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living with alzheimer's

for people with alzheimer's

Part One



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Objectives

- Explain Alzheimer's disease, dementia and the diagnostic process.
- Describe the important things to plan after a diagnosis of Alzheimer's.
- List effective strategies for coping with the day-to-day challenges of Alzheimer's.

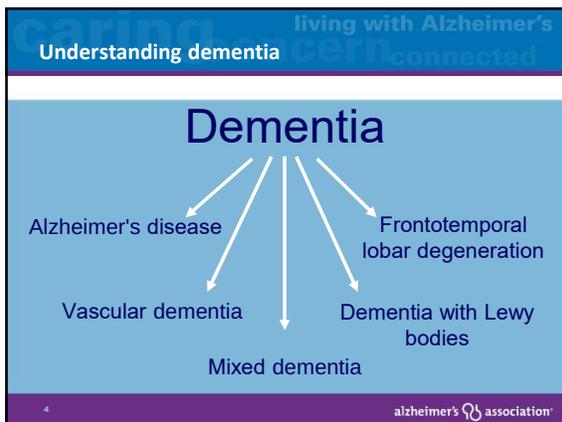
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Understanding memory loss

- Normal Aging
- MCI
- Dementia
 - Recent memory
 - Language
 - Visual and spatial function
 - Executive function
- Alzheimer's





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 Understanding Alzheimer's

Causes and risk factors:

- Advancing age
- Family history
- Genetics
- Risk factors and brain health

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 Understanding Alzheimer's

Symptoms include:

- Memory Loss (short term, long term)
- Language difficulties (speaking, listening, reading, writing)
- Disorientation (time, place)
- Executive function difficulties (problem-solving, judgment, complex tasks)

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The importance of a diagnosis

- Physical examination
- Medical history
- Mental status evaluation
- Neurological examination
- Laboratory tests
- Neuropsychological evaluation
- Psychiatric evaluation



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Living with the diagnosis

Later in this program, we will talk to our panel about:

- How does it feel?
- Changing expectations.
- Dealing with stigma.



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Things to do now:

- Take time to adjust to this diagnosis.
- Discuss results of your memory evaluation with your doctor.
- Get a second opinion if needed.
- Ask lots of questions.
- Call the Alzheimer's Association for information on programs and services.
- Stay involved in the community.

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Partnering with your doctor

well informed safety family relationships connection making decisions changes understanding memory resources daily strategies caring legal and financial issues

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Preparing for a doctor visit

- Make a list of questions.
- Take a family member or friend.
- Write down all the changes.
- List all meds.
- Schedule appointments at a time you feel your best.

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At the doctor's appointment

- Be open and honest.
- Ask the doctor questions.
- Ask about medications/treatments.
- Ask for specifics. Ask until you understand.

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At the doctor's appointment



- Take notes.
- If you wear a hearing aid or glasses, make sure you wear them to the appointment.
- Ask for an appointment schedule.
- Ask when you should contact the office.

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Things to do now...

- Call the Alzheimer's Association for a list of local doctors, diagnostic centers, and current treatments.
- Keep a log of medical information. Record changes to share with my doctor.
- Before each visit, make a list of my top 3 concerns to discuss.
- Ask my doctor how much he or she knows about Alzheimer's disease.
- Consider clinical trials.
- Bring an updated list of my prescription and over-the-counter medications to each doctor visit.

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Effective communication



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Communication 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.



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Finding new ways to communicate

- Slow down.
- Find a quiet place.
- Tell people you are having difficulty.
- Come back to it later.
- Try describing when you can't name something.
- Carry a small notebook.

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It may help to know that:

- The changes are part of the disease.
- You will have good days and bad days.
- Everyone experiences the disease differently.
- Try different ideas for coping.
- Some ideas will work and others may not.
- You are not alone. Over 5 million Americans have Alzheimer's.
- People who understand what you are going through can help you and your family.

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 Things to do now:

- Take your time.
- Tell people that at times the disease causes problems concentrating, remembering and understanding.
- If you have a problem, let it go, move on, try again later.
- Write things down. Try using notes.
- Consider new ways to express yourself.
- Recognize that you have a neurological disease.

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Telling others about the diagnosis

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 Who do you tell?

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

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When do you tell?



- When it feels like the right time.
- When you know that they need to know.
- When you need help or assistance from someone.
- When it helps to explain what is going on with you.
- When planning or making decisions about your future.
- When you are alone with the person that you want to tell.

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Things to do now:

- Be proud of yourself for having the courage to tell.
- Inform family & friends. Ask for their help telling others.
- Tell people you sometimes have difficulties concentrating and remembering.
- Tell people that just because you have Alzheimer's does not mean you need help with everything.
- Attend a care consultation. Invite a family member to go with you.
- Educate others about Alzheimer's disease.
- Let people help. Know that it makes them feel good to help.

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End of Part One

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Part Two

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Family and friends: Caring for our most important relationships

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Do you need help? Ask yourself:

- Is an activity or task more frustrating and less enjoyable than before?
- If I make mistakes repeatedly, can 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, a hobby, sports or games?
- Have I been confused about my medication or forgotten to take it?

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Possible causes of family conflict

- Lack of understanding about the disease.
- Denial.
- Emotional response to role and relationship changes.
- Lack of awareness of how much help is needed.
- They haven't been asked to help.
- Combination of all the above.



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Dealing with conflicting views



- Have a family meeting.
- Discuss your concerns openly.
- Contact the Alzheimer's Association for a Care Consultation.
- Seek help from a trusted friend, attorney or clergy.
- Hire a geriatric case manager.
- Work with your physician.

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Important issues to discuss

- Handling finances.
- When to retire from driving.
- When to use community resources for help with:
 - Meals and transportation.
 - Activities.
 - Time-off for your primary care-partner.
 - Your care and living arrangements when a change is necessary.
- When to retire if you are still working.

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Things to do now:

- Allow yourself to accept help from others.
- Focus on what you can do.
- Learn as much as you can about Alzheimer's.
- Work with those you trust to identify where you need assistance.
- Share feelings about how it feels to accept help.
- Attend a support group to talk to others with similar concerns.
- Consider individual or family counseling.
- Remember to thank to those who support you.

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Developing Your Decision Team

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Making decisions as a family

- Identify members of your family who can assist you.
- Advise family of what's needed instead of assuming they know.
- Stay in touch.
- Hold a family meeting.
- Recognize differences.
- Share responsibilities.
- Continue to communicate feelings/tension.

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Who else do you want on your team?



- Professional support
- Community resources

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Things to do now:

- Delegate decision-making to someone you trust.
- Make a list of things you want to discuss.
- Discuss future living options.
- Build a support team of family, friends, professionals and community resources.
- Tell others your care preferences.
- Be willing to try new services and involve new people.
- Be patient and give yourself time to adjust to transitions.
- Speak up for yourself and make your needs known.

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Playing it safe



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Medications

- It can be difficult to remember important things like taking medication.
- Using a pill organizer can help.
- A care partner can help fill it once a week and provide reminders
- Predictable routine helps



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Living alone



- In early stages many people can live alone safely.
- Gradually more help is needed.
- At some point living alone is no longer a good option.
- Planning now can help support independence and quality of life.

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Prevent crisis and preserve choice

- It may be difficult to talk about safety issues.
- However planning ahead helps to:
 - Reduce the potential for crisis.
 - Reduce fear and confusion.
 - Reduce family conflict.
 - Preserve choice.



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To drive or not to drive



- Driving should be part of the safety discussion.
- Even in early stages driving can be affected.
- Discuss it openly with family and trusted friends.
- Make a plan for good transportation options so as to remain active when driving is no longer safe.

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Signs it's time to reevaluate driving

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



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Getting lost

- Temporary confusion with time or place is common.
- Depth perception and other changes can also contribute to disorientation.
- Familiar places can seem unfamiliar.
- Retracing steps can be difficult.



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Travel planning

- Keep travel simple and manageable: Consider short trips and avoid multiple stops.
- 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 mode of travel.
- Plan trips where medical services are easily accessible.
- If you are flying or staying in a hotel, inform the staff ahead of time of any specific needs.

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Things to do now:

- Keep emergency telephone numbers at each telephone.
- Incorporate kitchen safety strategies.
- Use a pillbox to help organize medication.
- Use nightlights.
- Ask for help as needed with grocery shopping, meal planning, cooking and household repairs.
- Ask family, friends, and physician for advice about when to retire from driving.

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Daily strategies

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Strategies for successful coping

- Put fewer demands on recent memory.
- Keep a notebook containing important information.
- Journal thoughts or ideas you want to hold on to.
- Post important phone numbers next to every phone.
- Do activities you enjoy at the time of day you feel best.
- Educate yourself about the disease.
- Try memory aid suggestions and checklists.

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Follow a familiar daily routine

- Maintain a consistent routine.
- Write down a daily, weekly or monthly schedule.
- Schedule important activities for the time of the day you feel best.
- Slow down – do fewer things and allow more time.
- Take a break if things get difficult.
- Mark off days on a calendar to keep track of time.
- Do one thing at a time.
- Remind yourself daily what you have to do.

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Tips for a helpful environment

- Eliminate clutter, noise, glare, and background noise.
- Use labels.
- Simplify tasks and routines.
- Find opportunities for exercise and activities.
- Develop soothing rituals.



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Coping with changes

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Dealing with feelings

Accept your feelings. Work through the bad ones to get to the good ones:

- Pay attention to your feelings and discuss them.
- Do things you enjoy.
- Express your emotions with people you trust.
- Use humor, music, massage, writing, gardening, exercise, etc.
- Join a support group of people with memory loss.
- Recount past times you've overcome challenges.

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Staying active

- Join an Early-Stage Support Group.
- Get plenty of exercise.*
- Get good nutrition.
- Connect with others.
- Engage in brain-stimulating activities you enjoy.
- Volunteer.

**Always consult a physician before starting any exercise program.*

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Coping with sensory changes

- Focus on strengths.
- Use humor.
- Normalize vs. stigmatize.
- Ask for help when you need it.
- Modify and simplify.

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People with Alzheimer's disease are:

- Writing books.
- Running 5K's with their grandchildren.
- Writing poetry.
- Creating beautiful artwork, some for the first time.
- Giving presentations about experiences with Alzheimer's.
- Serving as advisors to the Alzheimer's Association.
- Organizing a Walk to End Alzheimer's team.
- Making their voices heard and living meaningful lives.
- Advocating to their senators and representatives.

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Things to do now:

- Accept my changing feelings.
- Enjoy more time with family and friends.
- Stay active, get involved.
- Participate in activities for persons with memory loss.
- Have hope and advocate for myself and others.
- Laugh as much as possible.
- Be easy on myself when I feel down.
- Get a massage.
- Listen to music.

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Alzheimer's Association TrialMatch®

- Free service to help match people to current clinical trials.
- People can locate clinical trials based on diagnosis, location, etc.
- 800-272-3900 or www.alz.org/trialmatch.



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Get involved



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volunteer



THE LONGEST DAY

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Questions?

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