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Welcome to this issue of the Alzheimer's Awareness Guide, filled with informative content for anyone interested in learning more about Alzheimer's disease.

Advertisers in this Guide are featured sponsors of Walk to End Alzheimer's®, the signature fundraiser of the Alzheimer's Association. We thank these sponsors for helping us to increase awareness of this devastating disease and raise funds for care, support, and research.

Thank you for taking the time to learn more. We are pleased to bring this Guide to you and all those affected by Alzheimer's disease in the communities we serve.

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BUILDING BRIDGES TO A WORLD WITHOUT ALZHEIMER'S



Ben Biller Heart of America Chapter Board President

As an engineer, I am fascinated by connections — one of my specialties at Burns & McDonnell is working on complex bridges. How do we get people from here to there?

It's a question that fits in perfectly with the work I do as President of the Board of Directors for the Heart of America Chapter. The Alzheimer's Association works hard to make the "here and now"

better while always looking ahead toward a world without Alzheimer's. We believe the first survivor of Alzheimer's disease is out there.

How do we get there? By moving forward, together.

We are all impacted by this disease in one way or another; it's hard to find anyone who hasn't been touched by Alzheimer's. The Board and I are dedicated to educating the community at large about ways we can better address issues surrounding Alzheimer's. The stories in this Awareness Guide on creating dementia-friendly communities and partnering with community organizations support that effort.

A number of other stories — such as the articles on wandering and knowing when it's time to move a loved one — provide essential information for those of us personally involved in the battle. You'll also find stories about Alzheimer's heroes that both inform and inspire.

When you or someone you love is diagnosed with Alzheimer's

or any type of dementia (and you'll find a very helpful article on the various kinds of dementia in this Guide), it can feel like you're starting a journey you never wanted to go on — crossing a bridge into unknown territory. I understand. I've been there. I want you to know that you are not taking this journey alone. The Alzheimer's Association-Heart of America Chapter has a wealth of resources and support available and I encourage you to take advantage of them.

The infrastructure work I do as an engineer focuses on the future — just like the volunteer work I do as your Board President. As you learn more about the progress being made in the fight against Alzheimer's, I hope you share my faith in the future: The first survivor of Alzheimer's disease is out there, and we will get there together.

Benjamin J. Biller

Benjamin J. Biller

DEMENTIA

Dementia is an umbrella term for loss of memory and other mental abilities severe enough to interfere with daily life. Dementia is caused by physical changes in the brain.

ALZHEIMER'S DISEASE

is the most common type of dementia and accounts for an estimated 60 to 80 percent of cases. Early clinical symptoms include difficulty remembering names, events, and recent conversations; apathy; and depression. Later symptoms include impaired communication, disorientation, confusion, poor judgment, behavior changes and, ultimately, difficulty speaking, swallowing, and walking. To learn more about dementia, including symptoms and responses, visit alz.org.

Other kinds of dementia include:

Vascular dementia Dementia with Lewy bodies (DLB) Mixed dementia Parkinson's disease Frontotemporal dementia Creutzfeldt-Jakob disease Normal pressure hydrocephalus Huntington's disease Wernicke-Korsakoff Syndrome

Frequently Asked Questions

How is Alzheimer's diagnosed?

There is no single test that can show whether a person has Alzheimer's. While physicians can almost always determine if a person has dementia, it may be difficult to determine the exact cause. Diagnosing Alzheimer's requires careful medical evaluation, including:

- A thorough medical history.
- Mental status testing.
- A physical and neurological exam.
- Tests (such as blood tests and brain imaging) to rule out other causes of dementia-like symptoms.

Who gets Alzheimer's?

Today, 5.5 million Americans are living with Alzheimer's disease. including as many as 640,000 under the age of 65 (early-onset Alzheimer's). By 2050, up to 16 million will have the disease. Almost two-thirds of Americans with Alzheimer's are women. A family history of Alzheimer's is not necessary for an individual to develop the disease. However, individuals who have a parent, brother, or sister with Alzheimer's are more likely to develop the disease than those who do not have a first-degree relative with Alzheimer's.

Is there treatment available?

While there is currently no cure for Alzheimer's, drug and non-drug treatments may help with both cognitive and behavioral symptoms of the disease.

Ultimately, the path to effective new treatments is through clinical trials. Find out more about participating in a clinical trial through the Alzheimer's Association TrialMatch® service, a free tool to assist people with Alzheimer's, their caregivers, families, and physicians in locating trials based on personal criteria and location. See article on page 13.

What are the risk factors?

The most important risk factors are ones that we cannot change: age, family history, and heredity. However, evidence suggests there may be other factors that we can influence:

- Healthy aging: keeping your brain, as well as your body, fit by paying attention to the heart-head connection (page 33).
- Protecting your brain and avoiding head trauma by buckling your seat belt, wearing your helmet when playing sports, and "fall-proofing" your home.

Everyone with Alzheimer's disease or another dementia is at risk for wandering; six in ten people with dementia will wander at least once. This isn't surprising — people with Alzheimer's disease often lose their ability to recognize familiar places. However, wandering can be dangerous, even life-threatening.

Wandering can leave a person exposed to extreme temperatures, without food or water for hours or sometimes days, and at serious risk of injury. It is estimated that 20 percent of wanderers who are not found within 24 hours do not survive.

Caregivers who believe that their loved one will never wander are ignoring the facts. If your loved one can move, he or she can, and probably will, wander. There are preventive measures all caregivers can take. Here are just a few:

- Allow and plan for safe wandering. Wandering can be a natural way for those with dementia to disperse negative energy, such as anger and anxiety. Create pathways for walking around the house, and a safe route to walk outdoors.
- Monitor exits. Install little bells on top of doors to alert you when the doors are opened. Install a lock toward the bottom of the exit door and paint it the same color as the door. For those in advanced stages, you can put a mirror

or a STOP sign on the door. Don't ever lock a person with dementia in a home, unless there is someone, who is not also suffering from dementia, there with him or her. In case of emergency, first responders must be able to have access to the house.

• Provide activities. Too little activity can cause boredom and the individual with dementia will simply leave in search of something to do. On the other hand, too much activity can be overwhelming and may create a need to leave. Keep your loved one involved in activities that are appropriate for his or her cognitive abilities, such as gardening, sorting objects, or folding clothes. Consider enrolling him or her in an adult daycare program that provides dementia-friendly activities.

Signs of potential wandering include individuals who return later than usual from a regular walk, talk about fulfilling former obligations (such as going to work), ask the whereabouts of past friends and family, and desire to "go home" even when they are at home. If your loved one does or expresses any of these things, please consider preventive measures (additional options are explained at the right) or ask your physician for a referral.

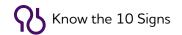
Solutions are emerging that address wandering to help keep your loved one safe and secure. A few options are explained below:

MedicAlert® + Alzheimer's
Association Safe Return®. Jewelry
is worn that has important medical
information engraved on it saying
either the person wearing it
has dementia or that they are
a caregiver for someone with
dementia. A 24-hour hotline is
accessible to law enforcement as
needed.

GPS Shoe or SmartSole. If having a loved one wear jewelry is worrisome to you, the GPS Shoe or SmartSole may be your solution. You can track your loved one's location through any smartphone, tablet, or web browser, and set up text and e-mail alerts if your loved one leaves or enters defined areas on a map.

PocketFinder. Their slogan, "If you love it, locate it," sums up the goal of this device. It is designed to be the smallest tracker on the market. The PocketFinder has a battery life up to one week and allows caregivers to track wearers through a user-friendly app on their smartphones.

For more information about wandering and preventive measures, please log on to alz.org.



10 Warning Signs of Alzheimer's Disease





1 Memory loss that disrupts daily life

Forgetting recently learned information, important dates, or events; asking for the same information over and over. Typical age-related change? Sometimes forgetting names or appointments, but remembering them later.

Challenges in planning or solving problems

Difficulty concentrating, working with numbers, and needing much longer to do things than you did before. Typical age-related change? Making occasional errors when balancing a checkbook.

3 Difficulty completing familiar tasks

Difficulty driving to familiar locations, remembering the rules to a familiar game. Typical age-related change? Occasionally needing help to use the setting on a microwave or record a television show.

4 Confusion with time or place

Trouble understanding something if it is not happening immediately, forgetting where you are or how you got there. Typical age-related change? Getting confused about the day of the week, but figuring it out later.

Trouble understanding visual images and spatial relationships

Difficulty reading, judging distance, and determining color or contrast, which may cause issues with driving a car. **Typical age-related change?** Vision changes related to cataracts or other eye-aging condition.

New problems with words in speaking or writing

Trouble following or joining a conversation; stopping in the middle of conversation; struggling with vocabulary and finding the right word. Typical age-related change? Sometimes having trouble finding the right word.

7 Misplacing things and losing the ability to retrace steps

Putting things in unusual places or losing things and not being able to retrace steps to find them; accusing others of stealing. Typical age-related change? Misplacing things from time to time and retracing steps to find them.

8 Decreased or poor judgment

Giving large amounts of money to inappropriate causes (telemarketers) and paying less attention to grooming or hygiene. Typical age-related change? Making a bad decision once in a while.

9 Withdrawal from work or social activities

Removal from hobbies, social activities, work projects, or sports. Typical age-related change? Sometimes feeling weary of work, family, and social obligations, but re-engaging after a break from those situations.

10 Changes in mood and personality

Becoming confused, suspicious, depressed, fearful, or anxious; becoming easily upset at home or work.

Typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

If you or anyone you know experiences any of these warning signs, please consult your doctor.

For more information, call 800.272.3900 or visit alz.org/10signs

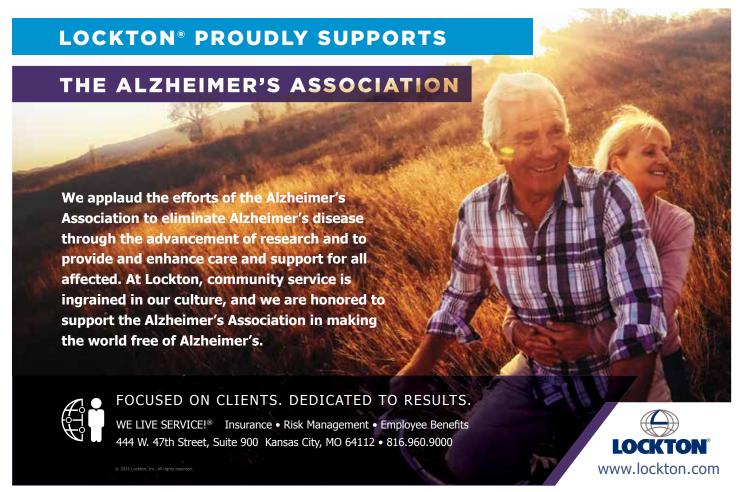


This photograph above of the magnificent Flint Hills adorns the board room of our office. It was taken by a client, Dr. Herman Solomon, of Wichita, Kansas. He was known as Buzz to all his friends. Sadly, Buzz passed away several years ago from complications due to Alzheimer's.

Like everyone else, we have been touched by the loss of a dear friend to this devastating disease. We are proud to walk in support of the Alzheimer's Association's goal to rid the world of this disease and keep friends like Buzz Alzheimer's-free.



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My Lifesong Document It is our priority to understand your loved one's history and the things that are important to them in order to greatly

the things that are important to them in order to greatly increase the quality of caregiving tasks and make daily interactions with them more meaningful.



As your loved one participates in an increased number of meaningful and purposeful activities throughout the day, they will experience enhanced daytime engagement, better nighttime sleep patterns and improved overall behaviors.

Setting

Our community is composed of a dedicated and intimate setting, resident safety and security, specialized dementia training for caregivers, visual and verbal communication techniques and validation therapy.



The number of Americans surviving into their 80s, 90s, and beyond is expected to grow dramatically due to medical advances, as well as social and environmental conditions. Additionally, a large segment of the American population — the baby boom generation — has begun to reach age 65 and older, ages when the risk for Alzheimer's and other dementias is elevated. By 2050, the number of people age 65 and older with Alzheimer's may nearly triple, barring the development of medical breakthroughs to prevent or cure Alzheimer's disease.

When these statistics are considered, it is highly possible that you or someone in your family will be affected by Alzheimer's disease. Learning as much as you can about Alzheimer's now is the first step toward empowering you and your family to take control and make decisions that will benefit you in your future.

It is normal to be hesitant or resistant to learning about a disease that may or may not affect you right away, but there are definitely benefits in doing so. Knowledge is power. Here are a few facts about Alzheimer's that everyone should know, whether you are affected by it today or not.

Caregiving can become anyone's reality. More than 15 million caregivers, friends, and family members experience the Alzheimer's crisis today in the United States. Recognizing this immense need for help and support, the Alzheimer's Association is available through a free 24/7 information and support line (800.272.3900) and online for caregiving consult.

Denial is a barrier to early Alzheimer's detection. Denial can be common with Alzheimer's, especially when early symptoms are relatively subtle. But early detection matters physically, emotionally, and financially — not only to the person diagnosed, but also to those around them. It allows better access to quality medical care and support services, and provides the opportunity for individuals with Alzheimer's to participate in decisions about their care. Knowing the diagnosis early also enables the person with Alzheimer's the option to participate in clinical trials. See article on page 13.

Alzheimer's is a fatal disease.

Everyone has those moments of "Why did I walk into this room?" or "Where did I put my cell phone?" However, it is important to decipher the difference between normal aging experiences and those of Alzheimer's. Symptoms of dementia usually develop slowly and worsen over time, becoming severe enough to interfere with daily tasks and ultimately robbing the body of its ability to function. Alzheimer's disease is the sixth-leading cause of death in the United States, and is the only cause of death among the top 10 that cannot be prevented, cured, or even slowed.

You can reduce your risk.

Although there is no cure for Alzheimer's, researchers encourage a consistently healthy diet, scheduled social interaction, brain healthy choices, and regular physical exercise to reduce the risks of cognitive decline.

There is an abundance of information about Alzheimer's available at alz.org. You are encouraged to learn as much as you can, so that if, or when, this disease touches your family, you are ready.

What is a Dementia-friendly Community?

The Alzheimer's Association strives every day to ensure that individuals with dementia feel valued and supported in their daily lives. Dementia-friendly communities embrace these efforts by helping people with dementia feel included and supported in the places they work, live, and play. Each of us has a role in promoting inclusion and reducing stigma, whether in our neighborhoods, professional groups, religious organizations, or businesses. In dementia-friendly communities, people are educated about dementia and know that a person with dementia may experience the world differently.

What can you do to help your community be dementia-friendly?

• Educate yourself about dementia in general — the Alzheimer's Association is a great place to start.

- Request dementia education at your place of business or faith community to help colleagues understand Alzheimer's and learn how to offer appropriate assistance.
- Urge city staff whether at libraries or community centers — to become educated about Alzheimer's and be able to communicate effectively with a person with dementia.
- Encourage others in the community, such as grocery clerks, bank tellers and bus drivers, to receive dementia education specific to their job.

Communities can easily address becoming dementia-friendly in many ways. The image below explains some of these initiatives. For more information, please contact Michelle Niedens at mniedens@alz.org or 913.831.3888.

Dementia-friendly communities might include these features:



A Dementia-friendly community can become a reality.

WHAT IF...

Neighborhoods had volunteers that would walk with their neighbors or walk their dog for them?

Convenience stores had training to recognize someone who might be lost or is wandering?

Technology-based stores, like Best Buy and others, had annual displays of technology products that can support memory and safety?

Doctor's offices had "dementia-friendly" time slots to see patients with limited wait times?

Grocery stores had a "slow down" line or designated times where shopping support is available?

Restaurants had finger-food menus in the middle of the afternoon?

Banks collaborated to provide regular education events on prevention of financial exploitation?

Pharmacies provided support information any time an Alzheimer's drug was prescribed?

Law enforcement went beyond Silver Alerts and had standardized protocol for individuals who wander?

Airports had dementia-friendly passenger screening lines and bathrooms?

Theatres showed old movies with the "dementia-friendly" icon on the website?

Hotels had incontinence products available for their guests?

Faith communities offered communion during the week for those families with loved ones in stages where sitting in church is difficult?

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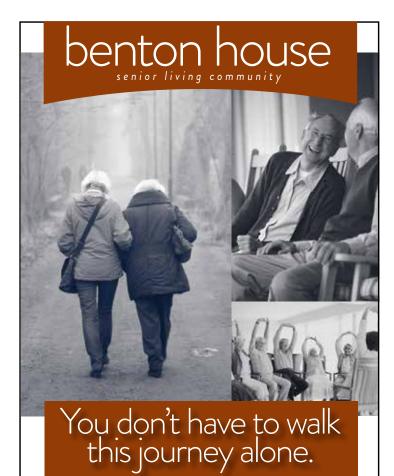
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Don't just hope for a cure. HELP US FIND ONE. trialmatch®

Without clinical trials, there can be no better treatments, no prevention, and no cure for Alzheimer's disease. Scientists work constantly to find better ways to treat diseases, but improved treatments can never become a reality without testing in clinical trials with human volunteers.

What is TrialMatch®?

Alzheimer's Association TrialMatch® is a free, easy-to-use clinical studies matching service.

Who can Sign up for TrialMatch®?

Everyone interested in advancing Alzheimer's research can use this matching service, including:

- Individuals with dementia
- Caregivers
- Healthy volunteers without dementia

250+ Reasons for Hope

Alzheimer's Association TrialMatch® provides access to more than 250 promising pharmacological (drug) and non-pharmacological (non-drug) clinical studies being conducted at sites across the country and online. These trials include:

- Treatment trials test new treatments or combinations of treatments.
- Diagnostic studies find new tests or procedures for diagnosing a disease or condition.
- Prevention trials investigate ways to prevent the onset of diseases.
- Quality of life studies explore different ways to improve quality of life for individuals who have a chronic illness, their caregivers and family members.
- Online studies are web-based and conducted entirely online.

New treatments for Alzheimer's disease require clinical trials, and many more participants are needed. Today, tens of thousands of volunteers, both with and without Alzheimer's, are urgently needed to participate.

Wonder if there's a clinical trial open to you or a loved one?

Finding potential studies through TrialMatch® is easy. Here's how TrialMatch® works:

1. Create a free account.

To get started, contact us in the way that works best for you:

- Visit alz.org/TrialMatch.
- Call 800.272.3900 (option 1).
- Email TrialMatch@alz.org.

2. Create your user profile.

Complete a brief questionnaire to create a profile.

3. Fill out a match questionnaire.

Answer a few questions. Your profile information is kept completely confidential. The Alzheimer's Association compares your unique profile to our comprehensive, continually updated clinical study database.

4. Review your study matches.

You will receive information about studies that might be a good fit based on your preferences, location, and personal characteristics. You can decide if you want to contact any of the studies for more information. You're under no obligation to participate.

Living With Alzheimer's



When Andrea Walters Saccone was starring as Sandy in the Broadway production of "Grease," she didn't think twice about memorizing lines, choreography, and stage directions — it was all in a day's work for this talented and successful actress. She never imagined the dramatic twist ahead in her own life story: At the age of 57, Andrea was diagnosed with Alzheimer's disease.

Andrea and her husband Mike were living in Los Angeles when Andrea went to the doctor seeking an answer to her forgetfulness. She was aware of it, but she was denying what it might be. She contributed her memory loss to symptoms of menopause. But, a second opinion at UCLA confirmed the Alzheimer's diagnosis.

One day Mike found Andrea just sitting in her car in the garage. She had been there for several minutes and when Mike went to check on her he asked her what she was doing and she said, "I can't remember how to turn off the lights in the car." Andrea had driven that car for eight years.

Andrea continued working in children's theatre until one day she couldn't remember her lines. "This

was a pivotal point for Andrea and brought her way down emotionally," says Mike. The stage curtain began to unravel for the Saccones.

With encouragement from his children, Mike began attending a support group. "It was interesting to hear the stories of others in this situation. Some stories were similar, others different, some sad, and some funny, but those of us in the group became like family, always being there for each other," Mike says. As Andrea's disease progressed, Mike decided to move them back to Kansas City to be near family. Mike retired from his stand-up comic profession to be Andrea's full-time caregiver. "It is challenging, but it is so rewarding to give someone you love, who is in a broken situation, a glimmer of happiness," Mike says. "Music lights Andrea up. We put on a Michael Bublé record and we sing, we dance, and I cry."

While Mike believes in taking each day as it comes, he admits there are often unforeseen bumps in the road — like the first morning when Andrea did not recognize herself in the mirror. "She kept

asking me who the woman in the mirror was," Mike says. "It frightened her, but over a couple of weeks she actually made friends with the woman in the mirror. Now, she will wave to the person in the mirror. She even introduced the woman in the mirror to me, her husband, and told her, 'He's a wonderful man.' I'm lucky," he chuckles. "She could have said a lot worse."

A proactive caregiver, Mike takes Andrea to adult daycare a few times a week, giving him a respite from the constant responsibilities and a little time out of the house. His daughter Sophia lives with them; he welcomes other help from family and friends; and encourages all caregivers to say "Yes" when any assistance is offered — even the smallest gesture.

Mike says there is only one thing to do, and that is to move forward. "Unfortunately Alzheimer's does take over, but when you are the caregiver, you keep loving them and keep being patient in very difficult situations — that's what we do."

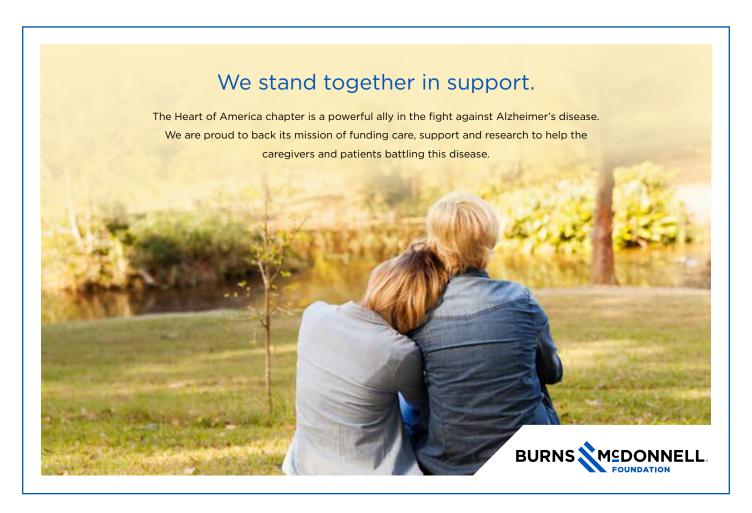
Andrea Walters Saccone's career has included starring roles in film, television, and theatre. She is most noted for her role as "Sandy" in the Broadway production of Grease.





"It is challenging, but it is so rewarding to give someone you love, who is in a broken situation, a glimmer of happiness."

Mike Saccone









Walking for a Cure

Husch Blackwell law firm is proud to sponsor the Walk to End Alzheimer's. We support the Alzheimer's Association in its efforts to raise awareness and funds to fight the disease.

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Partnering With the Community

When you look at our name
— Alzheimer's Association — it's
easy to focus on the first word. The
second word matters too. We're
encouraging people throughout
the community to associate with
the population we serve, and we're
providing the information needed to
make those interactions as positive
as possible. Groups we partner with,
mentor, and train include:

HIGH SCHOOL/COLLEGE STUDENTS: Reaching students interested in health-related fields can help eliminate stigmas around dementia, and may even inspire these students to go into a specialty area that addresses dementia disorders. Students are regularly involved in our Memory Room and Music and Memory projects, learning first-hand about an individual's life prior to diagnosis and painting a mural in the resident's room or creating a playlist on an iPod to prompt tender memories. The Heart of America Chapter also hosts the PAIRS Program, connecting an individual with early onset with a medical student for 10 months. Our experience shows that 10 months is often just the start; many "pairs" have maintained their friendships long after the program is over.

LAW ENFORCEMENT: Crisis Intervention Training (CIT) began in Kansas City in 1999 to help law enforcement personnel deal with crises that may arise on an actual call. Along with Alzheimer's/dementia training, CIT educates first responders on encountering autism, and mental health and psychological issues. The training is voluntary, but Sergeant Sean Hess,

Crisis Intervention Team, Kansas City Missouri Police Department, says, "Officers tell me that it is some of the best training they have ever received." CIT is offered four times a year in the Kansas City area.

SEMINARY/CLERGY: It isn't unusual for the family of someone with dementia to say that their place of worship "abandoned us." If that occurs, it typically isn't due to a lack of caring at the place of worship, but rather a lack of information. Workshops provided by the Alzheimer's Association assist clergy and lay leadership with ideas on how to keep those with dementia connected to their congregations. The Alzheimer's Association also provides information to help clergy and staff know what to look for and how to assess these situations.

FINANCIAL ADVISORS: Clients who work with financial advisors are often in their 50s and older, making them the target demographic for Alzheimer's disease. Staff from the Alzheimer's Association can help financial advisors understand and recognize dementia warning signs and how to best address the

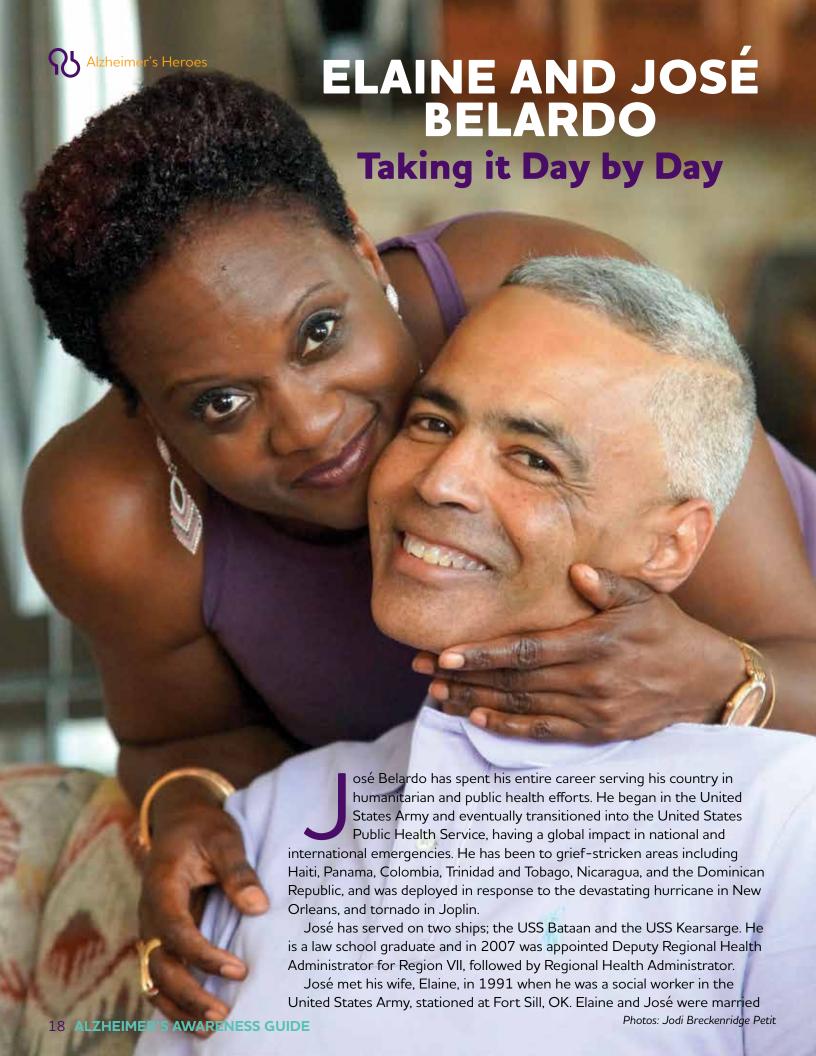
financial challenges someone with dementia may face.

HUMAN RESOURCES:

Although we generally associate dementia with older employees, symptoms can appear in younger employees as well. Estimates indicate that more than a halfmillion people in the United States have early-onset dementia. In addition, six in ten caregivers of people with Alzheimer's were employed in the past year while providing care to family members. The Alzheimer's Association helps employers recognize, and appropriately respond to, dementia symptoms that an employee might exhibit as well as support their employees who are serving as caregivers.

If you have a group that would benefit from training — even if you don't see it listed here — let us know. Our Alzheimer's Association staff offers training for many different organizations, and can tailor the presentation to your needs. For more information, contact Michelle Niedens, Director of Education and Programs, at 913.831.3888 or mniedens@alz.org.





in 1993 and they have one son and two daughters.

José has always been a romantic, and when he forgot their 20-year anniversary, but remembered it later, he attributed that to stress and working too hard. But Elaine wasn't so sure. "José never misses," she says. The 21st anniversary came and went. José never acknowledged it.

In 2015, José was deployed to Liberia to close out the Ebola mission. "When he came back. José was not the same. He was withdrawn, in a deep sadness, he wasn't engaged," Elaine says. José repeatedly told Elaine how difficult this particular deployment was, so family attributed the change in personality to work, stress, and exhaustion. Just to be sure, José began the process for a temporary medical retirement and went through a battery of tests. Those tests resulted in a diagnosis of Mild Cognitive Impairment with advice from a team of doctors to "watch him for a year."

That year was telling. Things happened that were not consistent with who José was. During a road trip to Maryland, José became very confused. Elaine immediately called the Public Health Service and voiced her concern about him. That is when José's colleagues confided in her that they had noticed things did not seem right with José. Elaine was surprised that no one had reached out to her, but she understood. "I greatly appreciate that his colleagues exercised caution in not making a lay diagnosis of his symptoms which could be attributed to varied factors." Because they were already in Maryland, José was able to sign up for Executive Medicine which allowed him to be at Walter Reed National Military Medical Center for an extensive three-month inpatient copious workup. This detailed

analysis, compared to the tests from the prior year, provided the data necessary to diagnose José with Alzheimer's disease.

Elaine's medical background led her to believe that maybe something else was causing these symptoms. But José's doctor said to Elaine in no uncertain terms, "Elaine, you are going to have to get familiar with this disease."

Elaine agreed to educate herself about Alzheimer's, but first she had a plan. She visited the Deputy Surgeon General and said, "The emotion associated with an event lasts longer than anything else. Every time we have sat in this conference room, José has only heard news that seals his fate in a negative way. I would like to change the trajectory of that — I want a full flag-officer retirement ceremony for José before we head back to Kansas." Family flew in and Rear Admiral José H. Belardo III, the professional who gave 26 years to the Nation, was gloriously honored.

To assist with the transition home, the Army social worker connected Elaine and José to the Alzheimer's Association – Heart of America Chapter. José is now a regular attendee at Our Place, a day program for individuals with early onset Alzheimer's, and they both attend a support group. Elaine looks at Alzheimer's disease as a ladder on which one can only descend. She, with help from her family, can steady José on whichever rung he is on as long as every rung includes dignity, unconditional love, grace upon grace, courage, laughter, the Golden Rule, and hope.

José and Elaine each have a sign that adorns their living room. Elaine's says, "Taking it day by day." José's says, "Today is a good day." They believe that reaching out to the Alzheimer's Association has helped them become and stay centered. "The staff never looks at anyone with the disease without hope — the Alzheimer's Association has been a gift to us."

José agrees that Elaine is everyone's dream advocate. Elaine says, "José has a beautiful mind, and I didn't want him written off up front. He is kind, good, patient, and his character is intact. As a Public Health Service officer. José has been an advocate for marginalized populations. My job is to continue what he started."

"In order to rally, you need to have two things: authentic hope and proactive courage."

ELAINE BELARDO



José H. Belardo III surrounded by his wife Elaine, daughters Lauren and Morgan, and son, Jared



YOUR VOICE MATTERS

Alzheimer's remains one of the most critical public health issues in America, and conquering this disease is as much a matter of public policy as scientific discovery. Your voice, your story, and your passion for the cause can positively influence policy decisions, from local priorities to national funding. How do you begin? Start here! Find the activity that best matches your interests, talents, and schedule.

Advocate for the cause

Alzheimer's advocates improve the quality of care and quality of life for people with Alzheimer's disease and their families. As an advocate, you will:

- —Receive regular updates about current legislative and public policy issues
- —Urge public officials and policy makers to support critical Alzheimer's legislation and policy changes.

- —Communicate with these officials via petitions, emails, phone calls, and social media.
- Participate in local advocacy and policy-related events.
- **Become an Ambassador**

The Alzheimer's Ambassador Program helps the Association achieve federal policy priorities by empowering volunteers to engage with elected officials. With support from National and Chapter staff, ambassadors serve as a main point of indistrict contact with a targeted member of Congress; they establish trusted relationships that drive progress.

Share your opinion

Write a letter to the editor, and mention your congressmen by name. These letters encourage legislators to support our policy priorities by exposing critical issues to

- their constituents and helping us gain consensus. To review current talking points, contact the Heart of America Chapter.
- Attend the 2018 Advocacy Forum (April 29 - May 1)

The Alzheimer's Association Advocacy Forum is the nation's premier Alzheimer's disease advocacy event. Join more than 1,000 of your fellow advocates in Washington, D.C., as we speak out for research, care, and support services. This forum beautifully demonstrates how our voices matter: Thanks to our advocates' support, we have had two consecutive years of historic funding increases at the National Institutes of Health for Alzheimer's disease research funding.

When we raise our voices, we raise our hopes. Thanks to all our advocates!

10 WAYS TO LOVE YOUR BRAIN



START NOW. It's never too late or too early to incorporate healthy habits.



BREAK A SWEAT

Engage in regular cocardiovascular exercise that elevates heart rate and increases blood flow. Studies have found that physical activity reduces risk of cognitive decline.



HIT THE BOOKS

Formal education will help reduce risk of cognitive decline and dementia. Take a class at a local college, community center or online.



BUTT OUT

Smoking increases risk of cognitive decline. Quitting smoking can reduce risk to levels comparable to those who have not smoked.



FOLLOW YOUR HEART

Risk factors for cardiovascular disease and stroke – obesity, high blood pressure and diabetes – negatively impact your cognitive health.



STUMP YOURSELF

Challenge your mind. Build a piece of furniture. Play games of strategy, like bridge.



HEADS UP!

Brain injury can raise risk of cognitive decline and dementia.

Wear a seat belt and use a helmet when playing contact sports or riding a bike.

FUEL

UP RIGHT

Eat a balanced diet that is

higher in vegetables and fruit

to help reduce the risk of

cognitive decline.



BUDDY UP

Staying socially engaged may support brain health. Find ways to be part of your local community or share activities with friends and family.



Some studies link depression with cognitive decline, so seek treatment if you have depression, anxiety or stress.

CATCH SOME ZZZ'S

Not getting enough sleep may result in problems with memory and thinking.





ZZ

Visit alz.org/10ways to learn more.

alzheimer's Ω association

potlight on RESEARC



Maria C. Carrillo, Ph.D., Chief Science Officer Medical & Scientific Relations, Alzheimer's Association

The Alzheimer's Association leads the worldwide effort to advance dementia research. Through our International Research Grant Program (IRGP), the Association has invested more than \$385 million in over 2,500 investigations since 1982, making us the world's largest nonprofit funder of Alzheimer's research. The Association also convenes the world's largest gathering of dementia researchers at its annual Alzheimer's Association

During AAIC 2017 this July, the Association announced the launch of a \$20 million clinical trial to test whether changes in a combination of lifestyle

International Conference®

(AAIC®).

factors can prevent cognitive decline and dementia. The launch of the clinical trial follows a 2015 Association evaluation of individual lifestyle interventions that found strong evidence that regular physical activity and management of cardiovascular risk factors (diabetes, obesity, smoking and hypertension) reduce the risk of cognitive decline and may reduce the risk of dementia, and that a healthy diet and lifelong learning/cognitive training may also reduce the risk of cognitive decline.

With the aging of the global population — and the slow

progress of developing and testing drug treatments — prevention is pivotal in managing the inexorable rise in global cases of Alzheimer's and other dementias.

The new two-year, multi-domain lifestyle intervention will enroll 2,500 Americans age 60-79 who are at increased risk for cognitive decline but do not yet have symptoms. The study to PrOtect

66 We now can effectively prevent and treat heart disease with a combination of drugs and lifestyle. The same may also be true for Alzheimer's disease and other dementias in the not too distant future. Maria C. Carrillo, Ph.D.

> through a lifestyle INTErvention to Reduce risk (U.S. POINTER) will include physical exercise, nutritional counseling and modification, cognitive and social stimulation, and improved self-management of medical conditions. The success of the combination of lifestyle interventions will be evaluated based on change in a global measure of cognitive function focused on short-term memory, attention and concentration. Recruitment of study participants will begin in 2018.

U.S. POINTER builds upon a study in Finland (the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability, or FINGER Study) that found a combination of lifestyle interventions had a protective effect on cognitive function. In addition to U.S. POINTER, studies of multidomain lifestyle interventions are being conducted in Europe, Singapore and Australia. This collection of prevention studies

> ensures inclusion of people from a variety of geographical and cultural backgrounds, facilitates harmonization of research methods, and enables sharing of experiences and data for maximum global scientific impact.

Local Alzheimer's Association offices

nationwide will play a very important role in U.S. POINTER by participating in intervention delivery. In addition, the Association will develop national partnerships with communitybased organizations to deliver the exercise, nutrition, social and medical aspects of the intervention.

We now can effectively prevent and treat heart disease with a combination of drugs and lifestyle. The same is true with some cancers and with HIV/AIDS. The same may also be true for Alzheimer's disease and other dementias in the not too distant future.



Independent & Assisted Living

12100 Wornall Rd. Kansas City, MO 64145 (816) 298-9824

seniorstar.com/villaventura





Independent Living 6500 N. Cosby Ave. Kansas City, MO 64151 816.587.5700

Assisted Living & Memory Support 6460 N. Cosby Ave. Kansas City, MO 64151 816.587.5400

seniorstar.com/wexfordplace



Questions to ask... when researching senior living

- · How do you ensure residents live a purposeful lifestyle?
- · How does your programming reflect overall wellness?
- · What specific training do your associates receive?
- · What makes your community unique?

Experience the Senior Star difference. Join us for a FREE lunch!

Wexford Place Villa Ventura

816.587.5700 816.941.0525



The decision to search for professional senior care is one to be made with confidence. You want to be sure that you're making the right choice. This is your family, after all.

Homestead Assisted Living, a member of the Midwest Health family of communities, offers residents specialized, compassionate care. With nearly 40 years of senior living experience and more than 60 communities throughout the Midwest, you will rest easy knowing your loved one is welcomed, cared for and cherished.

Our Homestead team provides the best, results-driven service in Memory Care and we are proud to support the Alzheimer's Association in their fight to end Alzheimer's and other dementia-related diseases.



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HOMESTEAD OF LEAWOOD

HOMESTEAD OF LENEXA

HOMESTEAD OF OLATHE ASSISTED LIVING 751 N Somerset Ter • Olathe, KS 66062

HomesteadofOlathe.com • 913.829.4663



THE LONGEST DAY

alzheimer's 95 association

Do something you love on June 21, 2018

For individuals with Alzheimer's and their caregivers, every day is the longest day.

The Alzheimer's Association has created a fundraising event that both symbolizes the daily challenges of Alzheimer's and honors those who battle these challenges daily.

The Longest Day events will be celebrated on the summer solstice, the longest day of the year, Thursday, June 21, 2018. However, your Longest Day team can fundraise at any time prior to June 21.

- Choose an activity you love...
 bowling, softball, bridge, dancing, baking, etc.
 Choose a day to do the activity
- Choose a day to do the activity before or on June 21st
- Encourage friends to join your team
- Celebrate your fundraising efforts on June 21st

For more information alz.org/thelongestday



The Guilt that Accompanies Caregiving

Some of the most incredible, creative, and compassionate people in the world are caregivers — and they all find caregiving to be a challenge at times. It's not surprising. Caregiving can be overwhelming, and there's no "how to" manual that covers every situation.

If you're a caregiver, the journey ahead may seem daunting, a road full of potholes. You may feel the need to be a manager, supervisor, aide, chef, personal shopper, financial manager, housekeeper, transportation and recreation director, and — not least — personal companion. To make it more challenging, those expectations often go on top of an already full plate of professional and personal responsibilities.

At the Alzheimer's Association. we understand, and we are ready to help you navigate this journey. One of the first steps is accepting that feelings can run rampant when you're caring for a loved one. While these feelings are often neutral, there are times when negative emotions, like flood waters, erode the healthy emotions of caregiving. We forget the wonderful job we did yesterday or how far we have come on this journey and are thrown headlong into the land of guilt.

There are two kinds of quilt, good guilt and bad. Good guilt spurs us to look at what is happening, to observe our behavior and change it. Good guilt, like a gentle whisper, urges you to be the best you can be. Bad guilt, on the other hand, immobilizes you. It consumes your joy and robs you of happiness. Bad quilt has no basis,



no real foundation. It is the guilt you feel about situations that you can't help. For example, Fred was a great caregiver, faithfully caring for Nada for eight years. However, as Nada became incontinent and Fred's own body became frail, he could no longer pick her up or bathe her. He had to place her. He felt he had let Nada down, and his guilt — over something he couldn't control — was overpowering. Bad guilt, like that, comes with a number of pitfalls.

The Pitfalls of Guilt

- Fear: of failure, of not doing it right or worrying about what others will think:
- Resentment: that no one is helping, feeling abandoned, or being angered by a loved one's behavior, mean words. or stubbornness:
- Worry: wanting things to be perfect, living on the "what ifs" instead of what is:
- Loneliness: friends and family may not always be available, favorite activities may be skipped because you are too busy or have no one to stay with your loved one;
- Anger and defensiveness: "Why is this happening to me? I don't deserve this." unresolved relational issues.

Crawling Out of the Pit

- Understand and accept your emotions, normalize your feelings;
- Find and create a support system;
- Take care of you, make room for downtime, start a new hobby:
- Find adventures for you and your loved one to explore: visit Powell Gardens, Deanna Rose Children's Farmstead, museums, or other outings;
- Be good to yourself: it's okay to have fun, treat yourself to a movie or a walk;
- Be prepared: know what is important to you and your loved one, know your resources, availability of help, out-of-home placements, day programs;
- Draw on your spiritual or religious tradition and community.

To find the resilience and strength needed to combat bad quilt, remember the cardinal rule: Take care of yourself first. On this journey, grief is real, and society will not always recognize the many losses you and your loved one face. We do. If you ever need help, call the Alzheimer's Association. We're here for you.







Expanding Horizons

Our organization has been helping
Kansas City families experiencing the impact of
Alzheimer's and dementia for more than a century.
We began providing focused care for
cognitive impairment in the early 1950s,
and were among the first to dedicate a specialized
area for Alzheimer's and dementia in the mid-1980s.

In 2019, we will unite our generations of expertise with the next generation of care.

We're transforming our Overland Park campus with an expansion set to include a Household Model memory care neighborhood, an independent living apartment community and resort-style rehab center.

Discover what we have in store at: www.VillageShalom.org/Future





Houored to be woven into a million life stories over a hundred years.



At the Alzheimer's Association Walk to End Alzheimer's[®], people carry flowers representing their connection to Alzheimer's — a disease that currently has no cure. But what if one day there was a flower for Alzheimer's first survivor? What if there were millions of them?

Help make this happen.

WALK, DONATE, SPONSOR, OR VOLUNTEER.

TOGETHER, WE CAN END ALZHEIMER'S.



Register today to walk as an individual or form a Walk team!

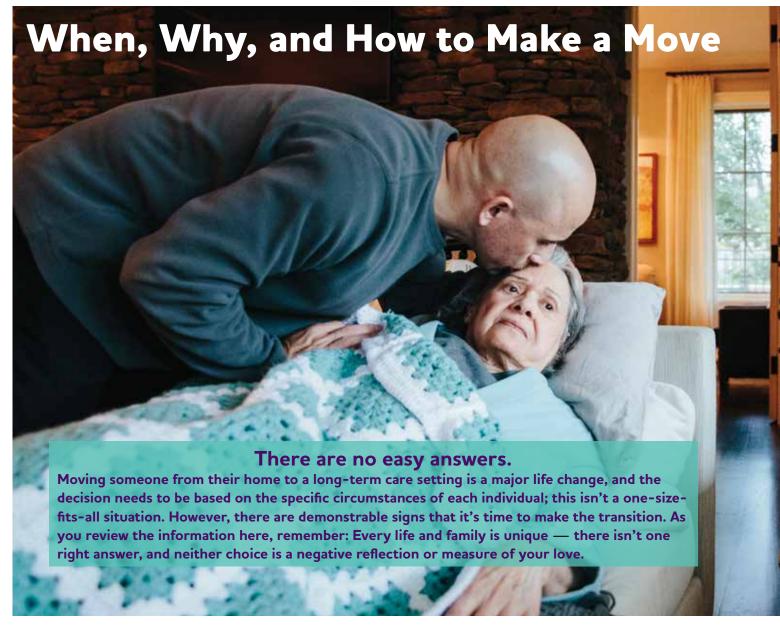
alz.org/walk

Your fundraising efforts make a significant difference in the lives of those with Alzheimer's!

For more information, please call 913.831.3888 or contact Scott Bradley • sbradley@alz.org







WHEN? When should I consider making this decision?

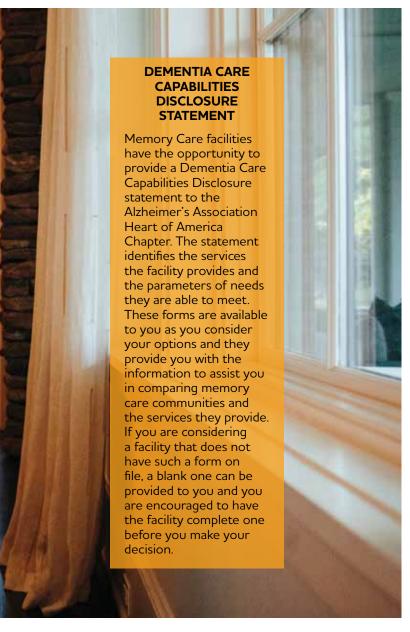
Is your loved one unable to weigh pros and cons as part of the decision-making process? When the disease progresses to the point where logic and reasoning are damaged, loved ones may not be able to come to a reasonable conclusion on their own. Determining what kind of help is needed and securing that help may have to come from others who understand their needs.

- Has the disease progression led to unsafe behaviors? Examples of unsafe behaviors might include wandering, dangerous use of kitchen appliances, or the inability to handle personal needs or medical care.
- Is the loved one's anxiety or paranoia increasing when alone, especially in the evening/night?

- As the disease progresses, individuals feel less confident. The loss of insight needed for daily decision-making may be accompanied by a rise in anxiety, distress, and paranoia as part of not fully understanding what to do.
- Are support services no longer available in the home, not practical, not therapeutic, or have been tried and are insufficient?

WHY? Why don't I feel comfortable making this decision?

 Remember: a move to a long-term care facility is not about giving up on someone. If a move is being considered, it means that there are concerns about remaining at home. Consider ways the move supports an improved quality of life for



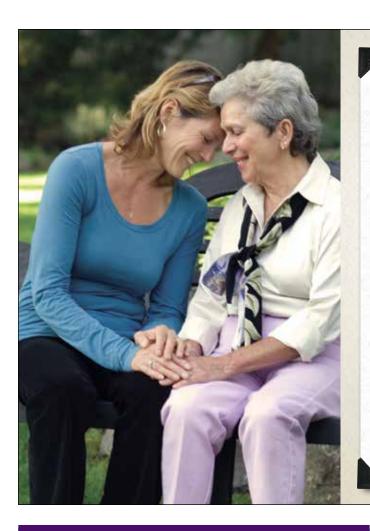
- your loved one, such as socialization, structured activities, and safety.
- While it's normal to have doubts, family members shouldn't express these doubts to the person with the disease. Instead, talk and listen to each other. Attend an Alzheimer's support group where others understand and have experienced similar challenges.

HOW? How can we best explain the move and ease the transition?

 Gain consensus. Try to involve all concerned family members in making the decision. Sometimes having an outside person, such as a counselor, Alzheimer's Association staff member, or other helping professional facilitate the meeting can help

- direct the discussion in a useful way.
- Keep it brief and simple. While telling your loved one too early can generate unnecessary anxiety, surprising them can also provoke anxiety and hostility. State simple facts such as, "It's not safe for you to live alone anymore. We've found a wonderful place for you." The best timing varies with each situation.
- Acknowledge feelings. If your loved one expresses sadness and/or anger about a move, simply responding, "I know this is hard for you," can help. Remind them they are loved and that you will be there for them wherever they live.
- Redirect. If the conversation seems to be circular, switch subjects, move to a different room, or begin another activity. Trying to convince is likely to escalate agitation.
- Pick a point person. Make a strategic decision regarding who introduces the move. If possible, select someone who doesn't provide the majority of the caregiving: an adult child who lives farther away, an in-law who does not regularly participate in direct care, or someone outside the family such as a physician or social worker.
- Plan the move for the earlier part of the day. On that day, the person with Alzheimer's should be otherwise engaged — perhaps having lunch or visiting at a family member or friend's home. Move the necessary items and have your loved one's room all set up when they arrive. Spend a bit of time in the room, then get the person engaged in an activity or meal. Leave while your loved one is involved with others.
- Watch for signs of depression: irritability, resistance, agitation, and/or anxiousness. If you see these or other symptoms of depression and other medical reasons have been ruled out, consider talking with the doctor about antidepressants. Antidepressants may take as long as two months for full benefit. It doesn't mean the person with the disease will need to remain on medication permanently.
- Send cards and notes often. Even though you are visiting regularly, cards can be looked at and re-read when you are not there. Reassurance is important.

When it comes to reassurance, please know that you are not in this alone. If you want to talk with someone about moving concerns, please call our 24-hour information and support line at 800.272.3900.



Memory care. Joys still to come.

Memory care assisted living is more than a secure place to live. It's a place where someone facing the challenges of dementia can thrive in mind, body and soul. A social environment. A compassionate, specially-trained staff. And services that fit your needs.

To learn more about our community in Olathe, call (913) 780-9916.







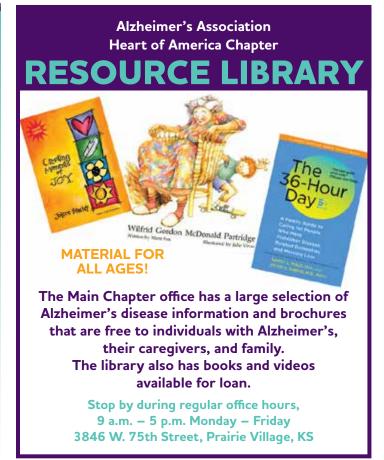


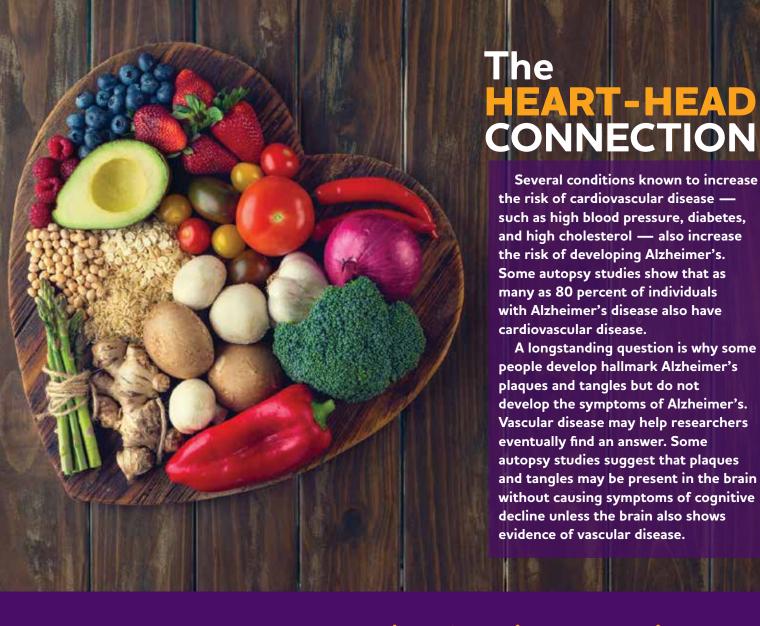
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Thank you to all of the sponsors of Walk to End Alzheimer's

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Interested in sponsoring Walk to End Alzheimer's? Contact Scott Bradley at 913.831.3888 or sbradley@alz.org.





How can you lower your risk of cardiovascular disease, and therefore lower your risk of Alzheimer's?

By eating a heart-healthy diet that benefits both your body and your brain. Heart-healthy eating includes limiting the intake of sugar and saturated fats and making sure to eat plenty of fruits, vegetables, and whole grains. No one diet is best. Two diets that have been studied and may be beneficial are the DASH (Dietary Approaches to Stop Hypertension) diet and the Mediterranean diet.

DASH

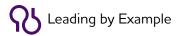
The Dietary Approaches to Stop Hypertension (DASH) diet aims to reduce blood pressure:

- Eat foods that are low in saturated fat, total fat, and cholesterol, and high in fruits, vegetables, and low-fat dairy.
- Consume whole grains, poultry, fish, and nuts.
- Decrease your intake of fats, red meats, sweets, sugared beverages, and sodium.

MEDITERRANEAN

The Mediterranean diet incorporates different principles of healthy eating that are typically found in the areas bordering the Mediterranean Sea:

- Focus on fruit, vegetables, nuts, and grains.
- Replace butter with healthy fats, like olive oil.
- Limit red meat.
- Use herbs to flavor food rather than salt.
- Eat fish and poultry at least twice a week.





TAKING ACTION WITH ALZHEIMER'S Empowering yourself and inspiring others

If you have Alzheimer's disease, you have a unique opportunity to contribute to the greater good by turning your experience into inspiration for others living with Alzheimer's, and those who love them. Your voice can make a difference. Your actions — big or small — can help raise awareness and empower others.

Where do you start? Consider:

• Becoming a Leader

As someone in the early stage of Alzheimer's, you can elevate your voice on a national platform through the National Early-Stage Advisory Group. These advisors serve as representatives of the Alzheimer's Association and models of early-stage leadership for the millions of individuals living with dementia. Nomination applications are accepted online. Please contact the Heart of America Chapter if interested.

Advocating for Change

You don't need a political background to become an advocate. By speaking to others about the issues you face every day, you can help to shape local, state, and federal laws. Advocates may sign petitions, write letters, make phone calls, or meet face-to-face with elected officials in support of the cause.

Advancing Research

Through clinical trials, researchers test new ways to detect, treat, and prevent Alzheimer's disease and dementia. Without clinical trials, there can be no better treatments, no prevention, and no cure. As a person living with the disease, you can have a tremendous impact on future generations by volunteering to be part of a clinical trial. To learn more about clinical trials, see the article on page 13.

Supporting the Cause

Your participation in fundraising efforts brings the mission of the Association to life. When you join us at the Alzheimer's Association Walk to End Alzheimer's® (see pages 28–29), or participate in the Alzheimer's Association The Longest Day® (see page 25), your presence makes a tremendous difference. You inspire others to work toward a shared goal: a world without Alzheimer's.

The first survivor of Alzheimer's disease is out there. But we won't get there without you. We won't get there without working together and joining forces to make a difference. Now is the time to take action. To learn more about the many ways you can participate in and support the fight to end Alzheimer's, go to alz.org/kansascity.



THANK YOU

MAKING THIS COMMUNITY A BETTER PLACE.

FROM YOUR FRIENDS AT



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2017 Alzheimer's Disease Facts and Figures



ALZHEIMER'S DISEASE IS THE 6TH LEADING CAUSE

OF DEATH IN THE UNITED STATES

MORE THAN 5 MILLION **AMERICANS ARE** LIVING WITH **ALZHEIMER'S BY 2050, THIS NUMBER COULD RISE AS HIGH AS 16 MILLION**

EVERY



SECONDS

someone in the **United States** develops the disease MORE THAN

15 MILLION AMERICANS

provide unpaid care for people with Alzheimer's or other dementias

2016

these caregivers provided an estimated **18.2 BILLION HOURS** of care valued at over \$230 BILLION

In 2017, Alzheimer's and other dementias will cost the nation \$259 billion

By 2050, these costs could rise as high as

\$1.1 TRILLION

35% of caregivers for people with Alzheimer's or another dementia report that their health has gotten worse due to care responsibilities, compared to

19% of caregivers for older people without dementia



with Alzheimer's or another dementia

IT KILLS MORE THAN

breast cancer and prostate cancer

COMBINED



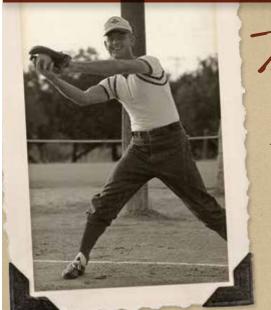
Since 2000, deaths from heart disease have decreased by 14%

while deaths from Alzheimer's disease have increased by 89%



alzheimer's 95 association

Memory Care Assisted Living Made Better. By Design.



Then Ernie's fielding skills were legendary.

Cow He's still an MVP.

Autumn Leaves' award-winning care for Alzheimer's disease and other forms of dementia builds upon each resident's life portrait. So whether he was a ball player, builder, or biologist, every aspect of his care and routine is personalized to his wants, needs, and life history – to promote cognition, serenity, and meaningful moments. Call today and learn why there's So Much More®...at Autumn Leaves.



LEE'S SUMMIT

3101 SW 3rd St. | Lee's Summit, MO 64081

OVERLAND PARK

12701 Pflumm Rd. | Overland Park, KS 66213 913-490-5035 License#106074

AutumnLeaves.com



Life at Cross Creek will be built on the five pillars of brain health designed to encourage residents to move, discover, relax, nourish and connect. To learn more, visit our information center

816.607.5700

3320 NE Wilshire Drive | Lee's Summit, Missouri 64064

www.crosscreekatleessummit.com

alzheimer's



Individual and Family Support

The Heart of America Chapter has resources and support services for those with memory loss, their families, and care partners. We are here to help you 24 hours a day, seven days a week.

- Family Connections Program: Individualized care consultations in your home or our office
- A library of books, brochures, and videos available for loan
- Support Groups: Meet regularly throughout the area for peer support and to exchange information
- Minds in Motion: Social and engaging activities for individuals with dementia
- Memories in the Making[©]: Individuals with Alzheimer's express themselves creatively through watercolor art classes

Education and Training

We offer regularly scheduled classes and workshops for individuals with memory loss, their care partners, and health professionals.

- Family Series
- Understanding Alzheimer's Disease
- Early-onset Alzheimer's
- Helping Children Understand Alzheimer's
- Professional and Caregiver Conferences
- Building Effective Skills Training
- For a full listing of available educational programs, log on to alz.org/kansascity or call the Main Chapter office at 913.831.3888

Awareness and Public Policy

The Heart of America Chapter staff and volunteers work to raise awareness of, and advocate for, the needs and rights of people with dementia.

- Action Alerts: Timely electronic updates on policies related to dementia
- Weekly e-news with national and local information
- Early-stage blog
- Chapter website and social media interaction
- Walk to End Alzheimer's
- Grassroots legislative efforts
- Speakers Bureau: Chapter representatives speaking out on dementia issues at a variety of community venues







association

Heart of America Chapter

No one should go through this alone.

For more information on any of our Chapter services, please consult our website at:

alz.org/kansascity

or call one of our offices listed at the bottom of this page.

Alzheimer's is relentless. SO ARE ME

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's[®].

Main Chapter Office

3846 W. 75th Street Prairie Village, KS 66208 913.831.3888

Northeast Kansas Regional Office

3625 SW 29th St., Suite 102 Topeka, KS 66614 785.271.1844

Northwest Missouri Regional Office

927 Faraon St. Joseph, MO 64501 816.364.4467

Available 24/7 at 800.272.3900

All Chapter services are offered free of charge to individuals with Alzheimer's and their caregivers.



Alzheimer's is all around us.

The power to stop it is within us.

alzheimer's % association

alz.org/kansascity