



# WHAT TO DO

# AFTER A DEMENTIA DIAGNOSIS



CAREGIVER SUPPORT  
AND RESOURCES

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Hello. My name is Maureen Rulison, President of 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 WeAre#DementiaStrong 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 e-book sets you on the right path toward effective life-care planning, care-partner team building, patient advocacy, financial security and end-of-life preparations. Download it to your desktop. Print it out. Keep it handy to light the way when the path is most dim.

Of course, we're always here to chat. Contact us at [maureen@caregiversupportandresources.com](mailto:maureen@caregiversupportandresources.com) and [thebrianleblanc@gmail.com](mailto:thebrianleblanc@gmail.com).

Warmest regards,

*Maureen*

Maureen Rulison, BCPA, CMP, CDMCP

President and Founder

Caregiver Support and Resources, LLC



# 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. We 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 an unexpected 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*.

Our 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 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 is the person diagnosed with dementia?
- How advanced is their dementia currently?
- What is their general health status?
- What is their current financial health?
- Does their current living environment suit progressing needs?
- Do they live in a community with plenty of amenities?
- How can their network of family and friends serve important care roles?
- Will their 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 your loved one has 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 own 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 around \$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.

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 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 may be some feelings that accompany the dementia diagnosis that are uncomfortable. You may feel angry. You may even have the sense of grieving for the parts of your loved one that 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. 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 and your loved one beyond just surviving, so you can concentrate once again on *quality of life*. And we at Caregiver Support & Resources help persons Living with Alzheimer's and other forms of dementia and their families to live fulfilling and rewarding lives.







# WHERE DO WE BEGIN?





## 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*.





**SECOND CIRCLE OF SUPPORT**

**FIRST CIRCLE OF SUPPORT**



**FAMILY  
LEAD  
PERSON**

**IMMEDIATE FAMILY  
CLOSE FRIENDS  
NEIGHBORS**

**PATIENT ADVOCATE  
HEALTH PROFESSIONALS  
OTHER PROFESSIONALS**



## 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.

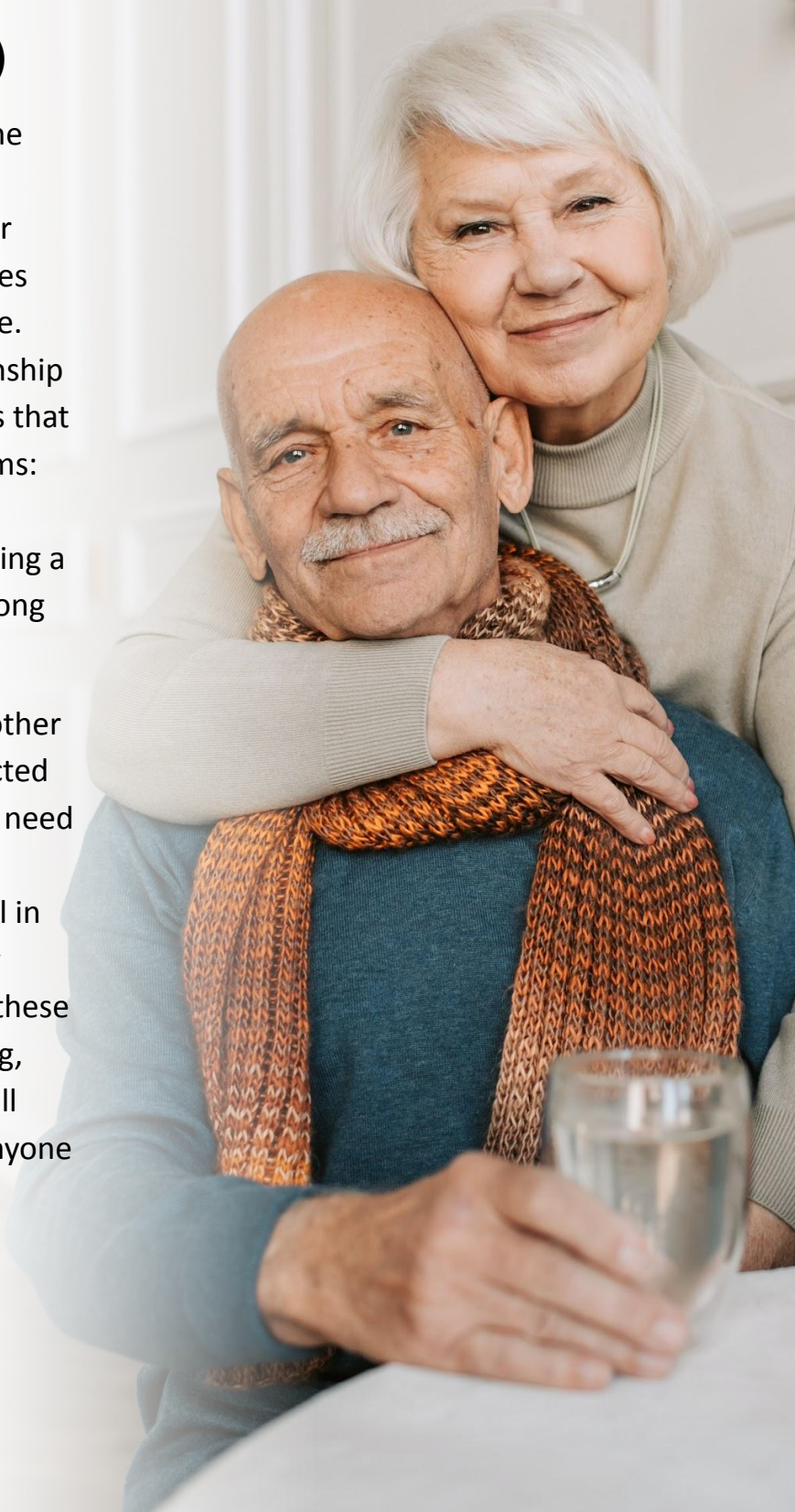




## Appoint a Family Lead Person (FLP)

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.





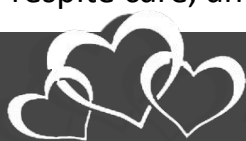


## The Second Circle of Support

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
- 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.





**WE ARE #DEMENTIASTRONG**



# WeAre#DementiaStrong

We built WeAre#DementiaStrong 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.

WeAre#DementiaStrong 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 WeAre#DementiaStrong, Brian (my life partner/care partner) uses his greatest strength -- his voice -- 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 [WeAre#DementiaStrong](#) 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.





# 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 retaining 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.



## 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 – \$12,400 if they file as single or married filing separately; \$24,000 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





## 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 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.**

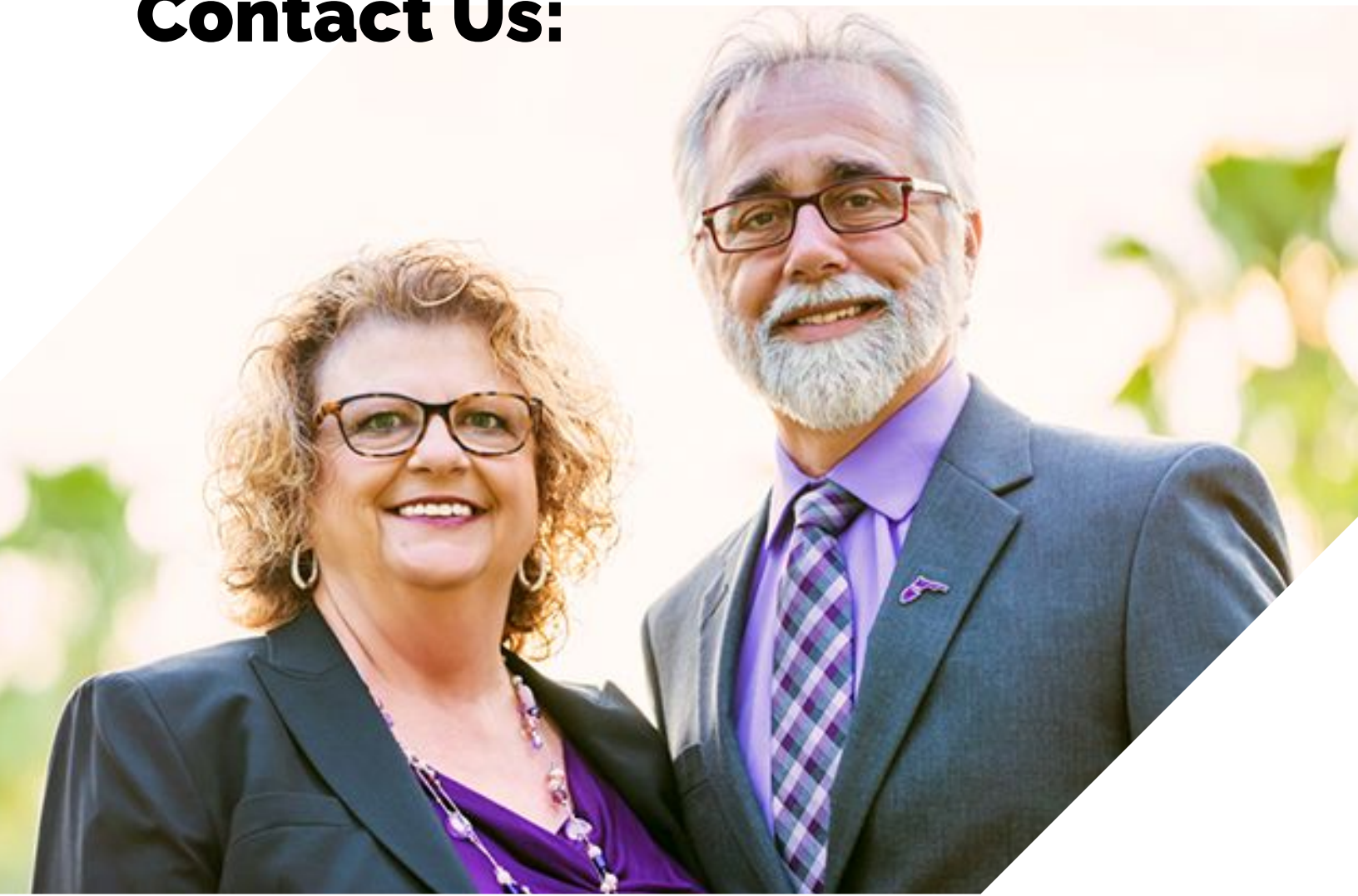
Sometimes aging at home is no longer an option. This is especially true in dementia diagnoses, as your loved one's memories and cognitive functions regress to require 24/7 expert care. This may involve a move to a memory care, assisted-living or nursing facility. It may also involve transitions to new 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.





# Contact Us:



***Reach out to us today!***

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