone cooperates for a *life worth living!*

#WeAreDementiaStrong

The path ahead will be hard. But nothing good in life is easy. Just know #WeAreDementiaStrong. Let's work together to make a plan for memory loss while cherishing the memories that remain.

Knowing where you and your loved one stand is the first step to creating a solid life-care plan. For these decisions and more, Caregiver Support and Resources, LLC helps you to build a plan for today and tomorrow.

Come as You Are: Preparing for a Dementia-Friendly Worship Service

By Maureen Rulison

The hymns are unfamiliar. The scripture is being read from an unfamiliar translation. The pastor's sermon is long and hard to follow.

This can be a jarring experience for many people. For those with dementia it can add to a sense of isolation they may already feel. A place of worship -- no matter the faith or denomination -- **should not be a place of isolation**. It is a community where people can experience a Heavenly Spirit who cares about them and where they know they are not alone. It is a place where people can be reminded that they were created in the light and design of a Higher Power and that they are loved.

Churches, synagogues, mosques, nursing home chapels (or even your own living room, if that's your style) can team up with persons living with dementia and their care partners to create a welcome environment and prepare a dementia-friendly worship service.

Some Things to Consider in Building a Dementia-Friendly Worship Service

Dementia-friendly houses of worship can make needed adjustments to ensure people with dementia are able to participate in worship in ways that are meaningful to them.

Bring Everyone to the Table

Don't guess about what changes can make worship more dementia friendly. General changes will not do, as not everyone experiences dementia in the same way. (As Brian and I always say, if you know one person with dementia, you know one person with dementia.) Invite those with dementia, their families and friends, and care partners to meet with those planning worship. **Get to know the specific needs of your parishioners and come to solutions together.**

Familiarity is Important

People with dementia often connect with things from their past. A common prayer and familiar hymns (music for dementia is a powerful memory-care tool) can go a long way in nourishing their faith. Consider reading prayers like the Lord's Prayer or Muslim Call to Prayer with traditional wording. Perhaps there is a canonical translation that is more familiar, like the King James Version, the New International Version or the New Revised Standard Version.

Don't underestimate the power of music. Music has the ability to reach parts of the brain where other means of communication fail. Consider familiar hymns like "The Old Rugged Cross," "Amazing Grace" or "To God's Ear" (for our friends of the Jewish faith). Be sure to ask about favorite hymns and even play some audio of the hymns while you are making a list to jog their memory.

Keep It Short and Simple

A service for people with dementia **should be short -- perhaps 20 to 30 minutes**. This helps keep them engaged and helps with issues of concentration. A simple and clear structure works best. The service should include a clear beginning with a welcome, a couple of familiar hymns, prayers, scripture readings and a short message.

Consider using an order of service and keeping the **same structure week to week**. Keep prayers short and simple, and be sure to pray for people with dementia and their care partners. You could also consider including this at the beginning of your regular service, after which those with dementia could leave for a time of fellowship, if they wish, and the rest of the service could continue. This would allow those with dementia and the care partners to worship with or without the rest of the congregation or gathering.

Come as You Are: Preparing for a Dementia-Friendly Worship Service (Continued)

Encourage Participation

Worship that connects to the senses can encourage persons with dementia to more fully participate. Candles, crosses, Communion elements, Holy books, and the baptismal font are all powerful visuals in a church. So make them prominent. Allow their creative side to shine through music and painting.

Ask them to write or deliver a prayer, or even share their story with the congregation. Include them in your greeting team or as help in your after-service fellowship gathering. Be open to the gifts that people with dementia have to give.

Create a Care Team

A pastoral care team would be a great asset to people with dementia and their care partners. **Invite a small group to be trained in assisting those with dementia.** Be sure they are easily identified with a name tag or t-shirt. Care team members can assist those with dementia and their caregivers if help is needed.

It may be helpful to have **a quiet place where someone with dementia can go if they feel overwhelmed** -- perhaps just into a separate room to “cool down” or in a fellowship hall for a cup of coffee. Pastoral care team members could assist in this.

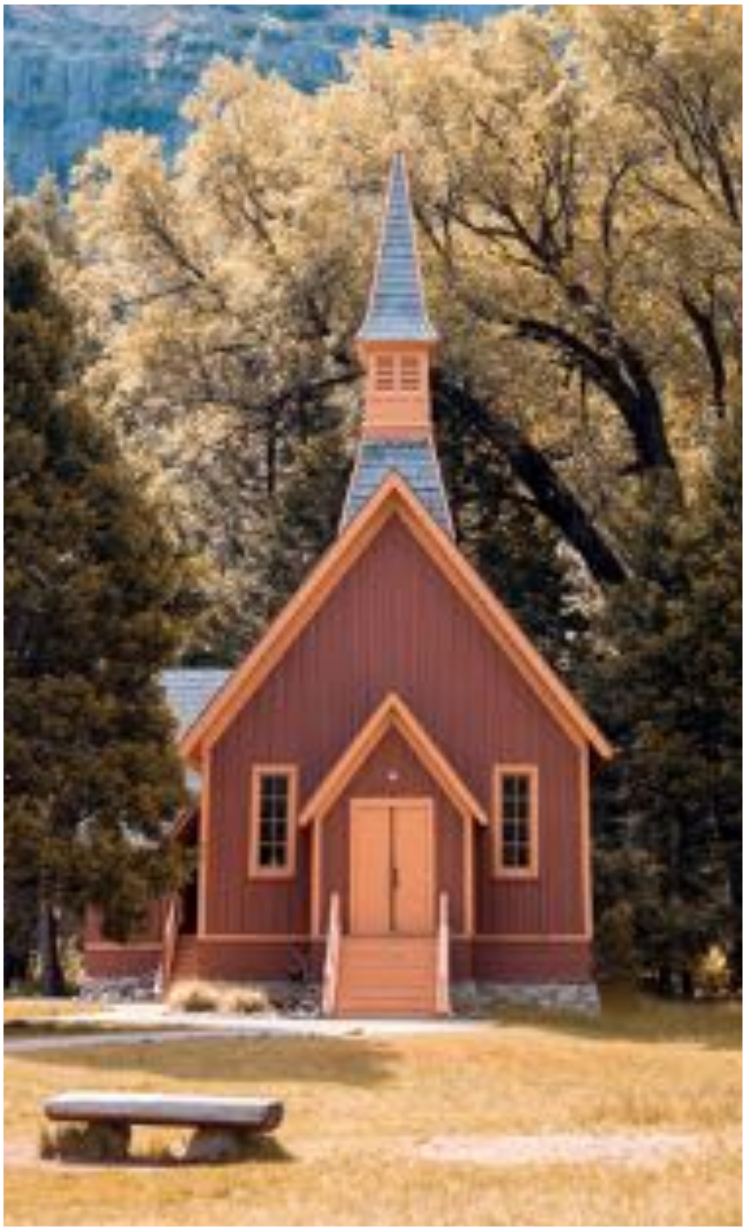
Learn From Others

There’s a lot to learn in creating dementia-friendly worship. Connect with worship groups who already minister to people with dementia and their care partners. Speak with health care professionals and others who work with them. Have them attend your services and give constructive feedback. You may not at first be perfect at ministering to people with dementia, but it’s good to start somewhere.

Are You Ready to Host a Dementia-Friendly Worship Service?

Dementia-friendly worship just takes some thought and consideration. A loved one of any faith, regardless of their current stage of dementia, still has a longing to be close with their Lord. **Their communion with a Higher Power may be brief and on their own terms, but it’s meaningful nonetheless.**

#WeAreDementiaStrong. If you need help, Caregiver Support and Resources, LLC, has over 25 years of experience with all aspects of dementia care. We’re happy to provide referrals and guide the process in a caring and compassionate way.



#WeAreDementiaStrong

We built #WeAreDementiaStrong as an educational resource for persons living with dementia and their care partners. As Brian and I well know, the road of living with Alzheimer’s disease and other forms of dementia can be long and winding, with bumps and potholes and unexpected villains along the way. That’s not to say it can’t be a beautiful and fulfilling journey. With a little education, preparation and enlightenment, your loved one living with dementia and the entire care-partner team can enjoy a great many years together.

#WeAreDementiaStrong is an online community. We invite you into our “virtual home” for a visit you can leave feeling informed and refreshed to overcome any challenge dementia may throw your way. As the co-founder of #WeAreDementiaStrong, Brian (my life partner/care partner) uses his greatest strength -- his words -- to spread awareness for Alzheimer’s and dementia while **teaching the realities from his own lived experience**. He was diagnosed with Alzheimer’s in 2014 and vascular dementia in 2019. While we are professionals and experts in preparing for needed care, **we also live many of the same realities as you!**

In 2021, we began hosting Facebook Live events on our #WeAreDementiaStrong page, inviting experts to discuss areas like:

- Dementia care
- Legal, financial and real estate matters
- Therapy and treatment (traditional and non-traditional)
- Home care
- Hospice and palliative care
- Person-focused care
- End-of-life planning
- & so much more

We deliver new and innovative ways to share educational information, personal experiences and perspectives, and other resources that help us to create our own *life worth living*. We hope by sharing that you, too, can build your own *life worth living*. We also remain committed to serving as nationally and internationally renowned public speakers and advocates for greater spending on research from all levels of government.

Dying with Dignity

By Brian LeBlanc abitofbriansbrilliance.com

I made a video to my future care partners. In case you didn't see it, you can view it here: *https://bit.ly/30fWF5O.*

In the video, I talk to my future care partners, telling them my likes and my dislikes so when I am struggling with my dementia, anxiety and anything else that may make me a little difficult to deal with, they will know what to do.

We realize that how you will pass from this Earth is not exactly a fun discussion to have. We also realize that death can come along at any time, so it's always important to have a plan. Don't you want to be assured that, when your time comes, you will depart in a manner in which you choose? I know I do.

With that said, Maureen and I have had many conversations about this topic because we both want to make sure that whoever goes first, the other one will know their wishes. We are going to write these wishes in our journals, making changes and additions as we go along. It's important to both of us that we give each other what the other wants.

One of the things we agreed on from the get-go is that we want to be cremated. We figured, why would we want to rent space in the ground when we could have our ashes planted in the ground and become a beautiful tree? That is such a beautiful thought that, when in full bloom, people could come sit under our branches and enjoy the shade we provide them. To us, that is such a beautiful way to spend eternity.

This writing is not entirely about dying, but more about our dignity. Simply said, I don't want to spend the last days of my life being kept alive by a machine just to prolong the inevitable. I have work to do (meaning: I am donating my body to science).

– I want them to study my brain to see if something they find could be used to help further understand this most misunderstood disease.

– I want them to use my organs to keep someone else alive.

– I want them to use anything they can to benefit others.

I can't think of a better way to help others, rather than just put me in a hole in the ground.

In preparing for this piece, I did some research. One of the things I looked at were websites with the title of "Death with Dignity." This was not what I was looking for. But a lot of folks, today more than ever, are choosing it.

Right from the start it states, "You're joining a growing movement that works to ensure terminally ill Americans have the freedom to choose from a full range of end-of-life options, including how they die. Seventy percent of Americans support the end-of-life option allowing qualified terminally ill people to end their lives through physician-prescribed medications. That's right: seven in ten Americans want this option.

Like I stated above, this is not for me, but I respect those who choose this alternative. So, what do I want to happen during the dying process?

First of all, I want music. I want the room to be filled with my favorite music. I am currently working on my playlist, so that when I pass, I will be relaxed and non-stressed. That's important to me.

Dying With Dignity (Continued)

One thing I DON'T WANT is people staring at me during my last moments. I know it will be sad, however, living with Alzheimer's, vascular dementia, type 2 diabetes and no telling what else awaits me in my later years, I want to be in my own bed, with nice sheets and soft pillows.

I want to have Hospice involved.

I want laughter. I don't want it to be solemn, for that is not who I am, and I have discussed all of this with Maureen.

I DON'T want to be left alone (unless Maureen leaves to get a Diet Dr. Pepper from Chick-Fil-A).

This will all be put in writing, so in case Maureen is not around it will still be carried out. Why is this so important to have this written? I may not be verbal at that time. (Maureen says jokingly she couldn't be so lucky to have me non-verbal.)

I feel people should talk about their fears, no matter how serious, funny or anything in between because we don't want to be trapped with those fears inside.

Before Maureen, I had no idea how I was going to spend my final days and moments, nor did I have anything in writing. The only thing I knew for sure is that I wanted to be cremated and have my body given to science. I was living by myself, and I had a fear of something happening to me and no one finding me for days. I had a fear of dying alone.

Now, with Maureen ever present in my life I no longer have that fear, for we have a plan in place. And even if Maureen is not there, there will still be people by my side and I won't be alone. I feel safer, less anxious, more loved, and assured that my wishes will be carried out just as they were planned. There is a feeling of security and peace that is now with me.

You see, in Maureen's line of work, at times she is the only one standing by the bedside of one of her clients, holding their hand as they pass away. She offers comfort, but has at times had no idea what their wishes were. She promised me that would never happen with me.

I want to have a Celebration of Life -- while I'm alive.

I want music to be played, and at one point I want the song, "Feelin' Good" by Michael Bublé to be played. I want food and, yes, alcohol. I don't want anyone to wear black. Instead, I would love it if everyone would wear brightly colored clothes. If you have a tropical shirt, that would be even better. (I may add more to this as I think about something new. It's kind of like me … a work in progress. You never know what you're gonna get!)

If you don't already have a plan or haven't had conversations with your family as to how you want to spend your final days and moments, plan now, so when that time comes you will pass away in peace and your loved ones will also know they gave you exactly what you asked for.

Doing this is one of the greatest gifts YOU can give to your loved ones.

DON'T WAIT UNTIL IT'S TOO LATE!!!

Editor's Note: Abitofbriansbrilliance.com is written and managed by Brian LeBlanc, who lives with Alzheimer's and vascular dementia.

Aphasia: ‘I Couldn’t Speak and I was Terrified’

By Brian LeBlanc abitofbriansbrilliance.com

I woke up Saturday morning just like any other day. Maureen, my life partner/care partner, was up before me, of course, as she moves like a lightning bolt and I take my sweet time. The gentle waves of Tampa Bay just outside our bedroom window glistened in the morning sunlight. So relaxing and peaceful, a wonderful way to wake up and prepare my mind for the daily grind of functioning and remembering.

I said something brief to Maureen -- although I’m a bit foggy and can’t remember what it was. I sat up and … nothing. I couldn’t speak. I could think. I had my inner monologue. I could mouth the words. They were right there on the tip of my tongue. But nothing. Silence. Pure silence. Frightening silence. Another attack of aphasia -- thankfully a relatively infrequent consequence of my Alzheimer’s disease and vascular dementia -- had robbed me of my ability to communicate verbally.

What is Aphasia? And How Does it Affect People Diagnosed with Dementia?

I looked to Maureen in panic. She could see by my eyes I was terrified. We were scheduled to do a Facebook Live conversation for #WeAreDementiaStrong that morning. But that hardly mattered at all. She promptly and politely canceled the event with a nice post explaining that I wasn’t feeling “well.”

Not feeling “well” was an understatement. I was in full-blown crisis mode in my own head, and Maureen was doing her best to comfort me and coax me out of silence. That’s easier said than done.

Oh yeah, did I mention I’ve had several bouts with aphasia before? It’s often a dementia-related illness or stemming from a stroke or traumatic brain injury. In my case, the Alzheimer’s and vascular dementia slowly stealing my memories also causes global aphasia to sap my ability to speak. For some, aphasia symptoms may include a total or partial inability to write or understand language. Some say words in the wrong order; others say sentences comprehensible only to themselves.

My aphasia causes a complete loss of speech. No words can escape my lips, whatsoever. I may be able to mouth some words, but I rely mostly on gesturing and a text-to-speech app that allows me to communicate. I often laugh, wishing Maureen could just read my mind, but I can’t even read my own mind most days. In the meantime, my girlfriends Alexa and Siri can speak for me, much to Maureen’s playful chagrin. It’s sometimes funny to have the app speak for me in a British accent or a woman’s voice.

But whatever fleeting joy joking around with apps may bring, the sad reality of aphasia is not fleeting at all. A few years ago -- I hardly remember this -- I was unable to speak for six months. Another incident lasted three or four days.

The Uncertainty of Aphasia: When Will It End?

There’s no answer to that question. When will it end? Will it end at all? I’ve entered each attack of aphasia facing the reality that whatever I said the moment or night before could be the last words I ever say. Maureen later told me, “The first thought that went through my head: ‘What if the last thing I ever hear you say is what you just said to me?’”

Maureen went to the office and cried. Even as an expert in dementia care and life-care planning who walks the talk in professional and personal shoes, the random, uncontrollable and sometimes cruel effects of dementia are a lot to handle. “I was like, ‘I can’t deal with this. I just can’t deal with this,’” she said. “I have plans in place if I couldn’t leave you alone at any point. I just wasn’t ready to put them into action.” I understand better than most that dementia is incredibly difficult for both the diagnosed person and their care partners.

Aphasia (Continued)

I must say, she does a fantastic job as my care partner. She knows exactly what to do, not just to keep me happy or distracted, but to address dementia symptoms and provide holistic relief. She's a saint for taking my hand and leading me out of the fog and darkness, time and again.

Bringing Out My Voice Again

Maureen sat me down on the couch with my headphones. I can vaguely recall tapping my toes to the beat. She says my lips moved with the lyrics. I was remembering, but still no voice.

Music is the perfect therapy tool. We remember music. We remember art. They realign and reset minds with ties to specific emotions and functions. I love all kinds of music, and I have some 4,800 songs on my phone. There's scientific proof that music and art therapy can actually replace dementia drugs.

Music works. I hear the melodies and beats and lyrics. I feel the emotion. It's soothing, and it brings me back to reality. But that's not what brought back my ability to speak.

We made the day as normal as possible. I watched TV. We went to the store. We even had a little argument, as couples often do. Expertly using my text-to-speech app, I'm sure I won (but don't tell Maureen that).

Later, we sat together on the back patio, overlooking Tampa Bay as the sun began to set. I snapped a great picture of some dolphins. I stood up and tripped, yelling a certain four-letter word on the way down.

"#&*@!"

I spoke! Maureen didn't even check to see if I was OK from the fall. "You talked! You spoke!" she exclaimed. Thankfully, this round of aphasia lasted less than 24 hours. I'm not sure if it was the shock of tripping, but something about the experience hit me like a lightning bolt.

Since that first time, I've always tried to speak first thing in the morning after regaining the ability to speak. That's my test. That fear never loosens its grip now.

Communicating with Aphasia and Dementia

Last week, Maureen wrote a terrific blog about communicating with loved ones in certain stages of dementia. Coincidentally, we ended up living the extreme of that reality, however briefly, that very weekend.

"Trust me, Brian LeBlanc will always try to find a way to communicate," Maureen said. And she's right. Communication is my life. It's who I was before dementia as a marketing and PR professional. It's still who I am now.

Thankfully, I'm always prepared to use gestures, facial expressions (and, of course, my beautiful girls Siri and Alexa) to speak for me when speechless moments like these become more frequent … or permanent. Later that night, Maureen and I were talking and she said, 'You know, I kind of wish you didn't talk anymore.' We had a good laugh at that. As I've said since being diagnosed with Alzheimer's Disease in 2014, "I have Alzheimer's, but it doesn't have me!"

Editor's Note: Abitofbriansbrilliance.com is written and managed by Brian LeBlanc, who lives with Alzheimer's and vascular dementia.

The Attack of ‘The Nothingness’

By Brian LeBlanc abitofbriansbrilliance.com

I can’t tell you how many times I’ve sat down to write something new and absolutely nothing came to mind. I would come up with ideas and type it into the Notes app on my iPhone, so I wouldn’t forget what I wanted to write about. But when the time came to write, I looked at what I had saved and had no idea what the words meant or what I wanted to write about.

This is what brought me to write about **“The Nothingness.”**

I remember (yes, I can still remember things from a long time ago) a movie from 1984 titled “The Neverending Story.“ It follows a boy who reads a magical book that tells a story of a young warrior, Atreyu, whose task is to stop a dark force called “The Nothing” from engulfing a mystical world, Fantasia. “The Nothing” was just as it sounds, just NOTHING.

So now, in addition to my ever-present “BRAIN FOG,” along comes “THE NOTHINGNESS.” (That’s the only name I could come up with, yet it ever-increasingly takes up residence in my brain.) I have to tell you, writing the title of this piece, I began to wonder, “How can I talk about something taking up space in my brain when it’s NOTHING?”

Yeah, if you’re waiting for me to explain that, have a seat and make yourself comfortable. It’ll be a loooooong wait.

Because of my “BRAIN FOG,” I continue to utilize the magic powers of my girlfriends, Siri and Alexa. Without the technology they possess, I would be hard pressed to continue living alone. To add another wrinkle, my diabetes has recently gotten out of control (or I should say, due to MY forgetfulness) and I’m back on insulin.

I looked at that as a huge failure on my part, but as my endocrinologist so aptly stated: “It happens!” So now I have four reminders at different times of the day and evening that remind me to check my blood sugar and take my insulin. If I don’t do it exactly when I’m reminded, I forget, so I’ve now included backup reminders.

I still have the reminders as to when to eat breakfast, lunch and dinner; two reminders per day to remind me to play my “Favorites Playlist” in case I go into a “BRAIN FOG”; and also a daily reminder to bathe. Without those reminders, I would be hungry, foggy and stinky. Nobody, especially me, wants that!

But let’s get back to “The Nothingness.” If you are familiar with my Alzheimer’s journey, you have heard me speak and write about my Brain Fog. The Brain Fog is more of a short-term hindrance. It would come and go, but never completely overpower my brain. It became something I got used to.

Now, more times than none, my Brain Fog is followed by “The Nothingness.” And yes, it is exactly as it sounds . . . it’s a whole bunch of NOTHING!!! I don’t think I’ll ever get used to that.

Think about sitting in a room with no windows, at night, wearing a blindfold over your eyes. It is the blackest of black. You can’t see anything . . . NOTHING, except the blackest of black. That’s my NOTHINGNESS. It’s the only way I can describe it. I am going to have another appointment with my neurologist to discuss this.

The Attack of “The Nothingness” (Continued)

The only time “The Nothingness” is not present is when I am trying to go to sleep. You would think that would be the ideal time for your brain to shut off, take a break, but NOOOOOOO! That would make too much sense. Instead, I’m interrupted by bad dreams and hallucinations.

I KNOW, RIGHT???? Waking up at odd times of the night, only to find shadowy figures standing at the foot (and sometimes on the side) of your bed is not something you want to wake up to. I then wonder, how/why can I remember THAT? I DON’T KNOW, but I wish I didn’t.

I have found the more I am engaged with others helps me to stay focused. Seeing and talking to friends and family makes me happy, fills me with joy and helps to keep me Brain Fog-free and Nothingness-Free. It’s always the little things that make the biggest difference.

And then, there’s music. If I can leave you with one thing, it is this . . . take the time to make a playlist of your favorite songs -- not just songs of today, but from years ago.

When you’re having a tough time, a sad time, a confusing time or just want to reminisce, play YOUR music, YOUR playlist, the songs of your life. I hope it can make the difference for you that it does for me.

Editor's Note: Abitofbriansbrilliance.com is written and managed by Brian LeBlanc, who lives with Alzheimer’s and vascular dementia.

Planning the Financial Future

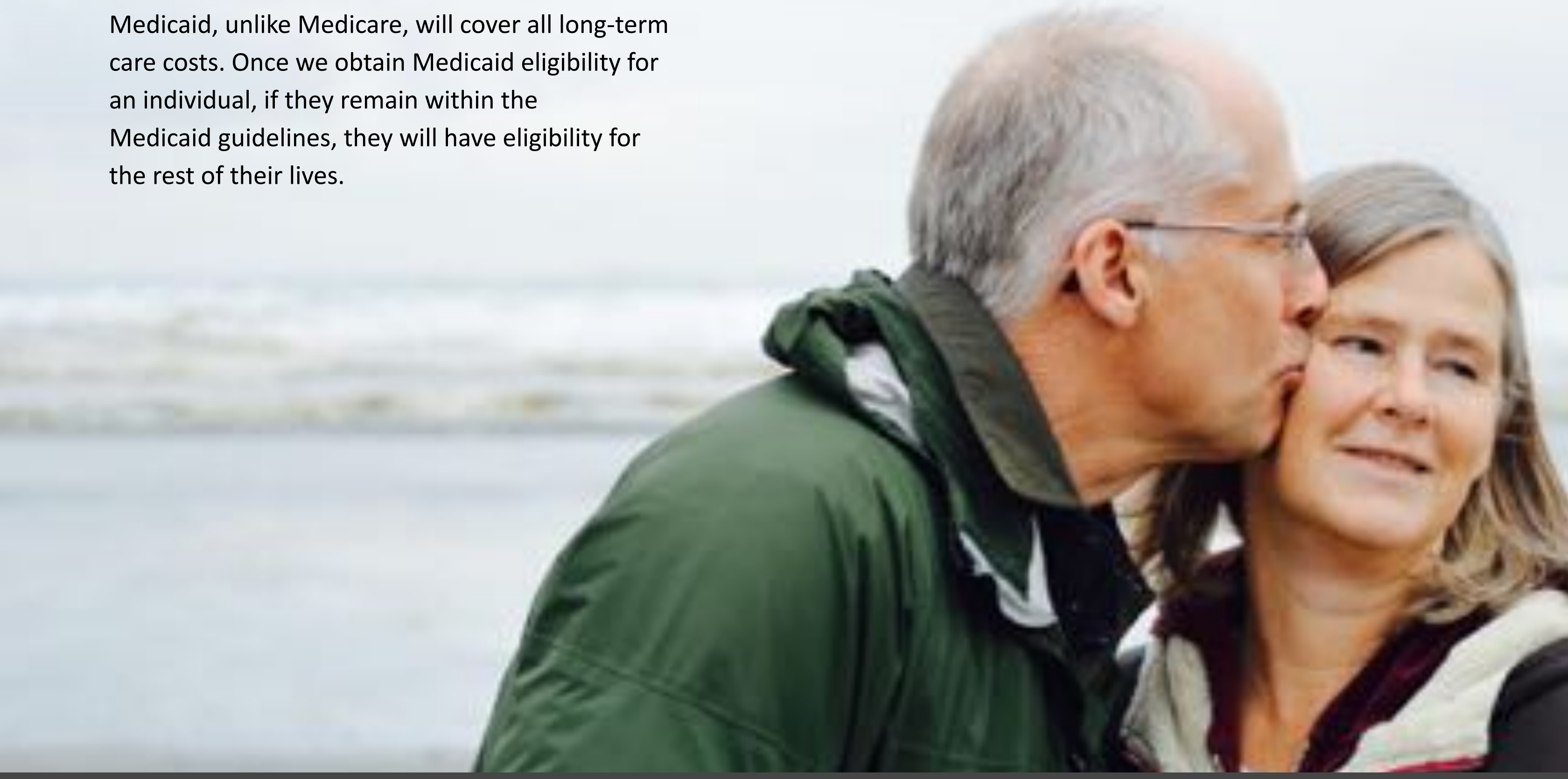
Medicaid & VA Planning (with Asset Protection)
Most people work hard and squirrel money away their whole lives with at least three goals in mind:

- Living out their own golden years in comfort and security
- Setting aside enough for a rainy day
- Leaving a legacy to their children, grandchildren and/or favorite charity

Then, the unexpected happens: your loved one is diagnosed with Alzheimer's or another form of dementia. Without protection, medical care and facility placement in late stages can potentially wipe out all of your savings and even leave you deep in debt.

There's no reason anyone should live in poverty for transitioning to higher levels of care. Our clients, their families and future generations may still live in comfort and dignity. Medicaid protection allows individuals to retain an income from sources like Social Security in addition to personal possessions of value and a burial fund. Medicaid will also pay for some home health care and a portion of an assisted-living facility bill, if it accepts Medicaid. Transferring wealth and property to chosen beneficiaries allows you to protect those assets for years to come. But remember, it must be done before Medicaid's five-year "lookback" period.

Medicaid planning can legally protect an individual's assets from being recouped to cover both short- and long-term care expenses. Caregiver Support & Resources, LLC works with elder-law attorneys to legally and ethically protect people's assets to help them qualify for Medicaid. Medicaid, unlike Medicare, will cover all long-term care costs. Once we obtain Medicaid eligibility for an individual, if they remain within the Medicaid guidelines, they will have eligibility for the rest of their lives.



Planning the Financial Future (Continued)

Tax Deductions

Tax deductions are one often-overlooked tool for addressing medical costs. Anyone, regardless of age or disability, is allowed to take a deduction for what the IRS calls “Qualified Medical Expenses.” If you have high medical bills, including in many cases long-term care costs, tax deductions are a good place to start. In fact, around 9 million Americans currently claim tax deductions to help them lower their tax liability and pay for their medical care.

Your loved one can do this in two ways.

1.) Claim the standard deduction – $12,950 if they file as single or married filing separately; $25,900 if married and filing a joint return.
2.) Itemize their deductions on their tax return, claiming the total amount of their medical expenses that exceed 7.5% of their adjusted gross income (AGI).

And if you do go the route of deducting costs on your tax return, don’t forget to deduct the costs of all the other medical-related expenses that are eligible, such as:

- Prescription medications – any medication your doctor prescribes is deductible.
- Doctor-prescribed nutrition supplements.
- Rent or utilities for a live-in nurse or medical attendant.
- Doctor’s co-payments – keep receipts because they can add up quickly.
- Costs of medical-related travel – including mileage and parking fees for all your medical appointments.

Planning the Financial Future (Continued)

Other Financial Options

1. If your loved one qualifies for Medicare, use that to pay for as much of the medical care as possible.
2. Use Medicaid and Medicare for home health services. Over 40 percent of people with Medicare and 24 percent of those with Medicaid use those government programs to pay for home health care. To qualify, your loved one's doctor must certify the need for skilled nursing care or must certify that the patient is homebound. Keep in mind that Medicare only pays for a part-time skilled nurse, not a home health aide or 24-hour-a-day care.
3. Don't forget assistance specific to military veterans, if you qualify.
4. Check with your state's Department of Aging to find out what health and home care services are available at the state level.
5. Contact the nonprofit Family Caregiver Alliance. The Family Caregiver Alliance operates the National Center on Caregiving and can refer you to multiple organizations that help with medical care, as well as providing information on supports for caregivers.
6. Consider private fundraising. Local fundraisers to help cover the cost of treatment for a community member are becoming very popular and much more common. These are community events you hold that allow the community to donate money directly to your family to help pay for the care of someone they know and love. Public events usually include food, a band or other entertainment, and raffles and multiple other ways to give besides an admission fee.
7. Another private fundraising option is a GoFundMe. This is an internet-based "crowdfunding" platform that allows anyone to donate money to your family cause. This can be an excellent solution when your loved one has a high profile in the community.

Patient Advocacy: *The Expert in Your Corner*

Maureen Rulison, BCPA, CMP, CDMCP, is a Board-certified Patient Advocate in the State of Florida.

Our services to clients in the Tampa Bay, Clearwater and St. Petersburg, FL areas prepare families for care needs. We also coordinate a variety of resources that may be needed as a loved one enters home care, assisted living and nursing facilities, and end-of-life care.

Patient advocacy is all the more important after a dementia diagnosis. There will come a day when your loved one will no longer be able to speak and act for themselves. Talk about a person-centered care conundrum. You must have an expert in your corner to help your loved one and the entire care-partner team prepare for steps they must take and services needed to help quality of life, now and through the end.

We help you build your life-care plans and care-partner teams, which in turn help clients to:

Develop treatment regimens aligning with your loved one's needs and wishes. Many traditional care methods force individuals to "comply" with medication, physical therapy and nutritional recommendations. A person-centered care approach gives an individual autonomy and authority over their own care, as long as possible, and prepares a seamless transition of control to appropriate team members when the time comes.

Navigate through complex health care systems. We assist in care coordination among multiple clinicians, settings and affiliated providers. We ensure clients understand the various treatment options and who can deliver them (and to seek second and third opinions when appropriate). We empower clients and their loved ones to ask questions by coaching and role-playing various scenarios with different providers.

Plan care transitions to ensure continuity of care. Sometimes aging at home is no longer an option. This is especially true in dementia diagnoses, as your loved one's memories and cognitive functions regress to require 24/7 expert care. This may involve a move to a memory care, assisted-living or nursing facility. It may also involve transitions to new clinicians and other medical professionals tasked with continuing care. Transitions require many logistics and moving parts. Your patient advocate can help plan and coordinate them.

Become an educated consumer for prescriptions and other treatment methods. Top-down health care expects persons living with dementia and their families to follow orders. Well, what if the experts are wrong? Promoting person-centered care, we teach you to ask pharmacists to review new medications for interactions with existing medications. And much more.

Changes in Latitudes, Changes in Attitudes…

By Brian LeBlanc abitofbriansbrilliance.com

As Jimmy Buffett sings, "It's those changes in latitudes, changes in attitudes. Nothing remains quite the same." When you stay in one place too long (or maybe I should say, when I stay in a place for too long) it's time for a change.

I spent the first 30 years of my life in New Orleans, LA. It was a great place to grow up. Mardi Gras, Saints, food, friends, phenomenal music, food, family, fun, food . . . (did I mention FOOD?) I mention food because it was a huge part of my life . . . 285 pounds of huge and probably the cause of my type-2 diabetes and heart disease, but I digress.

When 1990 rolled around, after a divorce, it was time for a change. I had met someone and she moved from New Orleans to Pensacola, FL (her home) and asked me to join her there . . . so I did. Sadly, that relationship ended seven years later, but I had grown to love Pensacola, so I stayed. I made new friends, found my niche in public relations and marketing, and was very happy.

Through a few more relationships -- all the while battling diabetes, three heart attacks, a diagnosis of Alzheimer's disease, a brief move to Knoxville, TN, questionable decisions, neck surgery, back surgery and a triple bypass in July 2019 -- the third 30 years was approaching. I had no idea what waited in store for me. Then, Maureen entered my life, at least that's when I "THOUGHT" she entered my life.

I say Maureen entered my life in 2019, but unbeknownst to me, I actually met her in 2014 (I was married at the time) . . . again in 2015 (still married) … again in 2016 (still married) … again in 2017 (yup, still married), skipped 2018 (divorced) and then in 2019, well, y'all know how that story ended and is still being written! From what Maureen says, it was all up to me.

I say, "I don't remember meeting her until 2019." She says, "WOW, guess you weren't impressed."

I say, "I have Alzheimer's." She says, "Your subscription for using the Dementia Card has expired and can no longer be used." And she isn't kidding!

I say, "WHATEVER" and roll my eyes!

What I'm trying to get at is I moved to Largo, FL in December 2019 to start my life with my LIFE PARTNER. It's ironic that in 1990 and 2019 (almost the 30-year mark) I made yet another move. What I can say is being a stone's throw away from Tampa, St. Petersburg, Clearwater and an hour and 14 minutes away from the "Happiest Place in the World," I have finally found my forever home and my forever person.

When I told some friends and family that I was moving 700 miles away, let's just say I was "cautioned and reminded" about my past moves by those same friends and family. I was once quoted as saying, "if I ever say, 'Hey, I've got a great idea. I'm going to pack all my stuff, drive hundreds of miles to a new place, to a city I have never been to, and start my life over again,' just reach over and slap the CRAP out of me and say, 'You stupid, stupid man. Haven't you learned anything?'"

Well, no one did that and I'm thankful, for I am sure it was not going to be an easy slap. I also know they all meant well, and I hold no negative feelings towards any of them. They were doing it all out of love and I appreciated their support. I still do.

So, here I am, starting over, AGAIN, and as you may have heard others say, "BUT THIS TIME IT'S DIFFERENT!" But this time, it really is different.

We are approximately the same age (I won't say who's older by 7 months, but it's not me). We both love music, movies and family. We work out at the gym. She more than me, but I'm improving. We love one another, but we also like each other. We started out as friends and that friendship, as well as our love, strengthens daily.

Has it all been a bed of roses? No, but I have learned that sometimes, the hard/difficult things in life are so much more rewarding when they are conquered than the easy things.

For all the folks who were worried about me making this move, look at it from Maureen's perspective. She was questioned also by the people who loved and cared about her:

"Are you sure you know what you're doing?"

"You know he has Alzheimer's, right?"

"Do you know anything about being a 24/7 care partner?"

Funny thing is, I also wondered if she knew what she was getting into. I told her:

"Life with me can change by the day, the hour and the minute."

"I forget stuff you may have told me yesterday, or an hour ago, or a minute ago."

"I have Alzheimer's anger which may or may not be directed towards you. I may not even know why I am angry."

Her response to me solidified my decision to move. She said, "I love you. You are going to have to put up with me, as well. I've been living on my own for 13 years! We're just going to have to get used to it. Failure is NOT an option. Plus, now that all your stuff is unpacked, I ain't helping you pack it up again unless we are both moving to a new place!"

I just love it when she gets all sweet on me.

A while back, I came up with an analogy of who we could be compared to. Maureen is like a cheetah. The cheetah is the fastest land animal in the world, reaching speeds of up to 70 miles per hour.

They can accelerate from 0 to 68 miles per hour in just three seconds. As soon as morning comes, she is up, moving at lightning speed, moving in circles around me as I try to figure out what day it is.

As far as me, I'm more like a sloth. I move at an extremely slow speed for it takes some time for my brain to kick in, some days longer than usual. I just like to take my time, taking in the beauty of the day, taking photos, and sometimes just sitting and listening to music, letting the memories float in and out depending on the song I am listening to.

Maureen had to get used to that.

We also realized, upon watching the new (and old) episodes of "Mad About You" with Paul Riser and Helen Hunt, that our interactions are very similar to theirs. We laugh at them and then realize we are seeing ourselves in their characters and laugh even harder.

That is one thing we do a lot of: we laugh A LOT!

And so, the story of our lives continues to be written, one page, one chapter at a time, full of love, laughter, tears, and smiles. We still learn a little something new about each other every day and can't wait for what awaits us tomorrow.

Editor's Note: Abitofbriansbrilliance.com is written and managed by Brian LeBlanc, who lives with Alzheimer's and vascular dementia.

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We Are Dementia Strong

OUR MISSION

#WeAreDementiaStrong is a 501(c)(3) educational non-profit that provides persons living with dementia and their care partners information on creating a purposeful and healthy life worth living after receiving a diagnosis of dementia. We achieve this, in part, by providing:

Educational opportunities ● Live presentations for persons living with dementia and their care partners (family and professional) ● Interviews with Brian LeBlanc and Maureen Rulison, as well as leaders in the field of dementia, person-focused care, aging in place, and all other issues that interest and affect the people that are walking our same journey ● Webinars

Our goal is to provide tools for each person to identify what "a life worth living" means to them. Everyone is unique because of their life's experiences, race, color, religion (creed), gender, gender expression, age, national origin (ancestry), disability, marital status and sexual orientation.

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SOUTHERN TIER Communications STRATEGIES
Magazine Produced by Southern Tier Communications Strategies, LLC
www.stcommunicationsstrategies.com