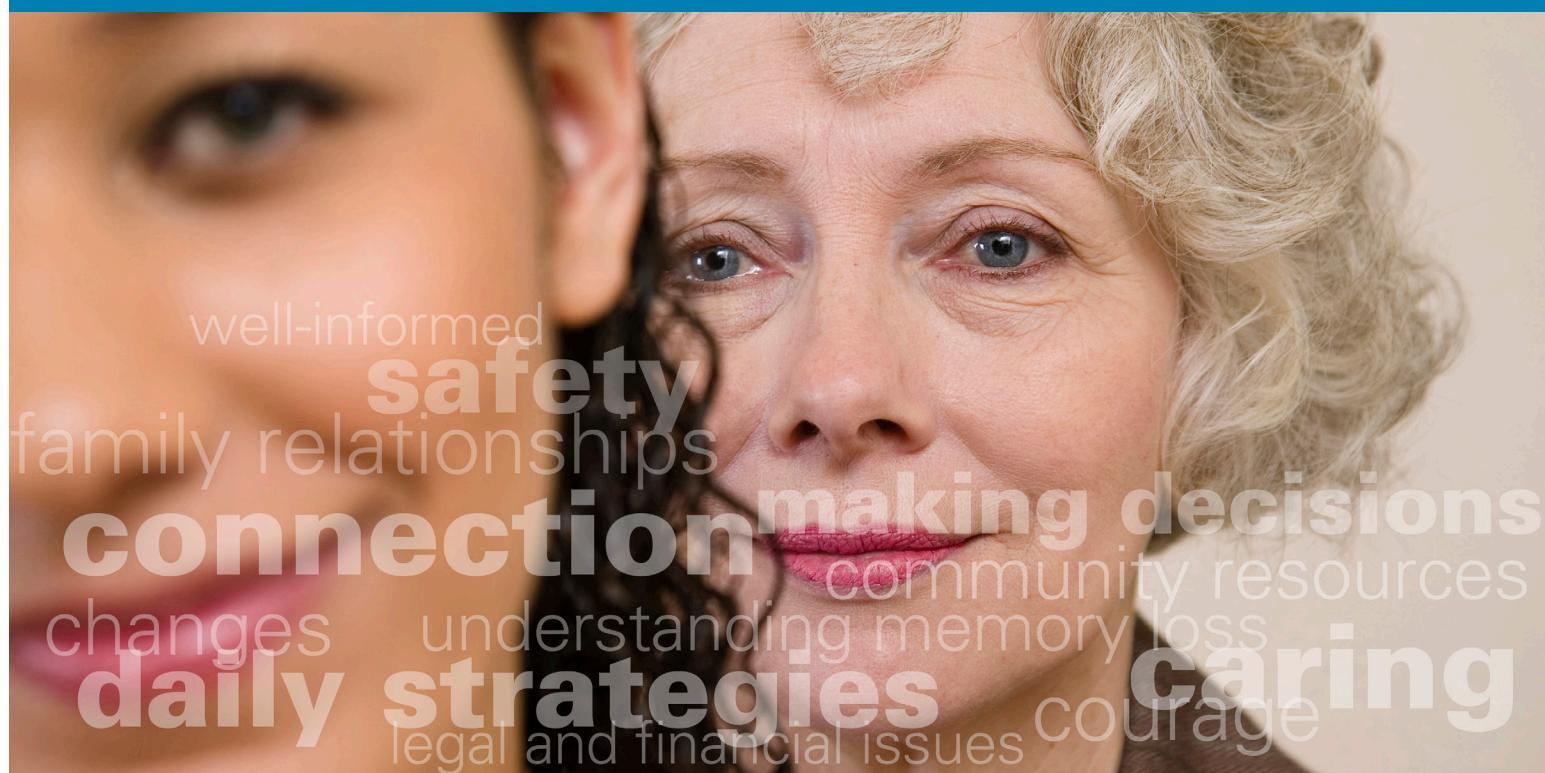


# living with alzheimer's

for people with alzheimer's



taking action workbook



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# introduction

If you are a person living with Alzheimer's disease or another dementia, then this book was designed for you. Think of it as a personal guide and workbook to help you in learning about the disease and steps you can take to help yourself. This book is designed to help you learn about the disease and the steps you can take to live your best life with Alzheimer's disease. You may also want to attend the *Living With Alzheimer's for People with Alzheimer's* education workshop in person or online at alz.org.

The **Taking Action Workbook** addresses common concerns and issues faced by individuals living in the early stage of Alzheimer's or a related dementia. Each section includes educational information, perspectives of people with early-stage Alzheimer's, and space to write down personal ideas, plans and feelings. A checklist page of "Things I Can Do" is a quick summary of strategies for taking care of yourself.

People learn in different ways — either by reading, writing or talking to others. You may find the workbook useful in educating yourself and others. It can be used as a way to begin conversations about changes and how you feel about what is happening to you.

Writing down important ideas and information is a helpful memory aid. Written information can be easily shared with others too. You may experience new and different feelings associated with the disease. This is a normal part of the process. Journaling your feelings is a great way to keep a record of them and is also a good coping strategy. This book may help you to identify those feelings and talk to others about your feelings, ideas and plans.

# 1. understanding memory loss

Aging, memory loss, dementia and Alzheimer's disease: what's the difference?

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## Normal aging

We all know that many things change as we age. In normal aging, our bodies and brains slow down, though intelligence remains stable. We are less physically and mentally flexible, and we take more time to process information. Memory changes occur as well, and it's common to have greater difficulty remembering names of people, places and other things.

## Mild cognitive impairment (MCI)

In MCI, a person has problems with memory or another core brain function. These problems are severe enough to be noticeable to other people and show up on tests of mental function, but not serious enough to interfere significantly with daily life. People with MCI have an increased risk of developing Alzheimer's disease in the near future, especially when their main symptom involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another type of dementia.

## Dementia

Dementia is not a specific disease. It is a general term that describes a set of symptoms that may be caused by a number of different brain disorders. These symptoms involve mental decline severe enough to disrupt daily life that affect more than one of the following core brain functions:

- **Recent memory** — the ability to learn and recall recently learned information.
- **Language** — the ability to write, speak or understand written or spoken words.
- **Visual spatial function** — the ability to understand and use symbols, maps and the ability to correctly judge where objects are.
- **Executive function** — the ability to plan, reason, solve problems and focus on a task.

## Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. It is a slow, progressive illness that damages nerve cells in the brain. Symptoms gradually get worse over time as more brain cells are destroyed. Though people can have Alzheimer's in their 40s, and 50s, the disease is most prevalent in people over age 65.

***Because there are many causes of dementia, it is important to find out the disease responsible for these symptoms. Alzheimer's disease is the leading cause of dementia, accounting for 70 percent of cases.***

## Getting a diagnosis

If you are reading this workbook, you may have a diagnosis of Alzheimer's disease or another dementia. If so, you already know how important it is to rule out the other conditions that can look similar and may be treatable or curable.

The first problem many people with Alzheimer's disease notice is forgetfulness severe enough to affect their daily life, hobbies, social life or work. Other common symptoms include mood changes, difficulty multitasking, misplacing things, repeating things, confusion, trouble organizing and expressing thoughts, and becoming disoriented or lost in familiar places. Although there is currently no cure, treatments for symptoms are available and most effective when used early in the disease. Getting a diagnosis is the first step toward understanding what's causing your symptoms and taking action. Treatment can only be started when the disease has been identified. A complete medical evaluation often includes:

- **Physical examination** includes the evaluation of a person's nutritional status, blood pressure and pulse.
- **Medical history** provides information about current mental or physical conditions, prescription drug intake and family health history.
- **Mental status evaluation** assesses a person's sense of time and place and his or her ability to remember, understand, talk and do simple calculations.



- **Neurological examination** tests the nervous systems (brain and spinal cord) for evidence of other neurological disorders. A magnetic resonance imaging (MRI) or completed tomography (CT) study of the brain may be used to search for other possible causes of dementia (e.g., stroke). Scans of the brain are not yet accurate enough to determine the cause of the person's dementia.
- **Laboratory tests**, such as blood and urine tests, provide additional information about other problems that may be causing dementia.
- **Neuropsychological evaluation** tests memory, reasoning, vision, motor coordination and language function. This evaluation may provide the only evidence of dementia, especially in the early stage.
- **Psychiatric evaluation** provides an assessment of mood and other emotional factors that could mimic dementia or that may accompany Alzheimer's.

# Principles for a Dignified Diagnosis

Principles for a Dignified Diagnosis is the first statement of its kind written by people with dementia on the subject of the Alzheimer diagnosis experience. These principles are their insights on how to make that experience better. Although you may already have a diagnosis, it may be helpful to share these principles with your doctor to communicate more effectively.

**Talk to me directly, the person with dementia.** I am the person with the disease, and though my loved ones will also be affected, I am the person who needs to know first.

**Tell the truth.** Even if you don't have all the answers, be honest about what you do know and why you believe it to be so.

**Test early.** Helping me get an accurate diagnosis as soon as possible gives me more time to cope and live to my fullest potential and to get information about appropriate clinical studies.

**Take my concerns seriously, regardless of my age.** Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because I am old. At the same time, don't forget that Alzheimer's can also affect people in their 40s, 50s and 60s.

**Coordinate with other care providers.** I may be seeing more than one specialist — it is important that you talk to my other providers to ensure you all have the information so that changes can be identified early on and that I don't have to repeat any tests unnecessarily.

**Explain the purpose of different tests and what you hope to learn.** Testing can be very physically and emotionally challenging. It would help me to know what the purpose of the test is, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

**Give me tools for living with this disease.** Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community.

**Work with me on a plan for healthy living.** Medication may help modify some of my symptoms, but I am also interested in other recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

**Recognize that I am an individual and the way I experience this disease is unique.** This disease affects each person in different ways and at a different pace. Please be sure to explain how this disease may change my life with this in mind.

**Alzheimer's is a journey, not a destination.** Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's.

## Some people with Alzheimer's say...

**"Getting a diagnosis can be a relief.** It helps explain why I feel this way and why things are harder to do. I accept it and live with it."

**"I'm not the same as I was since diagnosis.** It's so exasperating! Sometimes my mind goes someplace else...I cannot get a hold of it!"

**"It's much easier when you have a name for your problem** because you know why something is wrong and it is not your fault."

## My thoughts...

**When I first received my diagnosis, I felt:**

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**What the words "Alzheimer's" and "dementia" mean to me:**

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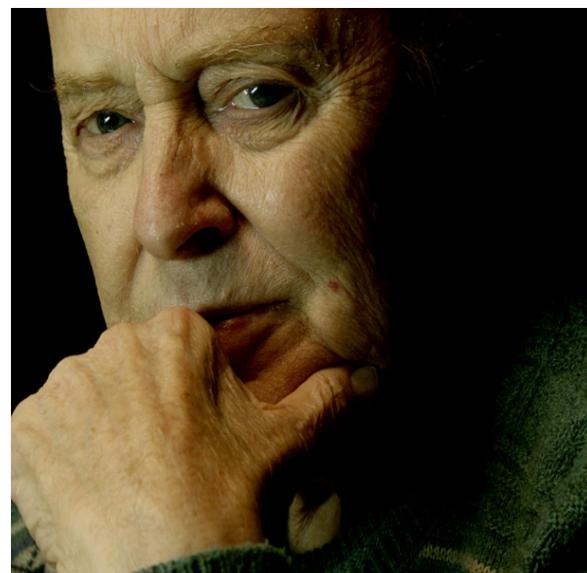
**What I want to know about Alzheimer's disease and dementia:**

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## Things I can do now:

- **Take time to adjust to the diagnosis.**
- **Discuss results** of my memory evaluation with my doctor.
- **Get a second opinion** if needed.
- **Ask lots of questions.**
- **Call the Alzheimer's Association** for information on programs and services.
- **Stay engaged and connected with others like you.**

### Notes:

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## 2. partnering with your doctor

Developing a working relationship with your doctor is a very important part of managing your illness. It can take some time, but it is very important that your doctor gets to know you. You can help by being open and honest.

Here are a few suggestions from professionals and people with memory loss that may be helpful.

### Prepare for the visit

- **Make a list of questions** as they come up, and take them to your next doctor's appointment. (Sometimes it is hard to remember everything you wanted to ask while you're at the doctor's office.)
- **Ask a family member or friend** to go with you. It helps to have someone there to ask questions and remember what the doctor said.
- **Write down the changes** that you and/or family members have noticed. Share this information with your doctor.
- **List all prescription medications, vitamins and over-the-counter medications** that you take, and share the list with your doctor (*use medication log on page 47*).

### At the doctor's appointment

- **Be open and honest** about how you feel mentally and physically. Truthfully answer the questions that the doctor asks. If you don't know the answers, let him or her know. This helps the doctor to understand how the disease is affecting you and what treatments can be prescribed to help.
- **Ask the doctor questions** that you have about the results of your memory testing or any other symptoms that you have.
- **Ask what medications or treatment options are available.** Inquire about whether you would be a good fit to participate in any clinical studies. Clinical trials can provide access to cutting-edge treatments and expert medical care.
- **Ask for specific information** about how to take care of yourself. Ask about options. Agree on a treatment plan.
- **Take notes during the doctor visit.** Request written information about your medical condition (*use appointment log on page 46*).

*In business and in family relationships, the most important thing is trust.*

— Anonymous

## **Some people with Alzheimer's say...**

Doctors can be helpful...

**"by giving clear information** about memory testing, evaluations and results."

**"by being honest about the diagnosis** and periodically discussing the progression of the illness."

**"by staying informed** about the latest medications and interventions."

**"by letting me know** about current research and clinical studies."

**"by treating me as a person,** not a disease."

## **My thoughts...**

**The people I want included on my health care team:**

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**The qualities I look for in a doctor:**

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**What I want my doctor to know about me:**

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**Questions for my doctor:**

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## Things I can do now:

- **Call the Alzheimer's Association** for a list of local doctors and diagnostic centers, as well as information about current treatments.
- **Keep a log of medical information.** Record physical, mental and emotional changes to share with my doctor.
- **Before each visit**, make a list of my top three concerns to share with my doctor.
- **Ask my doctor** what he or she knows about Alzheimer's disease.
- **Learn clinical studies** and decide whether or not they are a good option for me.
- **Bring an updated list of my prescription and over-the-counter medications** to each doctor visit.



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# 3. effective communication

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Alzheimer's disease affects many parts of your brain. Because of this, you may need to explore new ways to communicate with people.

## You may experience some of the following changes:

- Problems finding the right words or losing your train of thought.
- Repeating words, stories or questions.
- Getting words confused or out of order.
- Problems understanding what someone is saying to you.
- Problems with spelling or writing.

Communication is more than talking and listening. Communication is a way of letting people know what you are thinking, feeling or wanting.

Communication is an important part of your relationships with family and friends. If words and sentences become difficult for you, explore new ways to communicate. Be open and honest with your family and friends about how the disease is affecting you.

## Find new ways to communicate

- Slow down, take your time and don't worry about small facts or details.

- Find a quiet place where you will not be disturbed or distracted.
- Tell people when you are having difficulty speaking or understanding.
- Come back to it later.
- Try describing the person, place or thing if you cannot recall a name.
- If you use a notebook as a memory aid, carry it with you and refer to it as needed to help you communicate.

## It may help to know that:

- The changes you are experiencing are because of the disease.
- You will have good days and bad days.
- The disease affects each person differently and symptoms will vary.
- Trying different ideas will help you find comfortable ways to cope.
- Some suggestions may work for you and others may not.
- You are not alone — more than five million Americans have Alzheimer's.
- Talking with others who are also living with the disease can help you feel understood and supported.

## **Some people with Alzheimer's say...**

**"It feels good when people listen to me instead of telling me what to do."**

**"Do not keep asking me questions.** This can frustrate me and make me feel like I am being tested."

**"Because I cannot remember** does not mean that I am dumb."

**"When I forget, be patient with me.** Please do not make excuses for me. When you do, it makes me very angry and I may feel you do not understand what I am feeling inside."

## **My thoughts...**

**Talking is most difficult or frustrating when:**

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**The best time for me to discuss important matters is:**

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**When I have problems communicating, I want people to:**

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**When I have problems communicating, it helps me to:**

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## Things I can do now:

- **Take my time.**
- **Tell people that I have problems** concentrating, remembering and understanding at times because of the disease.
- **If I have a problem remembering, let it go, move on, forget it;** maybe it will come back later.
- **Write things down.** It may be easier to communicate and remember by using notes.
- **Find new ways to express myself.** Try painting, singing, writing, drama, etc.
- **Work out a signal to my family** when I need assistance with a word, thought, or when I want to take a break.
- **Recognize that I have a neurological disease** that can make it difficult to communicate.



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*A friend is someone who knows the song in your soul and sings it back to you when you have forgotten the words.*

— Anonymous

# 4. telling others about the diagnosis

When you learn that you have Alzheimer's disease or a related dementia, you may not believe it, or you may feel overwhelmed, confused, or angry. You may be hesitant to tell family and friends about your diagnosis due to concerns about how they will react. Perhaps you worry that they will treat you differently. You may not want sympathy or help, but you may want the people you are close with to know because you care about them. Having the support and understanding of your family and friends can help you enjoy life and live more independently.

## Who do you tell?

- People you know well and trust.
- People you love.
- People to whom you are responsible (partner, spouse, others).
- People from whom you may need assistance (neighbors, strangers).
- People who "need to know."
- Anyone you want.

## When do you tell family, friends and others about having Alzheimer's disease?

- When it feels like the right time.
- When it helps to explain what is



going on with you.

- When planning or making decisions about your future.
- When you need help from someone.
- When you know they need to know.
- When you want to educate someone about the disease.

*Friends in your life are like pillars on your porch. Sometimes they hold you up, and sometimes they lean on you. Sometimes it's just enough to know they're standing by.*

— Ralph Waldo Emerson

## **Some people with Alzheimer's say...**

**"Now that they know, they can help if something comes up...it's a relief that they know."**

**"I tell them when they recognize I'm not quite like I used to be. It helps explain what is going on."**

**"Your friends are your friends. Tell them what is happening to you."**

**"At first I tried to hide that I had memory problems, but when I finally told people, it was like a huge weight lifted off my shoulders."**

**"I can't change the diagnosis, but I can educate others. Talking about what it is like to have this disease reminds me that I still have something important to say."**

## **My thoughts...**

**I will know it is time to tell others about my diagnosis when:**

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**Deciding to tell others about my diagnosis makes me feel:**

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**My fears about telling others are:**

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## Things I can do now:

- **Be proud of myself** for having the courage to tell people.
- **Inform my family and friends.** Ask for their help telling others.
- **Tell people** that I sometimes have difficulty concentrating and remembering.
- **Tell people** that even though I have Alzheimer's, There are many things I can still do.
- **Participate in Alzheimer's Association programs** for people with early-stage memory loss. Invite a family member or friend to join me.
- **Educate others** about Alzheimer's disease. Provide materials from the Alzheimer's Association. The more they learn, the more comfortable they may feel.
- **Let people help me.** Know that it makes them feel good.

## Notes:

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*Courage and openness go hand in hand. Our courage helps us take the risk to try something new. When we are fearful, we see only one way. Courage opens the ways to new possibilities!*

— Anonymous

# 5. caring for our most important relationships: family and friends

Memory loss and other symptoms can bring about changes that affect relationships with family members and friends. In the beginning, it is natural for you and some family members to experience denial about your condition. Denial is common and it is a way to buffer oneself from the painful feelings that go along with having a diagnosis of Alzheimer's disease.

It is important to recognize that every individual will have a different reaction to your diagnosis. For each of them, as well as for you, it will take time to adjust. During this time, like some friends and family members may pull away and distance themselves a bit, while others will show an increasing amount of support and want to help.

In addition, you may feel that you need to rely on family and friends more than you used to and probably more than you want to. This shift in responsibility can lead to feelings of frustration, guilt or resentment. And unwanted help can feel overprotective or intrusive. Keep in mind that at some point in life, we all need help from others. Accepting help is a sign of strength even though it can be uncomfortable.

## **The following questions can help you determine if you need help:**

- Is an activity or task more frustrating and less enjoyable than before?
- If I make mistakes repeatedly, could I harm myself or others, such as when driving, paying bills or managing finances?
- Have I stopped doing something I enjoy because I can't do all the steps, such as baking, doing a hobby, or playing sports or games?
- Have I been confused about my medication or forgotten to take it?

It is essential to listen to trusted family members or friends when they express concern and ask for your cooperation in letting go of an activity or task. They may be aware of a change that you may not be because of your memory loss. As a person living with dementia, you can help friends and family by allowing others to help you. This new partnership not only helps in getting tasks done, it can also provide the opportunity to spend precious time with family and friends.

*The foundation of relationships is based on the premise of mutual purpose.*

— Ralph Waldo Emerson

## Some people with Alzheimer's say...

**"I don't like it when they tell me they are caregivers.** The word 'partner' seems better. We help each other. I don't need a babysitter."

**"Together we can get better results."**

**"People want to help where needed.** You do them a favor when you let them help you."

**"I don't want to be totally dependent.** I find ways that I can still contribute and be involved."

## My thoughts...

**The way Alzheimer's has affected my relationships:**

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**Ways I would like to see family and friends support me:**

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**Accepting help from others makes me feel:**

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## Things I can do now:

- **Allow myself to accept help from others.**
- **Focus on and celebrate the things I can do.**
- **Learn as much as I can about Alzheimer's** and encourage family and friends to ask me about what it is like to live with the disease.
- **Work with others I trust to identify activities** I need assistance with in order to reduce stress.
- **Share my feelings about how it feels to accept help** (what am I gaining and what am I losing?)
- **Connect with others** who have to talk to others with similar concerns.
- **Get individual or family counseling** to help resolve conflict and adjust to changes.
- **Remember to say "thank you"** to those who support me.



### Notes:

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# 6. making decisions

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We are all faced with making many decisions over the course of our lives. We make decisions daily such as what to eat, wear or do today. Other decisions are more complex and can affect our lives now and in the future.

Making decisions will gradually become harder because the disease can block your ability to process information — to remember, organize things, solve problems and even recognize when you are having difficulty making decisions.

It is important to choose someone to help you with decision making.

## Things to consider:

- Choose a person you trust to help you — often it is a family member.
- Choose a second person if the first person is unable to help when needed.
- Your feelings about receiving help with making decisions may fluctuate from relief to resentment.
- Get an outside opinion if you disagree with decisions that are made. An Alzheimer's care consultation can help.

- Discuss your wishes with your family or care partner. Important issues to discuss include: handling finances; when to stop driving; when to use community services for help with meals, transportation and activities; time-off for your primary care partner; your care and living arrangements when a change is necessary; and when to retire if you are still working.

## Tips for involving family:

- Identify those family members who can provide assistance.
- Advise family of what's needed instead of assuming they know.
- Stay in touch.
- Hold a family meeting.
- Recognize differences.
- Share responsibilities.



## **Who else do I want on my care team?**

Creating a support system early on in the disease process is important to ensure people are well aware of your wishes. In addition to your family, evaluate professional and community support systems:

### **Professional Support**

- Alzheimer's Association
- Case managers
- Geriatricians
- Neurologists
- Psychiatrists
- Counselors
- Lawyers
- Financial planners

*We may not always see eye to eye,  
but we can try to see heart to heart.*

— Sam Levenson

### **Community Support**

- Place of worship/faith community
- Neighbors
- Friends
- Clubs
- Senior centers
- Volunteer organizations
- Gym



## **Some people with Alzheimer's say...**

**“Feel OK about the change. Trust others to understand.”**

**“Being able to solve problems with others gives me hope.”**

**“Every bit of help is so important. Use please and thank you.”**

# My thoughts....

## **Two people who I would like to help me with making decisions:**

**1)** \_\_\_\_\_

2) \_\_\_\_\_

**If more assistance than my care partner, family and friends can provide, I would like:**

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**I want help with making decisions about/plans for:**

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**Allowing others to make decisions on my behalf makes me feel:**

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## Things I can do now:

- **Delegate decision making to someone I trust.**
- **Make a list of things** I want to discuss and for which I need to make plans.
- **Discuss with my family or care partner** what I want to happen if I can no longer take care of myself. (e.g., move to a residential setting or bring care into the home).
- **Build a support team** of family, friends, professionals and community resources.
- **Tell others my care preferences.** Complete advance directives and identify a durable power of attorney.
- **Be willing to try new services or involve new people** in my life to give my care partner time off.
- **Be patient and give myself time to adjust** to transitions.
- **Speak up for myself.** Make my needs known.

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# 7. legal and financial issues

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## Legal planning

There are a number of legal and financial documents that will help you formalize your plans and wishes. These are documents that everyone should have in place. However, when a person has an Alzheimer's diagnosis, there is no time to delay. Taking the time to put these documents in place now will be a big help to you and your family in the future. Encourage family members to complete these documents for themselves as well. If your situation is complex, consult with an elder law attorney, who can provide you with up-to-date, state-specific expertise.

- **Financial durable power of attorney.** In this document, you name a person to take care of your financial matters, in the event that you become unable to do so for yourself.
- **Medical durable power of attorney.** In this document, you name a person to carry out your medical decisions for you, in the event that you are unable to do so for yourself.
- **Living will.** This document states your preferences regarding life-sustaining treatments, in the event that you are unable to make decisions for yourself (e.g., use life support).
- **Will.** This document describes your financial estate, identifies an executor and beneficiaries and itemizes its distribution in the event of your death.
- **Do not resuscitate (DNR) order.** This document is a doctor's order that tells emergency personnel what to do if your heart and/or lungs stop. Talk with your doctor if you want to obtain one. State laws vary.
- **Hospital visitation form.** This document states who can visit you in the hospital and under what conditions.

It is especially important for people in domestic partnerships because in some states hospitals may enforce strict visitation laws and/or require special forms if the relationship is not legally recognized in that state

All of these documents express your wishes. Planning takes time and careful consideration. Once you have completed your plan, you can enjoy a feeling of confidence. Knowing that your wishes have been shared.

## Financial planning

Cost of care and household expenses can be big concerns after an Alzheimer's diagnosis. Whether you were retired or working when diagnosed, plans should be made for future care costs, including in-home help or residential care. Work with family members and develop a financial plan. If your finances are complex, consider meeting with a financial planner.

Many different sources can help pay for care and it is important to understand what services and types of care each one covers. These sources include:

- Insurance (e.g., Medicare, disability, retiree coverage, life insurance, long-term care insurance, employer-paid plan).
- Retirement benefits (e.g., individual retirement accounts, employee-funded retirement accounts, Social Security).
- Personal savings and assets (e.g., stocks, bonds, savings accounts, real estate).
- Government programs (e.g., Medicaid, Supplemental Security Income, Social Security Disability Insurance, Veterans Benefits, tax deductions and credits).

## Some people with Alzheimer's say...

**"I had someone help complete my advance directives and medical durable power of attorney."**

**"Write your wishes down. Make a list."**

**"I hope to be able to talk with my family about future plans."**

**"Do only what you can reasonably manage!** Reduce obligations and delegate details whenever possible."

**"I felt so much better** knowing my family wouldn't have to wonder what I would want."

## My thoughts...

**People who I want involved in my legal and/or financial affairs:**

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**Things that are important to me in my future care:**

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**I may need professional legal and/or financial guidance on:**

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## Things I can do now:

- **Make legal, medical and financial decisions early.** Talk with my family or friends about them. Make sure they know what kind of decisions I want made for my future.
- **Appoint a trusted family member or friend to help manage my finances.** This person can be a joint signer on bank accounts and could assist with bill paying.
- **Ask family members or friends to accompany me at appointments** with lawyers or other professionals. They can help explain and interpret information for me.
- **If I choose to work with a legal and/or financial professional,** I can bring a list of questions to ask.
- **Contact the Alzheimer's Association** to find out where to get lists of local elder law professionals who provide legal and financial assistance.



### Notes:

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*We have prepared for the worst and now we are planning to live the best. If the worst comes, we are ready for it. If it doesn't, we will have not wasted today worrying about it.*

— Bette Davis

# 8. playing it safe

An Alzheimer's diagnosis means it's time to take certain safety measures. This can help you and your family members feel more relaxed and prevent unnecessary problems from occurring.

## At home and away

Most accidents occur at home during everyday activities such as eating, bathing and using the bathroom.

Nevertheless, in the early stage of Alzheimer's disease, people can live safely in the comfort of their own or a care partner's home as long as safety measures are in place. Assess your home and consider incorporating these changes:

- Purchase small appliances that have automatic shut-off features if left on for too long.

- Install automatic shut-off equipment on the stove and oven.
- Use timers and written reminders of things to do to stay safe, such as taking medications on time, getting your eyes checked regularly, etc.
- Move hazardous materials to a special spot away from the kitchen.
- Check fire extinguishers, smoke detectors and carbon monoxide detectors, and replace batteries twice a year.
- Be sure the home and walkways are well lit, and use nightlights in bedrooms and bathrooms.
- Install grab bars and textured stickers to slippery tubs and showers.





- Remove clutter and tripping hazards throughout the house.
- Take precautions to ensure firearm safety. Keep firearms unloaded and locked. Consider moving firearms to a location outside of the home, or giving firearm collections as early inheritances to those who would have received them later.
- Prepare a kit containing extra sets of clothing and medication in case of an emergency. Include copies of important documents and phone numbers.
- Consider purchasing a MedicAlert® + Alzheimer's Association Safe Return® ID bracelet for you and your care partner. If one of you has an accident, the other will be contacted and the authorities alerted.

For more information about staying safe at home, visit the Tips for Daily Life section of the Alzheimer's Association website at [alz.org](http://alz.org).

### **To drive or not to drive**

A diagnosis of Alzheimer's disease or a disorder also means that driving will be impacted. While giving up driving does not seem to be a major issue for some, for others it represents a surrender of independence or a loss of freedom.

Even early Alzheimer's disease can make it hard to drive safely because the disease can cause temporary confusion, even in familiar areas. It also slows reaction time.

It is important that you, your family and friends all acknowledge what a difficult decision and change relinquishing your driving abilities

may be for all. Make sure you have alternative ways to continue doing the things you want to do. Try other forms of transportation such as taxis, public transportation or asking someone else to drive. Staying active and communicating your feelings about this decision will help you be in charge of your transportation plans. Take time to adjust to the change, when the time comes.

**Warning signs** that your driving may no longer be safe include:

- Incorrect signaling.
- Confusing the brake and gas pedals.
- Driving at inappropriate speeds.
- Frequently hitting curbs.
- Getting lost going to familiar places.
- Riding on the wrong side of the road.
- Failing to stop at red lights or stop signs.

At the earliest stage, a person with Alzheimer's disease may begin to have difficulty with complex tasks such as driving. Although family and caregivers can watch for signs of unsafe driving, a proactive strategy would be to get a comprehensive



driving evaluation by an occupational therapy driving rehabilitation specialist. The evaluation provides a more objective understanding of the current impact of the disease on driving capacity and results in a plan of options. The goal is always to retain the highest level of independence and mobility in the community. Initial recommendations may include strategies to reduce driving risk during the early part of the disease. The occupational therapist can offer strategies specific to the individual's goals and needs. The American Occupational Therapy Association website includes a national database of driving specialists as well as a wealth of resources for both persons with Alzheimer's disease and their families.

Ask your physician for a referral or call the Alzheimer's Association 24/7 Helpline at **800.272.3900** to learn if there are driving evaluation resources in your area. Although it may be hard to accept what others have to say, it's important to support your safety and the safety of others. Talking openly at this early stage will help everyone to plan for that time when you're no longer able to drive. If you have received a diagnosis and are still driving, it's probably a good idea to take a driver's test each year to make sure that you are still a safe driver.

To learn more about dementia and driving or to find driving evaluation resources, visit the Dementia and Driving Resource Center at **alz.org/driving**.

### **When you travel**

Traveling away from home also requires careful planning to ensure safety, comfort and enjoyment for everyone:

- Do what feels comfortable for you now, knowing that this may change.
- Be aware that changes in environment can trigger moments of confusion.
- Visiting places that were familiar before the onset of Alzheimer's may be easier than visiting new places.
- Evaluate options for the best type of travel. Based on your needs, abilities, safety and preferences, decide what would provide the most comfort and the least anxiety.





- If you have multiple health issues, plan trips where emergency health services and pharmacies (to refill prescriptions) are easily accessible.
- If you are flying or staying in a hotel, consider informing the staff ahead of time of any specific needs so they can be prepared to assist you.
- Consider a travel companion who can provide good company while easing the stress of travel logistics.
- Travel during the time of day when you feel the best.
- Allow plenty of time for rest. Don't over schedule.
- Have a backup plan in case your trip needs to change unexpectedly. This may mean buying traveler's insurance if you have booked flights or hotels.
- Create an itinerary that includes details about each destination. Give copies to family members or friends you will be visiting, or to emergency contacts at home. Keep a copy of your itinerary with you at all times.
- Keep a bag of essentials with you that includes medications, a comfortable change of clothes, water, snacks and activities.
- Necessary paperwork includes your travel itinerary, identification, a current medications list with all needed medical and insurance information, a list of emergency contacts and telephone numbers, and photocopies of important legal documents.
- Sign up for MedicAlert® + Alzheimer's Association SafeReturn® by calling **888.572.8566** or visiting [alz.org/safety](http://alz.org/safety).

## **Some people with Alzheimer's say...**

**"I love to drive and it makes me feel independent.** At the same time; I would hate to cause an accident and get hurt — or hurt someone else."

**"I moved to a senior living facility** and now I feel safe. It's reassuring."

**"Consider carrying a cell phone** so that if you get lost, you can call for help."

**"Take someone with you when you go out.** It is safer and more fun."

## **My thoughts...**

**People who can help me stay safe:**

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**I will know it is time to retire from driving when:**

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**Things that are important to me for my safety:**

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**The person I trust to tell me when to stop driving:**

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**Making safety plans about my future makes me feel:**

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## Things I can do now:

- **Keep a list of emergency telephone numbers** posted at each telephone.
- **Sign up for MedicAlert® + Alzheimer's Association SafeReturn®** by calling **888.572.8566** or visiting [alz.org/safety](http://alz.org/safety).
- **Use a pillbox** to help organize prescription medicine and vitamins. Have someone assist with reminders.
- **Use nightlights** in hallways, bedrooms, bathrooms and stairways.
- **Reduce the risk of falls** by removing tripping hazards such as throw rugs and clutter. Install grab bars in the shower or bathtub.
- **Ask family, friends and my physician** for their advice about when to retire from driving.
- **Consider getting assistance** with grocery shopping, meal planning, cooking and household repairs.
- **Find out about transportation services** in my community.



### Notes:

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# 9. daily strategies for living with alzheimer's

You and your family cannot see damaged brain cells in the same way that you can see skin rashes or infections. However, you will probably notice changes in your ability to do the things that you want to do. When you or your family notice these changes, it is time to make adaptations to your environment and/or daily routine to find new ways of doing things.

The disease affects different parts of your brain. Although you may clearly remember things from your past, you may not be able to remember recent events or schedules. Think of the changes you experience as symptoms of your disease and a "disability" that you can learn to live with. People with Alzheimer's disease have much to contribute. You have many abilities and other people to help you when you need support along the way.

## Strategies for successful coping with Alzheimer's

- Put fewer demands on recent memory by using notes, timers and other reminder tools.
- Keep a notebook containing important notes, such as phone numbers, people's names, appointments, your address and directions to your home.

- Write in a book or journal any thoughts or ideas you want to hold on to.
- Post important phone numbers in large print next to every phone.
- Do activities you enjoy at the time of day when you feel best.
- Educate yourself about the disease.
- For more tips from the others living with the disease, visit [alz.org/dailytips](http://alz.org/dailytips).

## Follow a familiar daily routine

- Maintain a consistent routine, taking advantage of the best time of day to undertake difficult tasks.
- Write down a daily, weekly or monthly schedule.
- Schedule important activities for the time of the day you feel best.
- Slow down — try to do fewer things each day and allow more time.
- Take a break if things get difficult.
- Use a calendar to keep track of time, schedules and appointments.

*It is time for all to stand and cheer for the doer, the achiever — the one who recognizes the challenge and does something about it.*

— Vince Lombardi

- Do one thing at a time.
- Remind yourself daily what you have and are able to do.

## **Partner with other people**

- Successfully complete things you can no longer do by delegating the tasks to others. You still enjoy the results.
- Be patient with yourself and others.
- Don't be afraid to ask for help.
- Try not to blame other people or yourself when the disease is to blame.
- Do things with others like shopping, preparing meals, housekeeping, exercising, yard work and paying bills.
- Have someone call to remind you of meal times, appointments or to take medication.
- Make a list of activities, people, or places that you enjoy now and schedule these things more frequently.
- Spend time with family and friends.
- Share your feelings with others.
- Acknowledge frustration or sadness by reaching out to others as needed.
- Celebrate small successes and occasions.
- Consider a support group, especially an early stage group for people with Alzheimer's who would like to take an active role in seeking help or helping others.

- Explain to others that you have a brain disease and need assistance.
- If you can't stop feeling sad or blue, consult a physician to determine if other problems are causing these feelings. Severe or prolonged sadness is not normal and can be treated.

## **Tips for a helpful environment**

- Eliminate clutter, noise, glare and too much background noise.
- Use labels as cues and reminders.
- Simplify tasks and routines.
- Find opportunities for exercise and activities geared toward your interests and abilities.
- Use stress-reducing activities like meditation, listening to calming music or exercise.



## **Some people with Alzheimer's say...**

**"Carry a calendar** in your purse or pocket and get a big wall calendar."

**"Try to stay organized.** I write things down by keeping a journal and making lists."

**"I use labels** on cupboards, drawers, etc."

**"Delegate to others or forget it.** Let some things go. Ask for help."

**"Ask people to give you reminders."**

## **My thoughts...**

**My biggest everyday frustration:**

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**Things I have found helpful:**

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**Things I would like help with:**

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**People I would like on my care team:**

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**Daily activities I participate in:**

- 1)** \_\_\_\_\_
- 2)** \_\_\_\_\_
- 3)** \_\_\_\_\_
- 4)** \_\_\_\_\_
- 5)** \_\_\_\_\_

## Things I can do now:

- **Keep clocks and calendars around the house** for easy reference. Use the calendar to mark off days and keep track of time.
- **Have a familiar routine each day.**
- **Keep important items like my keys, purse, glasses in the same place all the time.**
- **Make a “reminder” book.**  
**Keep it with me at all times.**  
Include emergency information, people's names, telephone numbers, important health information, a map of where I live, appointments, to-do lists, medications, thoughts I want to hold on to.
- **Use pillboxes** to remind me when to take my medications.
- **Hire someone to help with** housekeeping, cooking, yard work, etc.
- **Get an easy-to-read digital clock** that displays the time and date.
- **Use voicemail or an answering machine, and email to keep track of messages.**
- **Post important phone numbers in large print by the phone.** Include emergency numbers and my home address with a description of where I live.
- **Post daily activities and reminders on a whiteboard located in a prominent place.**



*Courage does not always roar.  
Sometimes courage is that quiet  
voice at the end of the day saying,  
“I will try again tomorrow.”*

—Mary Anne Radmacher

# 10. coping with changes

You are learning more about your disease and about what you can and cannot do. You are experiencing many changes in yourself, in your daily routine and in your relationships. Your feelings may be reflecting all of these changes as well.

It is very common for people with Alzheimer's disease to have periods of time when they feel like they are on an emotional roller coaster. You may feel worried, angry or sad more often than usual. You may have times when you are unsure of where to turn and that no one can possibly understand what you're going through.

You may also have periods when you feel lonely, embarrassed or guilty. Having these feelings is very normal. The ways you cope with them will be uniquely yours.

## **You are the only person who can change how you feel about your diagnosis.**

- Pay attention to your feelings and discuss them with your doctor, family and friends.
- Try to do things you enjoy to make yourself feel better.
- Express your emotions with people you trust.
- Use humor to cope with frustration. Laugh when you can.
- Use music, massage, writing, gardening, exercise and other activities to turn troublesome feelings into a hopeful, positive attitude. Always consult a physician before starting any exercise program.



- Join a support group of people with memory loss who are experiencing similar feelings. Use ALZConnected ([alzconnected.org](http://alzconnected.org)), an online social networking community powered by the Alzheimer's Association, to connect with others daily.
- Identify times that you have successfully dealt with challenges and feelings in the past.

See if you can use some of those techniques to help you adjust to your current situation.

*Not everything that is faced can be changed but nothing can be changed until it's faced.*

— James Baldwin

## **Some people with Alzheimer's say...**

**"Live each day to the fullest!"**

**"Do the things you can do."**

**"Get out of the house and walk. It helps keep you mentally and physically active."**

**"Don't give up. Keep trying."**

## **My thoughts...**

**My stress increases when:**

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**My stress decreases when:**

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**The things that help me reduce stress include:**

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**I feel best when:**

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**I feel sad when:**

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**I feel happy when:**

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**I feel angry when:**

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**I feel lonely when:**

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**I feel embarrassed when:**

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## Things I can do now:

- **Accept my changing feelings** as a normal part of living with Alzheimer's disease.
- **Enjoy more time with family and friends.**
- **Stay active, get involved,** volunteer, garden, take an art class; attend a movie, concert or ballgame; get involved with an Alzheimer's Association Social Engagement Program.
- **Participate in community centers** and activities for people with memory loss.
- **Have hope, and advocate** for myself and others.
- **Laugh as much as possible.**
- **Keep my body active.** Go for a walk with a friend or take an exercise class.
- **Listen to music.**
- **Be easy on myself** when I feel down. Know that this is normal. See my doctor if sadness persists.

*No one is useless in this world  
who lightens the burden of it to  
anyone else.*

— Charles Dickens



### Notes:

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# 11. opportunities for supporting research

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*Despite increasing momentum in Alzheimer's research, we still have two main obstacles to overcome.*

*First, we need volunteers for clinical trials. Volunteering to participate in a study is one of the greatest ways someone can help move Alzheimer's research forward.*

*Second, we need a significant increase in federal research funding. Investing in research now will cost our nation far less than the cost of caring for the rising number of Americans who will be affected by Alzheimer's disease in coming decades.*

—William Theis, Ph.D., senior scientist in residence, Alzheimer's Association

Over the last couple of decades, scientists have made enormous strides in understanding how Alzheimer's disease affects the brain. Many of these recent insights point toward new breakthroughs for treatment and risk reduction.

Scientists continue to make new discoveries, and progress is advancing very quickly on many fronts. In fact, at any given time, several hundred studies are recruiting participants to help explore these exciting new approaches.

You can make a difference! Research, including clinical studies, is the engine that powers medical progress. Scientists work constantly to find better ways to treat diseases. Improved treatments can never become a reality without human volunteers. No one ever chooses to become ill, but anyone can consider helping to advance knowledge about an illness affecting them or someone close to them.

Without participants, however, the progress is stalled, and scientists report growing difficulty finding enough volunteers to complete these studies.

Ultimately thousands benefit from the willingness of those who choose to become involved.

## Alzheimer's Association TrialMatch®

TrialMatch is a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's disease, caregivers, healthy volunteers and physicians with current studies. Our continuously updated database of 225+ Alzheimer's clinical studies includes both pharmacological (drug) and non-pharmacological (non-drug) studies being conducted at more than 700 sites across the country.

Participating in clinical studies gives us optimism for today and promise for the future. They provide many participants with access to cutting-edge treatments and expert medical care. And some day they will lead us to the end of this devastating disease.

We need clinical studies to accelerate progress and provide valuable insight into potential treatments and methods of prevention. Without participation, finding a cure is virtually impossible.

Access TrialMatch online at [alz.org/trialmatch](http://alz.org/trialmatch). For additional assistance, email [trialmatch@alz.org](mailto:trialmatch@alz.org) or call **800.272.3900**.

## **Some people with Alzheimer's say...**

**"Trust that researchers are trying to find the cure."**

**"Research gives you courage."**

**"We can all help contribute to research by participating and advocating."**

## **My thoughts...**

**I would be willing to participate in research studies if:**

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**Being in a research study would make me feel:**

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**Some questions I would have for the researchers:**

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*Participating in research is an active altruism, a way to give to future generations.*

— Unknown

## Things I can do now:

- **Stay informed** of new research findings and stories about Alzheimer's disease by visiting [alz.org/research](http://alz.org/research).
- **Ask my doctor** or call the Alzheimer's Association about current research studies that I might be interested in participating in.
- **Work with the Alzheimer's Association, family and friends** to help raise money for research and become an advocate and ask our elected officials to support Alzheimer's research.
- **Spread the word** that research is the key to us achieving our vision of a world without Alzheimer's disease.
- **Inform my doctor about any research studies** I am participating in.
- **Sign up for research e-news updates** at [alz.org/research](http://alz.org/research).

## Notes:

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# 12. resources for people with early alzheimer's disease

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## Individual and family care consultation

Care Consultation is a service that can help you and your family develop a road map to navigate through the many thoughts, emotions and questions you may have about memory loss and dementia. Care Consultation can be useful whether you or someone you love has just been diagnosed, or if you and your family are seeing things from different perspectives and perhaps disagreeing about the next steps to take.

## Education classes

The Alzheimer's Association provides workshops, in-person and online to help you and your family and friends increase understanding of memory loss, develop coping strategies, and learn how to make legal and financial plans. To learn more, contact the Alzheimer's Association at **800.272.3900** or visit [alz.org](http://alz.org).

## I Have Alzheimer's Website

The I Have Alzheimer's Disease website ([alz.org/IHaveAlz](http://alz.org/IHaveAlz)) helps you learn about Alzheimer's and what to expect after a diagnosis, as well as information on treatments and research and tips on how to live your best life.

## Support Groups

The Alzheimer's Association offers professionally led support groups for people in the early stages of Alzheimer's disease and their care partners.

## Community Resource Finder

A comprehensive database of local programs and services, housing and care options, and legal experts all in one location, allowing users to quickly search, find and access support. Visit [alz.org/crf](http://alz.org/crf).

## Care Team Calendar

A free, personalized online tool, powered by Lotsa Helping Hands, that makes it easy to organize family and friends who want to help with caregiving and share activities and information among the care team. Visit [alz.org/carecalendar](http://alz.org/carecalendar).

## Alzheimer's Navigator®

An interactive online tool for people living with dementia and those who participate in providing care and making care-related decisions. This assessment tool evaluates needs, outlines action steps and links the user to Alzheimer's Association chapter programs and local services. Visit [alz.org/alzheimersnavigator](http://alz.org/alzheimersnavigator).

## ALZConnected®

An online community where people with Alzheimer's and other dementias, caregivers and others affected by the disease can share questions, experiences and practical tips via message boards or create private groups organized around specific topics. Visit [alzconnected.org](http://alzconnected.org).

## **Alzheimer's Association National 24/7 Helpline 800.272.3900**

The 24/7 Helpline is a constant resource of information and support. Information specialists and counselors are available 24 hours a day, 7 days a week and 365 days a year.

### **Other Online Resources**

- [nia.nih.gov/alzheimers](http://nia.nih.gov/alzheimers)  
National Institute on Aging



*Much of what we see depends on  
what we are looking for.*

— Phil Calloway

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# APPOINTMENT LOG

## APPOINTMENT

DATE	PATIENT
TIME	AM/PM
	DOCTOR

## TOP 3 CONCERNS

1.

2.

3.

## NOTES

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## TO DO

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## NEXT APPOINTMENT

DATE	PATIENT
TIME	AM/PM
	DOCTOR

# MEDICATION LOG

DATE	PATIENT
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<b>MEDICATIONS</b> Prescription, Over-the-counter, Vitamins, Herbal Supplements						
Prescribing Doctor	Medication	Dosage	Date Started	What for	Side Effects	Instructions
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						
9.						
10.						

<b>ALLERGIES</b>

<b>MEDICAL CONDITIONS</b>

<b>THINGS TO AVOID</b>

# acknowledgements

The *Living With Alzheimer's for People with Alzheimer's* **Taking Action Workbook** is the fourth edition of the *Taking Action Workbook* initially developed by the Alzheimer's Association Colorado Chapter and then revised and updated by the Alzheimer's Association Minnesota–North Dakota Chapter. It serves as the participant workbook for the Living with Alzheimer's for People with Alzheimer's constituent education program.

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The Alzheimer's Association is the world's 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®.**

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**800.272.3900**  
**alz.org**

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