



alzheimer's Ω association

Miami Valley Chapter

Dementia Resource Guide







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WELCOME

Dear Friend.

Every day at the Alzheimer's Association Miami Valley Chapter, we give hope.

Through education and support, we teach life-changing skills to caregivers to improve how they love and care for their family member with this disease. For those with Alzheimer's or dementia, we provide the tools to transform a diagnosis of defeat to a desire to live their best life possible.

This Dementia Resource Guide is designed to provide knowledge about Alzheimer's or dementia. Whether you are a caregiver or someone with the disease, the reality is that you are not alone because millions of people are experiencing this journey. We hope you find this guide educational.

The Importance of Getting Diagnosed

Alzheimer's is a fatal and progressive brain disease that cannot be prevented, cured or even slowed. In the Miami Valley, 30,000 people live with the disease and 90,000 family and friends act as caregivers.

But we estimate there are thousands of individuals in the Miami Valley experiencing symptoms who have never been diagnosed. If you have a concern about your memory or the cognitive function of a loved one, please see a doctor. Early diagnosis allows you and your loved one to plan for the future. Also, early and accurate diagnosis are critical to ensure that people receive high quality care. If you need support or resources, call our 24/7 Helpline at 800.272.3900.

Driving Transformational Change

This is an exciting time in the field of Alzheimer's research and because of research advancements. scientists are getting closer to earlier detection and strategies that reduce one's risk for the disease.

In Ohio, the Association is working closely with the state legislature to develop Ohio's first state plan to improve services and support for people living with Alzheimer's and their families. In addition, the Miami Valley Chapter is piloting a dementia care practice coaching initiative for the nation. We are working with assisted living facilities to help improve care for their dementia residents. We are able to provide that service for free because of some very generous donors.

We are doing all we can to live up to our mission.

We are here to support you and others so please spread the word about our services and get involved. Consider becoming a volunteer so we can reach more people.



Enc Van Vlyne



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Miami Valley Chapter

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2018 Chapter of the Year

The Miami Valley Chapter can help those affected by Alzheimer's live the best life possible.

Our Mission

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

A World Without Alzheimer's®



MIAMI VALLEY STATISTICS



30,000 people in the Miami Valley live with Alzheimer's disease

90,000 family and friends act as their caregivers



Please contact our local office for information, education and support.

24/7 Helpline 800.272.3900 or alz.org/dayton • 31 W. Whipp Rd., Dayton, OH 45459 Business Line: 937.291.3332













Celebrating community spirit



Friends, family, neighbors, and local business owners are the backbone of this community. Our vibrant spirit comes alive at events like these.

We're proud to be a part of Walk To End Alzheimer's.

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Together we'll go far



GET THE HELP YOU NEED

The Alzheimer's Association offers numerous free educational and support resources to equip you with the knowledge you need to help with a diagnosis of dementia or Alzheimer's disease.

24/7 Helpline 800.272.3900

The Alzheimer's Association 24/7 Helpline (800.272.3900) is available around the clock, 365 days a year. Through this free service, specialists and master'slevel clinicians offer confidential support and information to people living with the disease, caregivers, families and the public.

Education Programs

The Alzheimer's Association Miami Valley Chapter presents education programs in communities throughout the region. Topics include: Understanding Alzheimer's & Dementia; Communication and Behaviors; and Legal and Financial Planning. Dates, locations and topics vary month to month. Advance registration is requested.

Go to alz.org/Dayton to learn more.

Support Groups

The Miami Valley Chapter offers 17 caregiver support groups around the region. Support groups meet monthly at various locations and are open to the public. The Chapter also offers a telephone support group. Respite is available at some locations. For more information, call 800.272.3900.

Early-Stage Programs

Early-Stage education, support group and social engagement programs are available for those living in the early stages of the disease. The early-stage education and support group is for diagnosed individuals and, when possible, their care partners. An initial interview is required for early stage programs. For more information or to set-up an interview, call 800.272.3900.

Care Consultations

A licensed social worker will provide individualized education and care planning to caregivers and family members of individuals with Alzheimer's disease or related dementias. Call 800.272.3900 for more information.

Community Resource Finder

Individuals and families can easily locate dementia resources, programs and services close to home by going to alz.org/crf. Resources include adult day care programs and elder law attorneys.

MedicAlert® + Safe Return®

A 24-hour nationwide emergency response service designed to identify individuals with dementia who become lost or who have a medical emergency.

of callers to the Alzheimer's Association 24/7 Helpline put action steps into place within one week of using the service and nearly 30% reported lower levels of emotional distress

Source: AAIC Helpline Study

KNOW THE 10 SIGNS

Recognize the Warning Signs of Alzheimer's Disease

- 1 Memory Changes that **Disrupt Daily Life**
 - One of the most common signs of Alzheimer's, particularly in the early stages of the disease, is forgetting recently learned information.
- 2 Challenges in Planning or **Solving Problems**
 - Some people may experience changes in their ability to develop and follow a plan or work with numbers.
- 3 Difficulty completing familiar tasks at Home, at Work, or at Leisure
 - People with Alzheimer's disease often find it hard to complete daily tasks.
- 4 Confusion with time or place People with Alzheimer's can lose track of dates, seasons and the passage of time.

- 5 Trouble understanding visual images and spatial relationships
 - For some people, having vision problems is a sign of Alzheimer's.
- 6 New problems with words in speaking or writing People with Alzheimer's may have trouble following or joining a conversation.
- 7 Misplacing things and losing the ability to retrace steps A person with Alzheimer's disease may put things in unusual places and be unable to go back over their steps to find things.
- 8 Decreased or poor judgment People with Alzheimer's may experience changes in judgment or making decisions.

- 9 Withdrawal from work or social activities
 - A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports.
- 10 Changes in mood and personality
- The mood and personality of people with Alzheimer's can change.

If you or someone you care about is experiencing any of the 10 warning signs, please see a doctor to find the cause. The ability to diagnose Alzheimer's disease and related dementias is improving dramatically, and early diagnosis gives you a chance to seek treatment and plan for your future.

The Alzheimer's Association can help. Visit us at alz.org/10signs or call 800.272.3900.

What's the Difference?

Signs of Alzheimer's/dementia	Typical age-related changes
Poor judgment and decision making	Making a bad decision once in a while
Inability to manage a budget	Missing a monthly payment
Losing track of the date or the season	Forgetting which day it is and remembering later
Difficulty having a conversation	Sometimes forgetting which word to use
Misplacing things and being unable to retrace steps to find them	Losing things from time to time



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GETTING A DIAGNOSIS

There is no single test that can show whether a person has Alzheimer's disease. 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.

There is great benefit to getting an early diagnosis. While there is not a cure for Alzheimer's disease, medications may reduce symptoms or provide cognitive clarity for some. People in the early stage of Alzheimer's disease may have a better chance of participating in clinical drug trials, and an early diagnosis allows those living with Alzheimer's and their caregivers to plan ahead and make decisions about the future.

Getting a Medical Workup During the medical workup, your health care provider will review your medical history. He or she will want to know about any current and past illnesses, as well as any medications you are taking. The doctor will also ask about key medical conditions affecting other family members, including whether they may have had Alzheimer's disease or related dementias.

Mental Status Testing This part evaluates memory, ability to solve simple problems and other thinking skills. Such tests give an overall sense of whether a person is aware of symptoms, knows where he or she is, and can remember a short list of words or follow instructions. The mini-mental state exam and mini-cog test are two commonly used tests.

Neurological Exam During a neurological exam, the physician will closely evaluate the person for problems that may signal brain disorders other than Alzheimer's. The doctor will look for signs of small or large strokes, Parkinson's disease, brain tumors, fluid accumulation on the brain, and other illnesses that may impair memory or thinking.

Imaging Technologies These have revolutionized our understanding of the structure and function of the living brain. Researchers are exploring whether the use of brain imaging may be expanded to play a more direct role in diagnosing Alzheimer's and detecting the disease

Karen Dean



Living with Mild Cognitive Impairment (MCI)

Mild Cognitive Impairment, which can be a precursor to dementia or Alzheimer's disease, causes a slight but noticeable decline in cognitive abilities, including memory and thinking skills. Approximately 15 to 20 percent of people age 65 or older have MCI.

"I don't really have a caretaker. I am still trying to do things on my own," said Karen Dean. "I don't want to lose all of my self-worth."

JOIN THE FIGHT AGAINST ALZHEIMER'S

The Alzheimer's Association is the leading voluntary health association in Alzheimer's care, support and research. The Miami Valley Chapter hosts a number of special events where you can get involved and learn more about Alzheimer's disease and dementia:



The Walk to End Alzheimer's® is the world's largest event to raise money for Alzheimer's research, care and support. The Miami Valley Walks to End Alzheimer's are in September and October.



Interact with some of the nation's top Alzheimer's and dementia researchers and specialists at the Dimensions of Dementia Conference, which consists of a community forum and a professional symposium.

- The community forum highlights caregivers and presents the latest in dementia research
- The symposium focuses on best practices in dementia care.



Dial & Donate is a day-long radio telethon that raises awareness and funds for Alzheimer's support.



The Longest Day® is a fundraising campaign centered around the summer solstice, the longest day of the year.









To learn more, go to alz.org/dayton

2019 FACTS AND FIGURES

ALZHEIMER'S DISEASE IS THE

leading cause of death in the United States

MORE THAN provide unpaid 16 MILLION **AMERICANS**

care for people with Alzheimer's or other dementias

These caregivers provided an estimated

18.5 BILLION HOURS VALUED AT NEARLY \$234 BILLION

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say they receive regular cognitive assessments

Between 2000 and 2017 deaths from heart disease have decreased

while deaths from Alzheimer's disease have increased

7.145%

RESEARCH

The Key to Better Treatments, **Earlier Detection and Prevention**

This is a very exciting time in Alzheimer's disease research. Today, there are unprecedented levels of philanthropic investment and federal funding in Alzheimer's research. We believe this will accelerate the pace of discovery to slow, stop and prevent Alzheimer's disease.

As the world's leading nonprofit funder of Alzheimer's and dementia research, the Alzheimer's Association is currently investing over \$165 million in more than 450 projects in 25 countries. Because of that and other global research projects, we are confident that better treatments, earlier detection, and prevention strategies will be available in the foreseeable future.

Advancements in Detecting Alzheimer's and Relative Treatment

The Alzheimer's research field is developing new technologies to detect Alzheimer's earlier. Using

advanced imaging - such as PET scans - we can now see Alzheimer'srelated changes in living people up to 20 years before clinical symptoms of cognitive decline. Researchers are also getting closer to developing a simple blood test that would be cheaper, easier to administer, less invasive and more accessible.

Early and accurate diagnosis are critical to ensure that people receive high quality care, and can plan for the future. It also enables enrollment in clinical trials at the earliest stages of the disease - when effective treatment and prevention may still be possible. One goal is to find a treatment for the disease before dementia symptoms begin. As we work toward that goal, one benefit researchers are zeroing in on is how healthy lifestyles can reduce one's

Lifestyle Interventions to Slow **Cognitive Decline**

We've seen promise in lifestyle

interventions to slow cognitive decline and maybe dementia. The Alzheimer's Association is leading the U.S. POINTER study - a twoyear clinical trial to evaluate whether lifestyle interventions that target many risk factors can protect cognitive function in older adults at increased risk for cognitive decline. New developments show that adopting multiple healthy lifestyle habits provides high levels of benefit for brain health, and may offset genetic and environmental risks of Alzheimer's disease and other dementias.

Americans

are living with

Alzheimer's

BY 2050, this number is projected to rise to nearly

MILLION





Eric Thompson

Clinical Trial Participant

Clinical trials are research studies conducted in people to determine whether treatments are safe and effective. Doctors might suggest a clinical trial, also the Alzheimer's Association has TrialMatch[®], a free clinical studies matching service.

"Without clinical trials, there would be no cure for Alzheimer's disease," Thompson said. "The benefit is I could become the First Survivor."





Harbor Chase of Beavercreek

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Thank You

St. Leonard

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Helping people live more fully during life's final months.



Our mission is to celebrate the lives of those we have the privilege of serving by providing superior care and superior services to each patient and family.

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TIPS FOR CAREGIVER SELF-CARE

s a caregiver for someone with Alzheimer's disease, it can be easy to forget to care for yourself. It might be difficult to get a break, or you might feel guilty for needing one.

Practicing self-care actually gives you energy and resources to help your loved one. So here are some suggestions on how to care for yourself while being a caregiver.

Understand the Disease First

Educate yourself, for example through materials on alz.org or by attending an educational program offered by the Alzheimer's Association, so you can better understand the behaviors your loved one exhibits and determine if they may be caused by the disease.

Indulge in Small Treats

Find a quiet spot and close your eyes for five minutes, listen to an uplifting song, or work on a crossword puzzle for ten minutes. A short break just for yourself every day can work wonders.

Find Emotional Support

Building emotional support is crucial. You do not have to deal with this devastating disease by yourself. Talk to family and friends or get involved with one of the support groups organized by the Alzheimer's Association Miami Valley Chapter. It is natural to feel a range of emotions, and support groups can make you feel less alone.

Take a Break from Caregiving

Taking a break every now and then is important for both your emotional and physical health. Respite care allows you to recharge, take time for yourself, or run errands you've been putting off. Ask friends to spend time with your loved one or look into adult day centers and residential facilities. The Alzheimer's Association can help you find resources in your area.

Forgive Yourself

Caregiving is often difficult and exhausting and coping with the changes in your loved one is heartbreaking. There is no one right way to give care. When you falter, dust yourself off and learn from your mistakes.

MORE THAN BILLION

Hours of informal care were provided by Alzheimer's and other dementia caregivers in 2018

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Rebel Marcum

Sandwich Generation Caregiver

Approximately 25 percent of dementia caregivers are "sandwich generation" caregivers — meaning that they care not only for an aging parent, but also for children.

Rebel Marcum says she feels like she is living in two different realities - her world and her mother's world. "You have so much (stress)...l am almost numb," Marcum said. Her tip: do something relaxing like coloring in adult coloring books.

COMMUNICATING WITH AN INDIVIDUAL LIVING WITH ALZHEIMER'S

Alzheimer's disease makes communicating challenging. As the disease progresses, both the caregiver and the person with Alzheimer's will need to adjust their communication strategies. Below are some tips for caregivers to communicate successfully with their loved ones during all stages of the disease.

In the early stage, the person with the disease might withdraw from conversations as he or she struggles to find the right words or needs longer to respond. Encourage participation in conversations by being patient, speaking directly to the person.

As the disease progresses, the person might struggle with words more, use a smaller vocabulary than before, and invent new words to describe familiar things. He or she might start relying more on actions and behaviors to communicate. To engage your loved one in a conversation, approach him or her from the front, make eye contact, use his or her name, and say who you are. Be patient, repeat yourself if necessary, and give the person living with Alzheimer's plenty of time to respond.

In the late stage of the disease, communication is often reduced to a few words or sounds, and responses to what others are saying are similarly limited. With a calm and soothing tone of voice, treat your loved one with respect and respond to his or her emotions and needs.

Use all five senses to communicate. Gently touch the person, listen to favorite songs, pet animals or touch different fabrics, look at photos or pieces of art, smell and taste favorite foods, drinks, or popsicles. Touch can be especially soothing and allows you to connect with your loved one even if other contact is difficult.

Kim Willis



Cared for two parents with Alzheimer's disease

Kim Willis' father died of Alzheimer's disease in 2018 and her mother currently lives with the disease. She has learned a lot while caring for her parents.

"No one chooses this," Willis said. "You have to remind yourself mom is not 'choosing' to not communicate. She can't pull it together."

Throughout the progression of the disease,

keep talking to your loved one and remember that he or she retains a sense of self despite the losses of the disease. Accept that things change, but remember that you can change, too, and maintain contact with your loved one through the course of the disease.



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FOOD EQUIPMENT GROUP

BEING LEGALLY AND FINANCIALLY PREPARED IN THE FACE OF ALZHEIMER'S

Receiving a diagnosis of Alzheimer's is never easy — it's life changing. In the early stages of Alzheimer's, especially after a recent diagnosis, most people are trying to figure out how to manage day to day. However, putting financial and legal plans in place allows the person with dementia to express their wishes for future care and decisions.

Here are some tips for financial and legal planning:

Financial Planning

As the disease progresses, so will a person's care needs. While medical insurance covers some costs of care, there are many things insurance may not cover. Here are some common costs to consider:

- Safety-related expenses, such as home safety modifications or safety services for a person who wanders
- Personal care supplies
- Adult day care services
- In-home care services

In addition to planning for the cost of care, there are many ongoing financial duties to discuss, including paying bills, making investment decisions and preparing tax returns. Financial planners and estate planning attorneys are valuable sources of information and assistance.



Legal Planning

Legal planning is another essential piece of planning for the future. In order to ensure that a person's wishes are met, legal assistance may be needed. This early planning prevents families from struggling to make medical and financial decisions after their loved ones are no longer able to participate in those decisions.

The Alzheimer's Association recommends that every legal plan should include the following.

- Plans for health care and long-term care
- Plans for finances and property
- Identification of another person to make decisions on behalf of the person with dementia (i.e. Power of Attorney)

These strategies will ensure that a person's medical wishes and plans for finances and property are followed or that a designated person has the authority to make those decisions.

An Alzheimer's or dementia diagnosis is not something that anyone is prepared for, but the sooner plans for the future are established, the better prepared the caregiver and the person with dementia will be.



Call the Alzheimer's Association Miami Valley Chapter for help

800.272.3900

Alzheimer's Association Miami Valley Chapter alz.org/dayton

MAKE A DIFFERENCE

Volunteer with the **Alzheimer's Association**

Millions of Americans are impacted by Alzheimer's disease and you can do something to help by becoming an Alzheimer's Association volunteer. Our ability to reach and support those affected depends on people like you who are dedicated to the fight against this disease.

Our volunteers are passionate and inspired. Whatever time you have to volunteer, we can find the right fit for your interests and skills. The Alzheimer's Association offers opportunities to support families, do community engagement, help with events, or advocate with elected officials.

Program Volunteers

Some of the available roles are for Community Educators, Community Representatives, and Early-Stage Social Engagement Leaders. Educators present educational programs to groups and community representatives link people to our services by attending health fairs and working with community groups. Early-Stage volunteers help during social engagement events.

New to the Alzheimer's Association Miami Valley Chapter this year are our Faith Outreach Representatives, who act as liaisons between local faith groups and congregations and the Association. They share information about the disease and the Association's free resources.

For more information and other opportunities, go to alz.org/volunteer.

Advocacy

Conquering Alzheimer's is as much a matter of public policy as scientific discovery, and our advocates help change the future of this devastating disease. The voices of those who have personally faced Alzheimer's disease are critical to building a case for support. Your story is all you need to assist in our federal and state public policy work, which aims to educate our policy makers about the disease and urge their support for more research funding and better systems for caring for people with Alzheimer's.

With the help of lead volunteers called State Champions, we are urging Ohio legislators to make Alzheimer's a priority in the Buckeye State. They are the voice for the nearly one million Ohioans impacted by Alzheimer's disease. Interested in becoming an advocate? Contact Caitlin Purk at cpurk@alz.org.



Cedric Howard

Making a Difference as a Volunteer

Cedric Howard served on the 2019 Dayton Walk to End Alzheimer's Committee and he annually hosts the Making Memories Golf Outing to raise funding and awareness.

He participates in events "because my family was impacted - my grandmother and my aunt... I'm trying to make a point you need to be diagnosed with this disease."

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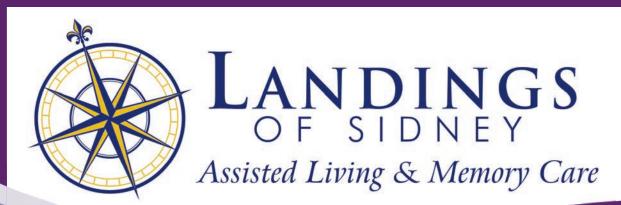












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THINGS TO CONSIDER WHEN **COMPARING CARE FACILITY OPTIONS**

The decision to place a loved one in a care facility is a difficult and personal one. When exploring options near you, keep these questions and tips in mind:



What is the ratio of residents to direct care staff?

What staff are included in that ratio? Make sure it is only direct care staff. Positions within departments such as maintenance or administration are not providing direct care and should not be included. The smaller the ratio the better.



Do they give on-going dementia care training to their staff? What staff attends?

Continued education can help keep skills fresh and ensure your loved one has the best care possible.



How often do they hold care

Care conferences are when the management team meets with you and your family to talk about your loved one and their care plan.



Observe the environment.

Take note of the smell of the building, expressions on the faces of the staff and residents. Accidents happen, so understand it's not always perfect in a memory care facility, but you need to observe the overall environment for indications of good care.



Get an activity calendar.

How often are things scheduled and what are they? Are there a variety of activities that will engage your loved one at all levels of care?



Are they able to take care of your loved one until the end of life?

What does that look like? Is there a chance your loved one will have to leave in the late stages of the disease because their level of care is too high?



Get a breakdown of costs.

Understand what the fees are and how you might incur more.



Is it a secured community?

Sixty percent of people with Alzheimer's disease will wander so investigating what each facility has in place to prevent it from happening is important.



Schedule a visit to get a good feel and in-depth understanding for the community. After scheduling this first visit, make a couple

unannounced visits.

Go back during activity time and ask to see the memory care area again. You should be able to see it during normal business hours without an appointment. Check to see if your perceptions from the first visit were accurate and if the activity is going on as scheduled.

Visit again during meal time. Meals occur three times a day and will be a large part of your loved one's memory care experience. Observe interactions with the staff, the noise level and if the residents are satisfied. If something concerned you from a previous visit, check to see if it's still the case. Remember, always go with your gut.

HOW TO HELP A FAMILY LIVING WITH ALZHEIMER'S DISEASE

Many of us know a family living with Alzheimer's disease and want to help but don't quite know how. Here are some tips to get you started.

Educate yourself about Alzheimer's disease.

This way, you'll know what to expect and you can respond to situations appropriately.

Stay in touch. Caregivers and people with Alzheimer's often report feeling isolated or alone. Keep reaching out – just being there is more important than finding the right words to say.

Spend time and connect with the person living with Alzheimer's. Continue to do favorite activities together, even if you need to make adjustments as the disease progresses. Again, being present and engaging with the person is what matters.

Make concrete offers for help. A family living with Alzheimer's may feel overwhelmed, or they might feel timid about asking people for help. Instead of saying "Let me know if there is anything I can do," ask if you can bring over a casserole, if you can clean the house, or if you can spend time with the person with Alzheimer's so the caregiver can go out for dinner or a movie. The online Care Team Calendar, provided by the Alzheimer's Association and available on alz.org, can help with scheduling, planning, and dividing up tasks.

Involve the person with Alzheimer's in **conversation.** Even as his or her ability to participate changes, it is important not to isolate or ignore the person living with the disease. If you worry about not having anything to say, you can brainstorm discussion topics and stories beforehand.

Do not give unsolicited advice. Every family and person has their own way of coping with the disease. Let them make their own decisions, medical and otherwise. Trust that they are capable of finding the resources and information they want and need, and only offer your advice if you are asked for it.

Be flexible. The family might need time to adjust to the diagnosis, they might be too tired to make plans, or the needs and abilities of the person with Alzheimer's might change. Keep offering your help even if you are turned down once, but don't pester.

Get involved with the Alzheimer's **Association.** Become an advocate, donate, or participate in a Walk to End Alzheimer's.

HONOR A LOVED ONE.

Join the Fight to Help Us Find a Cure.





Here are two opportunities to start a team to raise critical funds:



The Longest Day® is centered around the summer solstice, the longest day of the year. In honor of those fighting the long days, participate in an activity they love to raise funds for the fight against Alzheimer's disease.



The Alzheimer's Association Walk to End Alzheimer's is the world's largest event to raise awareness and funds for Alzheimer's care, support and research. Choose from five Walks in the Miami Valley: Dayton, Darke County; Miami County; Shelby County; Springfield/Urbana.

All contributions go toward Alzheimer's care, support and research efforts.