

alzheimer's  association®

LIVING WITH ALZHEIMER'S DISEASE

WHAT YOU NEED TO KNOW
TO LIVE YOUR BEST LIFE



*Theresa M., Rod B. and Don L.,
living with Alzheimer's*

ALZHEIMER'S DISEASE AND YOU

Alzheimer's is the most common form of dementia, which leads to changes in memory, thinking and behavior.

If you have been diagnosed with Alzheimer's or another dementia, you are not alone. Today, an estimated 50 million people worldwide are living with dementia, including more than 5 million Americans.

Learning as much as you can is the first step toward taking control of your life. In the early stage of the disease, you can live well by empowering yourself with the right information and resources.

We encourage you to take your time and learn at your own pace, as some information may be difficult to deal with.

“Alzheimer’s disease is a part of my life, but it doesn’t define who I am. I do my best to focus on what I can control, rather than what I cannot.”

- Brian V.,
living with mild
cognitive impairment





CONTENTS

- 1. Feelings after a diagnosis..... p.2**
- 2. Disease progression p.4**
- 3. Treatments and research p.6**
- 4. Sharing your diagnosis..... p.8**
- 5. Changes in relationships p.10**
- 6. Plan for your future p.12**
- 7. Live your best life p.16**
- 8. Get involved..... p.19**

1. FEELINGS AFTER A DIAGNOSIS

It's normal to experience a range of emotions after receiving a diagnosis of Alzheimer's or another dementia. Understanding your emotions will help you move forward and discover ways to live a positive and fulfilling life. Common feelings include:

- » **Anger.** Your life is taking a different direction than you planned and you cannot control the course of the disease.
- » **Relief.** Your diagnosis validated the concerns you had about the changes you were experiencing and provided an explanation.
- » **Depression.** Feeling depressed or anxious is common. If feelings of sadness persist, it may be time to seek the help of your doctor, as depression can be treated.
- » **Fear.** You may be fearful of the future and how your family will be affected.
- » **Isolation.** It might feel as if no one understands what you're going through or you may lose interest in maintaining relationships with others.
- » **Sense of loss.** It may be difficult to accept changes in your abilities.

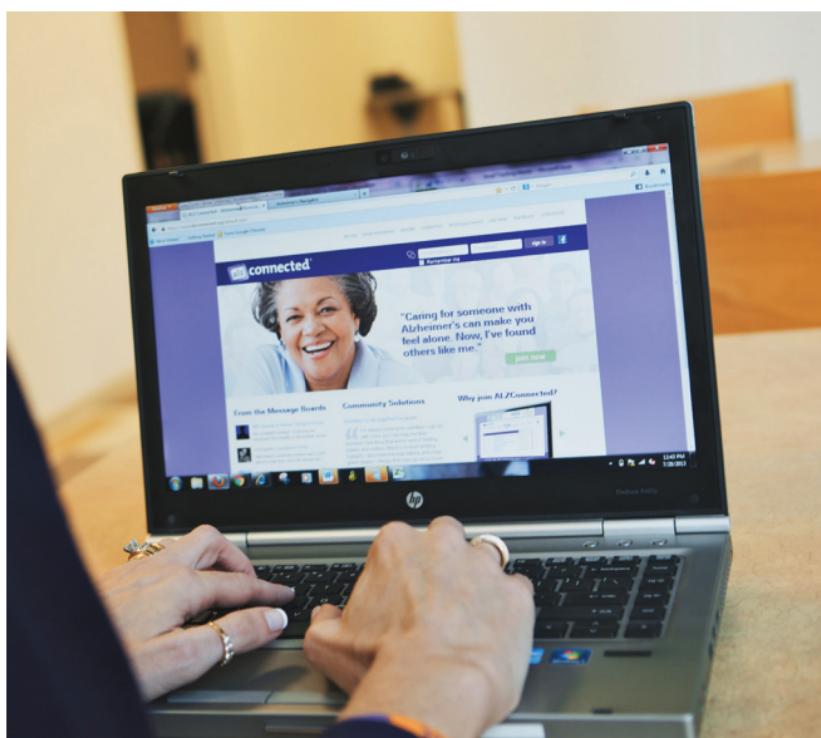
SADNESS OR DEPRESSION?

Visit alz.org/takecare to learn the warning signs of depression. Talk to your doctor if you or others are concerned about your emotional well-being.

Take care of your emotional needs

Although it can be difficult, taking care of your emotional needs can help you come to terms with your diagnosis and feelings. The following tips may be helpful:

- » Write down your thoughts in a journal.
- » Share your feelings openly and honestly with family members and friends.
- » Surround yourself with support.
 - > Join **ALZConnected® (alzconnected.org)**, our online community, to connect with other individuals living with early-stage Alzheimer's.
 - > Join an early-stage support group, which can provide you with a safe and supportive peer environment. Call **800.272.3900** or visit **alz.org/CRF** to find a group in your area.
- » Stay engaged by continuing to do activities you enjoy for as long as you're able, or consider trying new ones.
- » Take time to feel sad, mourn and grieve.



2. DISEASE PROGRESSION

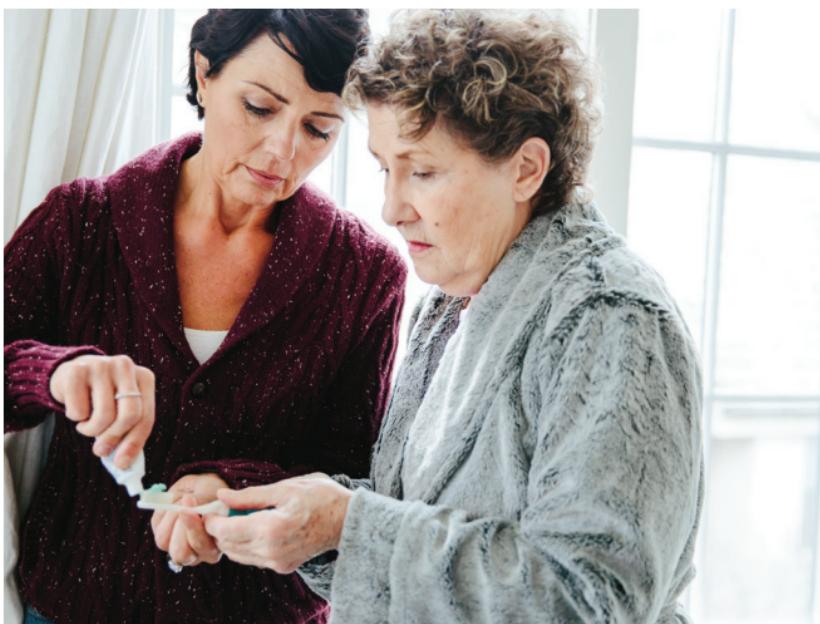
Alzheimer's affects everyone differently. By learning what to expect as the disease progresses, you can reduce the fear of the unknown and develop a strategy to help you manage the challenges you may face. Please note: Your health care provider may refer to the stages of Alzheimer's as "mild, moderate and severe."

Early stage

In the early stage of Alzheimer's, you will begin to notice changes in your memory, thinking or reasoning that interfere with daily life. You will still be able to perform many of your daily responsibilities or routines, but these tasks may become more difficult over time. Friends, family or co-workers may notice changes. Common difficulties in the early stage may include:

- » Problems coming up with the right word or name.
- » Trouble remembering people's names after introduced.
- » Greater difficulty performing tasks in social settings.
- » Forgetting material that was just read.
- » Losing or misplacing common objects.
- » Difficulty planning or organizing.





Middle stage

As the disease progresses into the middle stage, significant details about oneself and family may still be recalled, but gaps in memory and thinking are noticeable and assistance with daily tasks is required. Safety needs should be addressed, if measures are not already in place. Changes in the middle stage may include:

- » Inability to recall home address, telephone number or the names of family and friends.
- » Confusion about time or place.
- » Difficulty choosing appropriate clothing for the season or occasion.
- » Requiring some assistance with eating or toileting.

Late stage

In the late stage of the disease, losses include the abilities to communicate (e.g., respond to the environment and carry on a conversation) and, eventually, control movement (e.g., sit without support and hold head up). Assistance or supervision is required to complete most daily personal care, including eating or toileting. Reflexes will become abnormal, muscles grow rigid and swallowing becomes impaired.

3. TREATMENTS AND RESEARCH

The more you know about Alzheimer's medications, the better prepared you will be to discuss them with your physician, make informed choices about your treatment plan and effectively cope with symptoms.

While there is no cure, prevention or treatment to slow the progression of Alzheimer's or dementia, the following commonly prescribed FDA-approved medications are used to treat symptoms.

DRUG NAME	BRAND NAME	APPROVED FOR	POSSIBLE SIDE EFFECTS
1. Donepezil	Aricept®	All stages	Nausea, vomiting, loss of appetite, increased frequency of bowel movements
2. Galantamine	Razadyne®	Mild to moderate	Nausea, vomiting, loss of appetite, increased frequency of bowel movements
3. Rivastigmine	Exelon®	Mild to moderate	Nausea, vomiting, loss of appetite, increased frequency of bowel movements
4. Memantine	Namenda®	Moderate to severe	Headache, constipation, confusion, dizziness
5. Donepezil and memantine	Namzaric®	Moderate to severe	Nausea, vomiting, loss of appetite, increased frequency of bowel movements, headache, constipation, confusion, dizziness

The first three drugs are cholinesterase inhibitors, which treat symptoms related to memory, thinking, language, judgment and other thought processes. The fourth, memantine, regulates the activity of a different chemical messenger in the brain that is also important for learning and memory. These two types of drugs work in different ways to help manage symptoms.

The fifth drug is a combination of a cholinesterase inhibitor and a glutamate regulator. These three types of drugs work in different ways to help manage symptoms. The effectiveness of the types of treatments varies from person to person. While they may temporarily help symptoms, they do not slow or stop brain changes that cause Alzheimer's to become more severe over time.

Be sure to discuss all medications with your doctor to understand why they were prescribed and how to take them. To prevent drug interactions and unwanted side effects, make sure your physician, pharmacist and care team are aware of any over-the-counter and alternative remedies you are taking.

Clinical studies

As a person living with Alzheimer's, you have an opportunity to participate in clinical research. Some participants receive cutting-edge treatments and expert medical care. All participants provide valuable insight to help investigators accelerate research progress.

Visit **alz.org/TrialMatch** to learn more about clinical studies and **Alzheimer's Association TrialMatch®**, a free, easy-to-use clinical studies matching service.

I don't have a laboratory.
I have Alzheimer's disease.
And I'm helping to
discover a cure.
You can too.
alz.org/TrialMatch
800.272.3900

Paul H., living with Alzheimer's

alzheimer's  association®

trialmatch™

POWERED BY  EmergingMed

4. SHARING YOUR DIAGNOSIS

As the disease progresses, you will need the support of those who know and understand you in order to cope with the challenges ahead. Some relationships may be tested when you reveal your diagnosis, but others may be strengthened.

It's normal to experience fear or discomfort. However, talking openly with those you trust is a powerful way to engage their support and educate them about the disease.

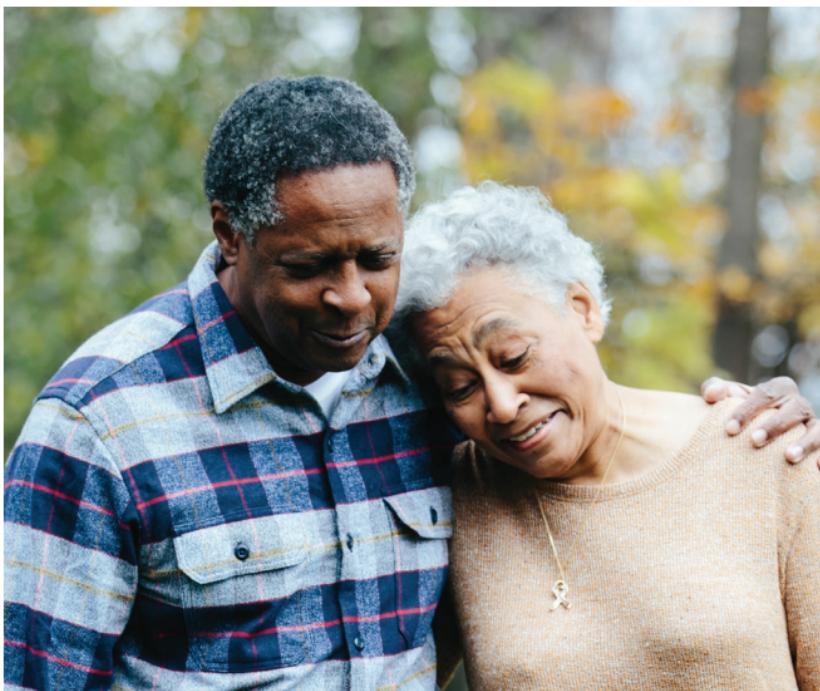
Some individuals choose to share their diagnosis with only their closest family and friends, while others are comfortable sharing it with a broader group of people. Assess your personal comfort level to determine your approach.

Negative reactions based on stigma or misconceptions about Alzheimer's may reflect a person's need for more time or education before he or she can respond to you in helpful ways. Allow your family and friends time to digest your news so everyone can move forward positively.

It's OK to talk about your Alzheimer's diagnosis with other people. Some might not understand the disease, but there are people who want to help. You are not alone.

- Jeff B.,
living with Alzheimer's





DISCLOSING YOUR DIAGNOSIS

ADVICE FROM INDIVIDUALS LIVING
WITH ALZHEIMER'S

- » You don't need to talk about everything in one sitting. If a person's reaction is difficult for you, consider continuing the conversation at a later time.
- » It's important to keep the lines of communication open as the disease progresses. Your thoughts and feelings, as well as other people's, may change.
- » Remind people that you're still the same person. Even though you're now living with an Alzheimer's diagnosis, what has made you close to each other continues unchanged.

Visit **alz.org/IHaveAlz** for more tips.

5. CHANGES IN RELATIONSHIPS

After sharing your diagnosis, some people you were once close with may pull away. It can be hurtful to realize that certain family and friends you thought would be there for you can't meet your expectations. They may have discomfort about your diagnosis, as it stirs up fears about their own future. People who can't be a part of your support circle now may join later once they have time to adjust.

Role changes

Your roles and responsibilities will change as the disease progresses. Some of these changes and the resulting emotions may include:

- » Loss of independence.**

Some of your primary responsibilities may be passed on to someone else.

- » Less involvement.**

Family members may have conversations or make plans for the future without your presence or feedback.

- » Concern.**

You may worry about burdening others with caregiving roles or responsibilities you once managed.

Asking for help

It can be difficult, but adapting to changes and accepting help from others may help you remain independent longer. Be specific when asking for help. You will benefit from their support and they may gain fulfillment from helping you.

KEEP YOUR RELATIONSHIPS POSITIVE AND PRODUCTIVE

- » Be open about your feelings and experience living with the disease.
- » Learn how to ask for help. Tell others what type of support you need and how they can assist.
- » Re-evaluate your relationships. Don't dwell on people unable to support you or provide a positive presence in your life. Give them time to adjust to your diagnosis and try not to take their behavior personally.



Carol M., living with Alzheimer's, and her daughter and care partner, Melissa

6. PLAN FOR YOUR FUTURE

Putting legal, financial and safety plans in place after receiving your Alzheimer's diagnosis is extremely important. It may be difficult to look ahead to the future, but it's critical to keep sight of planning and conversations that should take place while you're in the early stage of the disease and can fully participate. Having future plans in place can also provide comfort and confidence to you and your family.

Legal plans

Making legal plans will help ensure your wishes are met in regard to future health and end-of-life care. Although it can be emotional, you may find comfort in knowing that your expressed wishes will be followed and your family members will not be tasked with making difficult decisions when you no longer can.

Legal planning should include:

- » Taking inventory of existing legal documents, reviewing them and making the necessary updates.
- » Putting plans in place for future health care and long-term care.
- » Establishing advance directives — legal documents (e.g., durable power of attorney for health care and living will) that allow you to record your preferences regarding treatment and care, including your end-of-life wishes.



“Put legal and financial matters in place, survey options for future long-term care needs and seek advice that will help you maintain your independence for as long as possible.”

- Geri T.,
living with Alzheimer's



PREPARING IMPORTANT DOCUMENTS

Many documents, including advance directives, can be prepared without the help of an attorney. However, if you are unsure about how to complete legal or financial documents, you may want to seek assistance from an attorney specializing in elder law and/or a financial advisor who is familiar with elder or long-term care planning.

Visit alz.org/IHaveAlz to learn more.

Financial plans

Financial planning often gets pushed aside because of the stress and fear the topic evokes. However, you can reduce this stress by planning ahead. To make a financial plan, you should:

- » Organize your documents to take inventory of your assets and debts.
- » Identify family members who should be included.
- » Research potential care costs. Get started at alz.org/carecosts.
- » See if you are eligible for government benefits that can help with prescription costs, transportation and meals.
- » Review long-term care insurance to see how it can help with covering costs of future care.
- » If you have served in the armed forces, consider any benefits for veterans.

LEARN MORE ABOUT LEGAL AND FINANCIAL PLANNING



Call our **24/7 Helpline: 800.272.3900**



Visit **alz.org/IHaveAlz** for helpful information, tips and resources.



Take our free workshop, *Legal and Financial Planning for Alzheimer's Disease*, online at **alz.org/education** or at an Alzheimer's Association office near you (**alz.org/CRF**).



Visit **alz.org/publications** to download our *Money Matters* and *Legal Plans* brochures or call **800.272.3900** to request copies.

Safety plans

In the early stage of the disease, you can still lead an independent life. However, there are some preparations you should make to help you remain independent as long as possible and ensure your safety as the disease progresses.

Addressing potential safety issues now can allow you to work with your family to prepare for difficult decisions later, including when to stop driving and when to consider services to help prevent wandering.

Visit alz.org/safety to learn more.



7. LIVE YOUR BEST LIFE

You can live well with Alzheimer's, particularly in the early stage of the disease. Consider these tips to help you live your best life:

» Take care of your body.

Try to eat well and stay active. Visit your doctor regularly and rest when you're tired.

» Engage in mentally stimulating activities.

Learning new information, taking a class or challenging yourself to try a new hobby or activity may help increase your brain activity.

» Connect with your feelings.

Talking with friends or a counselor about your diagnosis can help you cope with difficult emotions.

» Stay social.

Meet others living in the early stage through **ALZConnected (alzconnected.org)** or a local support group (alz.org/CRF).

» Explore your spiritual side.

Focus on the pursuits that bring meaning to your life and help you experience peace.

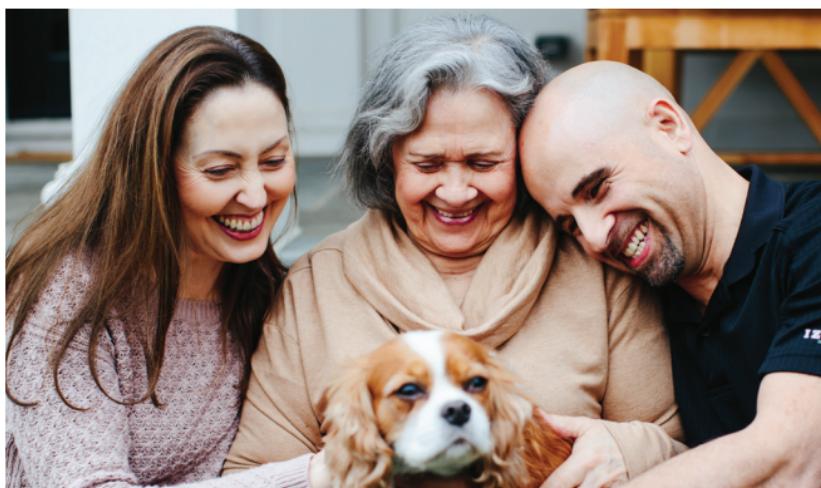
Daily living

Things you once did easily will become increasingly difficult, such as maintaining a schedule or managing money. Accepting changes in your abilities and adopting coping skills can help restore balance to your daily life and reduce stress as you continue to live with the disease.

Tips for developing your own coping strategies:

» **Identify:** Make a list of tasks that have become more challenging. Focus on the activities that are most important in your daily life.

» **Prioritize:** Determine if the task is necessary. If so, consider asking for help.



- » **Strategize:** Develop a daily routine and approach one task at a time.

What works well for one person may not work for another, and coping strategies that work one day may not work the next. Try to find which strategies work best for you in various situations.

Developing effective coping strategies can help you:

- » Remain engaged and active.
- » Respond to challenges that will maximize your independence and well-being.
- » Gain a sense of control over your life.

To view a list of coping strategies developed by individuals living with the disease, visit alz.org/dailylivingtips.

TOOLS TO HELP YOU LIVE WELL

LiveWell Online Resources is a collection of free interactive tools that helps users navigate the personal and emotional challenges accompanying an Alzheimer's diagnosis and provides personalized steps for living well with the disease.

Visit alz.org/livewell to learn more.

Reduce stress

Living with Alzheimer's or dementia can be overwhelming at times, which can affect your health and ability to function. Taking steps to reduce stress can help improve your concentration, decision-making ability and overall quality of life.

To help reduce stress:

» **Identify sources of stress in your life.**

Remove yourself from these situations whenever possible.

» **Establish boundaries and let others know your limits.**

What are you willing and unwilling to tolerate? Be as open as possible about this with others.

» **Change your environment.**

If you're in an environment that has too much stimulation and is causing you stress, take a break and find a quiet place to relax and regroup.

» **Let it go.**

If something becomes too difficult for you, consider whether you need to complete it now or if you can return to it later.



8. GET INVOLVED

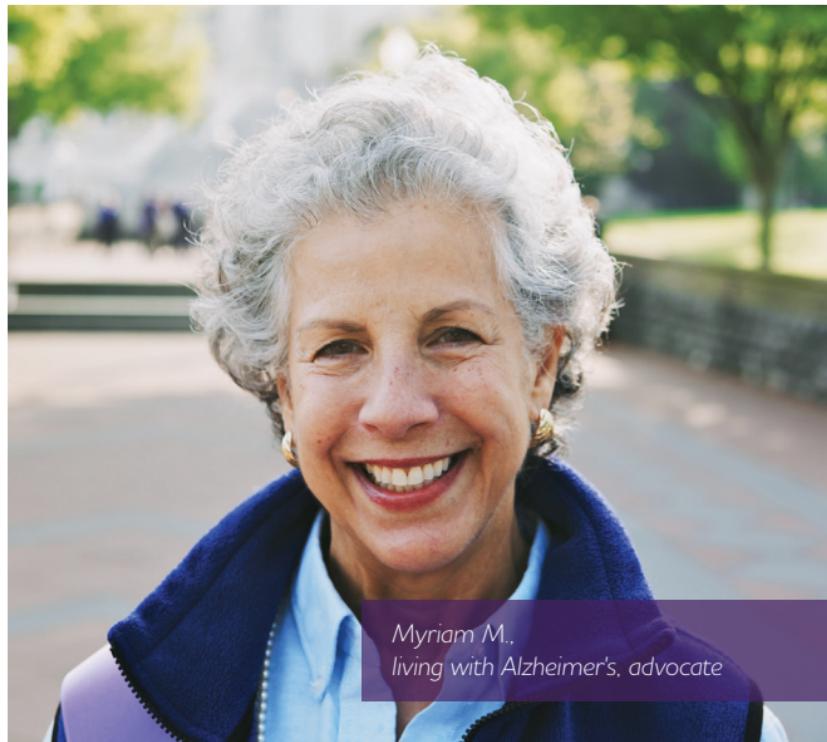
Some individuals living with Alzheimer's have found that by getting involved and raising awareness about the disease, they can strengthen their sense of purpose and connection to others.

You have a unique opportunity to contribute to the Alzheimer's cause by turning your experience into inspiration. The Alzheimer's Association offers ways to join the fight by raising awareness and funds.



When I was diagnosed, I couldn't even say the word 'Alzheimer's.' But in time I realized I could either sit down and let the disease take over, or I could fight.

- Chuck M.,
living with Alzheimer's



*Myriam M.,
living with Alzheimer's, advocate*

Advocate

As an individual living with Alzheimer's disease, you can add your voice to the thousands of others advocating for government action. By speaking out on the issues you face every day, you can help to shape local, state and federal laws. Visit **alz.org/advocate** to learn more.

Become a leader

The Alzheimer's Association National Early-Stage Advisory Group offers a unique opportunity for some individuals living in the early stage of Alzheimer's to elevate their voices on a national platform.

Early-Stage Advisors work with the Association to raise awareness about early-stage issues, advocate with legislators to increase funding for research and support programs, and provide input on the most appropriate services for people living with early-stage Alzheimer's.

By educating the public about the impact of Alzheimer's disease, advisors also help to reduce the stigma surrounding dementia. Learn more at **alz.org/earlystage**.



*Julie B. and LuPita G.,
living with Alzheimer's*

Raise awareness and needed funds

Your involvement in national fundraising efforts helps us work toward our vision of a world without Alzheimer's. By participating, you are helping the Association to raise awareness and funds for care, support and research efforts.

- » Participate in our signature fundraising events: **Walk to End Alzheimer's®** (alz.org/walk) and **The Longest Day®** (alz.org/thelongestday).
- » Volunteer at a local event (alz.org/CRF).
- » Make a donation (alz.org/donate).



Gary S., living with Alzheimer's,
and his wife, Nancy



alz.org/IHaveAlz

I Have Alzheimer's — an online resource created with input from individuals living with Alzheimer's and other dementias — offers information and strategies to help those living in the early stage of the disease.



alz.org/education

Free online workshops, including:

- » *Understanding Alzheimer's and Dementia*
- » *Living with Alzheimer's: For People with Alzheimer's.*



alz.org/CRF

We're in communities nationwide.



800.272.3900

24/7 Helpline – Available all day, every day.

alzheimer's association®

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 disease®.

800.272.3900 | alz.org®

This is an official publication of the Alzheimer's Association but may be distributed by unaffiliated organizations and individuals. Such distribution does not constitute an endorsement of these parties or their activities by the Alzheimer's Association.