

# Effectively Communicating with Clients and Families living with Alzheimer's

Presented to:



July 2016

alzheimer's  association®

# Housekeeping

- We are recording this session
  - Will be available on our website in the coming days
  - [www.colorado.gov/hcpf/long-term-services-and-supports-training](http://www.colorado.gov/hcpf/long-term-services-and-supports-training)
- Please use the chat panel to enter your questions
  - We will stop periodically to answer questions
- Files Panel
  - Click to download presentation

# What you will learn

- Understand the basics of the disease
  - Causes/Types
  - Symptoms
- Care and supports
- Communication Challenges
- Tips and Techniques
- Resources

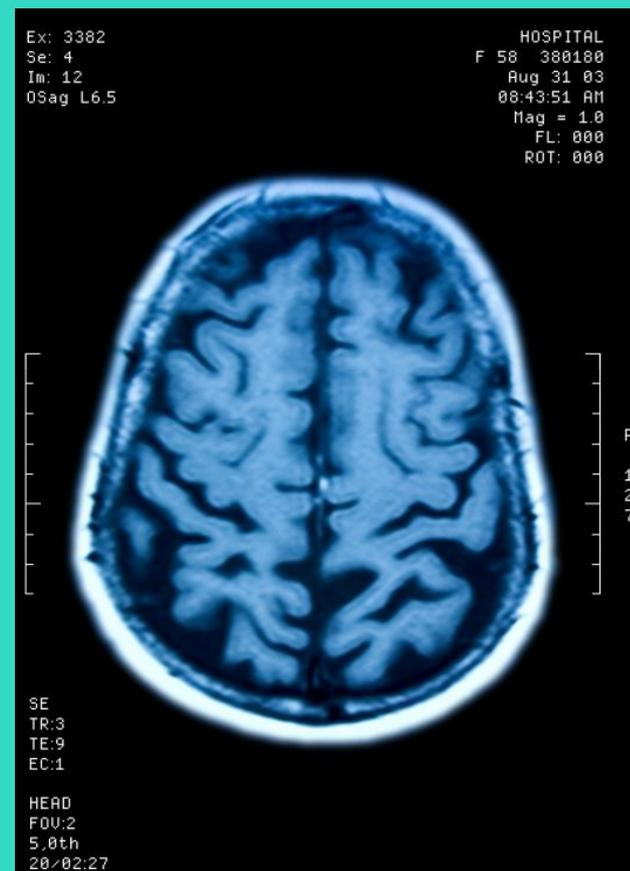
# Colorado Numbers

- 67,000 people age 65 and older with Alzheimer's disease
- 76,000 are expected in 2020
- In 2015 there were 239,000 caregivers in Colorado
- Those caregivers provided 272,000,000 hours of unpaid care



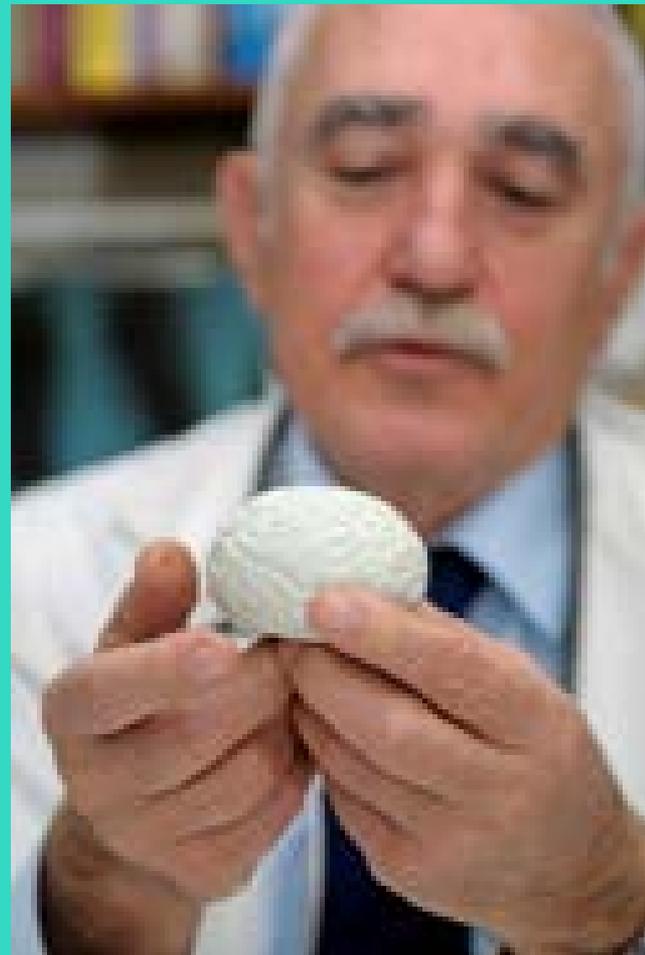
# Dementia

- Refers to a variety of symptoms that alert us to cognitive impairment
- Issues may arise with perception, organization, language, attention, reasoning, judgement, abstract thinking or memory
- Can be reversible or irreversible



# Reversible Dementias May Be Due To:

- Medication interactions
  - Infections
  - Thyroid disorders
  - Vitamin deficiencies
  - Depression
- 
- Accounts for up to 9% of people with symptoms



**See a doctor!**

# Non-Reversible Causes of Dementia

- An estimated 60-80% of the time the symptoms are caused by **Alzheimer's disease**
- **Vascular dementia** accounts for 10% of dementia cases but often co-exists with other types of dementia
- **Dementia with Lewy bodies** is more likely identified by the symptoms of sleep disturbance, well formed hallucinations and movement disorder
- **Frontotemporal lobar degeneration (FTLD)** often develops at a younger age and accounts for about 10% of dementia cases

# Different Causes = Distinct Symptoms

- The brain has 100 billion nerve cells (neurons). Each nerve cell connects with many others to form communication networks.
- Groups of nerve cells have special jobs. Some are involved in thinking, learning and remembering. Others help us see, hear and smell.
- When the cells in a certain area are affected by misfolded proteins (plaques and tangles) those brain cells malfunction and die.
- As brain cell death spreads to different areas of the brain, symptoms become more pronounced.

# This is a Fatal Disease

- Right now there is no cure
- Medications treat symptoms but do not address the spreading cell death as the disease progresses
- Persons become less mobile and more sedentary
- Persons are susceptible to opportunistic infections



# Diagnosis

Anyone with symptoms should see a physician that is skilled at diagnosing dementia related diseases

Clinical exam

Medical history

Assessment of multiple cognitive domains

Lab tests

Non-contrast CT or MR scan



# Probable / Possible Alzheimer's

- Probable Alzheimer's
  - All other disorders that could cause the dementia have been ruled out
  - Symptoms are most likely the result of AD
- Possible Alzheimer's
  - Alzheimer's is probably the primary cause of the dementia but other disorders may be affecting the progression of symptoms

# Questions



# Duration of Illness

- People age 65 and older survive an average of 4-8 years after receiving a diagnosis
- Some live as long as 20 years with the disease
- On average, a person with Alzheimer's or Dementia will spend 40% of their remaining years in the most severe stage
- Nursing home admission occurs by age 80 for 75% of people with Alzheimer's or Dementia (compared to 4% of the general population)

# Early Stage –

Friends, family or neighbors begin to notice difficulties

Elements of thought that will be affected include:

- P - perception
- O - organization
- L - language
- A - abstraction
- R - reasoning
  
- J - judgement
- A - attention
- M - memory



# Early Stage - Communication Challenges

- Size of vocabulary
- Ability to “find” the right word
- Speed of processing information
- Maintaining a train of thought
- Ability to remember details and/or new information



# Ways to Connect – Early Stage

- Give the person your full attention
- Allow time for them to process and respond
- Break down your messages
- Avoid pronouns and acronyms – be exact
- Do not generalize – be specific
- Summarize and confirm your understanding of what was said or done
- Avoid “reality checks”
- Validate the person and their reality
- Apologize even when “in the right”

# Middle Stage –

Symptoms will be obvious to others and may include:

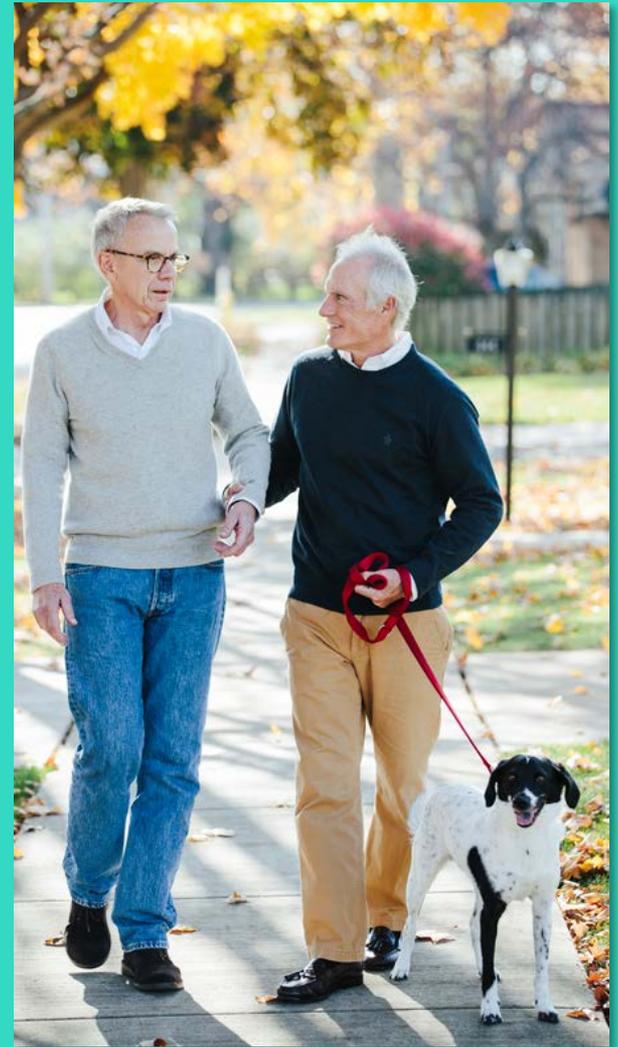
- Increased forgetfulness of events & recent history
- Feeling moody or withdrawn
- Increased confusion about where they are or what day it is
- Need more help with IADLs and ADLs
- Changes in sleep patterns
- An increased risk of wandering and becoming lost
- Personality and behavioral changes
- Mobility issues begin or worsen

# Middle Stage - Communication Challenges

- Difficulty expressing thoughts and emotions
- Trouble understanding others
- Speaking less often
- Continued word find issues
- Increased repetition
- Increased use of made-up words
- Continued issues with train of thought
- Increased frustration

# Ways to Connect – Middle Stage

- Anticipate needs
- Know likes and dislikes
- Know habits and preferences
- Validate the person and their reality
- Apologize even when “in the right”
- Avoid “reality checks”
- Break down your messages
- Avoid pronouns and acronyms



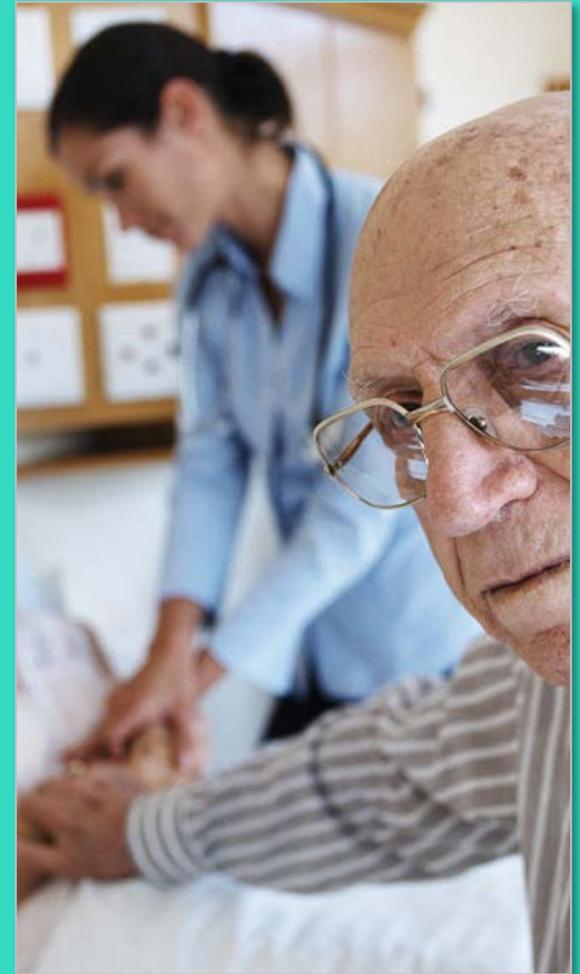
# Late Stage –

Caregiving changes from assistance to total care

- Unaware or unsure of surroundings
- Total care related to (ADLs and IADLs)
- Decline in physical abilities, including the ability to walk, sit and, eventually, swallow
- Communication less verbal – “word salad”
- Vulnerable to infections, especially pneumonia

# Ways to Connect – Late Stage

- Use the 5 senses
- Learn non-verbal cues
- Focus on emotion
- Be in the moment with the person



# Risks throughout the disease progression

## For the client

- Excess disability
- Social withdrawal
- Frustration

## For the caregiver

- Caregiver isolation
- Social withdrawal
- Burn out



# Questions



# Living with Alzheimer's

- Appropriate use of available treatment options
- Manage coexisting conditions
- Coordinated care with a team approach
- Live active and engaged lives
- Take advantage of supportive services

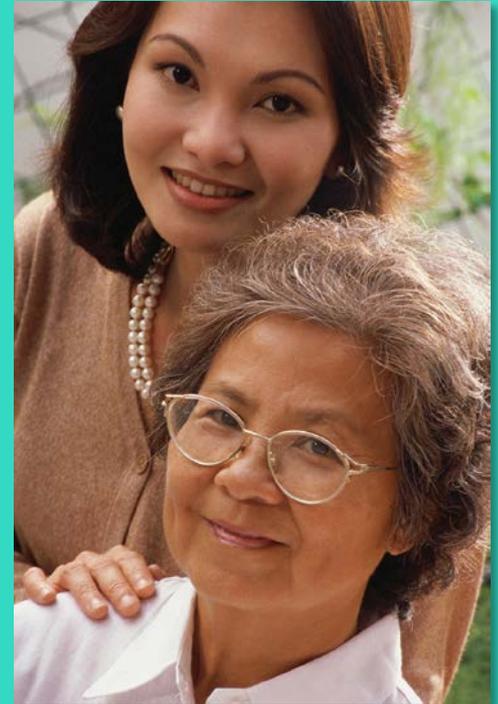


# Impact of Alzheimer's Caregiving

- As the disease progresses and symptoms worsen, the care required of family members can result in:
  - increased emotional stress and depression;
  - new or exacerbated health problems; and
  - depleted income and finances
- In the year before death, 59% of caregivers felt they were “on-duty” 24 hours a day, and many felt that caregiving during this time was extremely stressful

The care provided to people with Alzheimer's disease and other dementias is wide-ranging and in some instances all-encompassing

- ADLs and IADLs
- Medication management
- Adhere to treatment recommendations
- Finding and using support services
- Hiring and supervising paid help
- Communication with all concerned parties
- Financial management
- Emotional support



# Active & Passive Listening

- Respond in a way that lets the caller know you are listening and confirm your understanding of the person's needs by:
  - Paraphrasing – ensure you have the message right and encourages elaboration
  - Ask a clarifying question – another way to confirm need
  - Reflecting – focus on the emotion rather than the content

# Active & Passive Listening

- Respond to the caller's needs
  - Provide information
  - Provide referrals
  - Help problem solve
  - Provide emotional support
- Summarize the call
  - Review what was discussed
  - Resources provided
  - Review "next steps"

# Our Programs and Services:

- [alz.org](http://alz.org)
- [alz.org/co](http://alz.org/co)
- 24-hour Helpline: 800.272.3900
- Community Education Classes
- Professional Education Classes
- Support Groups
- Care Consultations
- Rapid Referral
- MedicAlert® and Alzheimer's Association Safe Return®

# Rapid Referral Program

- The easiest way to link families to a counselor at the Alzheimer's Association
- This free service offers your clients the benefit of personalized support
- Regional office fax numbers are listed
- This form is available in the **files panel**

**alzheimer's  association**

**RAPID REFERRAL**  
No Cover Sheet is Needed  
FAX NUMBER: 303-962-9069

DATE: \_\_\_\_\_

Person to Contact: \_\_\_\_\_ Phone: \_\_\_\_\_

E-mail: \_\_\_\_\_ Zip Code: \_\_\_\_\_

Language Preference: \_\_\_\_\_

Please contact within:  2-3 Business Days  1-2 weeks  Other (\_\_\_\_\_)

I am a person diagnosed with dementia.

Or  I am a caregiver for a person with dementia.

Person with Dementia's Name: \_\_\_\_\_

Caller's Relationship to the Person with Dementia: \_\_\_\_\_

Issue/Concern:  Wants General Information  New Diagnosis  Early Stage  Caregiver Stress  
 Other (Specify: \_\_\_\_\_)

I give my permission to:

Provider Name: \_\_\_\_\_ Title: \_\_\_\_\_

Phone: \_\_\_\_\_ E-Mail/Fax: \_\_\_\_\_

Give my name and telephone number to the Alzheimer's Association Colorado Chapter, so that a representative from the Chapter can contact me about the support and educational opportunities that are available.

I understand that my name and phone number will not be given to any other agency other than for the purpose stated above. This form will expire on the following date: \_\_\_\_\_

I understand that I can revoke my permission at any time by contacting the above named referring provider.

Signature: \_\_\_\_\_ or Verbal Permission Given:

ALZHEIMER'S ASSOCIATION COLORADO CHAPTER  
Office: 303.813.1669 Fax: 303.962.9069  
24-Hour Helpline 800.272.3900

12/2015

# ALZConnected.org

Online  
Social  
Networking  
Community



**Community Resource Finder**

Locate Alzheimer's and dementia resources with this free easy-to-use tool.

START  
SEARCHING





[Sign In](#) [ALZ.org](#) [Local Resources](#) [Donate](#) [Contact](#) [Site Help](#) [Feedback](#) [JOIN NOW](#)

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Q Search

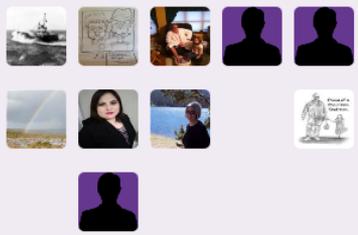
[Archive](#)

[Discussion Board](#)

Forum	Topics	Posts	Last Post
 <p><b>Caregivers Forum</b> A place to connect if you are a spouse, an adult child, a grandchild, a neighbor or a friend.</p>	19441	147356	Friday, May 13, 2016 4:12 PM by <a href="#">Stephanie Z</a>
 <p><b>Spouse or Partner Caregiver Forum</b> Although all caregivers face some common issues, there are unique experiences faced by spouses and partners. Here you will find others who share those experiences.</p>	9700	110713	Friday, May 13, 2016 5:37 PM by <a href="#">irisized</a>
 <p><b>I Have Alzheimer's or Another Dementia</b> If you have Alzheimer's or another dementia, this forum is for you.</p>	584	3301	Wednesday, May 11, 2016 6:08 PM by <a href="#">Mimi S.</a>
 <p><b>Younger-Onset AD or Other Dementia</b> If you are under age 65 and have Alzheimer's disease or another dementia, use this forum to connect with others in the same situation.</p>	2202	17569	Friday, May 13, 2016 4:26 PM by <a href="#">lisabramey</a>
 <p><b>LGBT Community and Allies</b> A place to connect for those facing issues affecting the LGBT community.</p>	37	133	Monday, May 9, 2016 7:42 AM by <a href="#">ALZC-Moderator</a>
 <p><b>Clinical Trials</b> Discuss questions, issues and concerns about FDA-approved treatments for Alzheimer's disease and clinical trials focusing on Alzheimer's disease and related dementias.</p>	817	3376	Friday, May 13, 2016 9:39 AM by <a href="#">Lane Simonian</a>

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**Online Now**



**Your Groups**

You are not in any groups yet.

[Find Group](#) | [Start Group](#)

# alzheimersnavigator.org

Create a  
customized  
action plan

## Action Steps ?

Knowledge of Alzheimer's

Take the online Brain Tour.

**I am finished**  Add Notes

Learning how Alzheimer's affects the brain will give you a better understanding of why memory, personality and physical capabilities are affected by the disease. Click [here](#) to take the online [Brain Tour](#).

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Knowledge of Alzheimer's

Learn about the facts of Alzheimer's disease.

**My needs changed** Completed 12/01/2015 by Liz  Add Notes

Click [here](#) to learn about the facts of Alzheimer's disease.

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Knowledge of Alzheimer's

Sign up for eNews.

**I am finished**  Add Notes

Stay up-to-date on the latest news and advances in Alzheimer's treatments, care and research. Get tips for living with Alzheimer's as well as simple ideas on how you can support the fight to end Alzheimer's. Click [here](#) to learn more.

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Knowledge of Alzheimer's

Read the "Basics of Alzheimer's Disease" brochure.

**I am finished**  Add Notes

As we age, most of us eventually experience some slowed thinking and have trouble remembering certain things. However, serious memory loss, confusion and other major changes in the way our minds work are not a typical part of aging. Read the [Basics of Alzheimer's Disease](#) brochure to learn more.

# Regional Offices & Counties Covered

Colorado Springs Barbara Caudle 719-266-8773  
Elbert / El Paso / Park / Teller **FAX: (719) 266-8798**

Greeley Kelly Walker 970-392-9202  
Kit Carson / Lincoln / Logan / Morgan / Phillips / Sedgwick  
Washington / Weld / Yuma **FAX: (970) 346-9025**

Fort Collins Katie Fahrenbruch 970-472-9798  
Grand / Jackson / Larimer / Grand / Routt **FAX: (970) 493-1571**

Denver Amelia Schafer 303-813-1669  
Adams / Arapahoe / Boulder / Clear Creek / Denver /  
Douglas / Eagle / Gilpin / Jefferson / Summit **FAX: (303) 962-9069**

# Regional Offices & Counties Covered

Grand Junction Teresa Black 970-256-1274  
Delta / Garfield / Gunnison / Lake / Mesa / Moffat  
Montrose / Pitkin / Rio Blanco **FAX: (970) 243-6924**

Durango Elaine Stumpo 970-259-0122  
Archuleta / Dolores / Hinsdale / La Plata / Mineral / Montezuma /  
Ouray / San Juan / San Miguel **FAX: (970) 422-3206**

Pueblo Ann Carter 719-544-5720  
Alamosa / Baca / Bent / Chaffee / Cheyenne / Conejos / Costilla / Crowley /  
Custer / Fremont / Huerfano / Kiowa / Las Animas / Otero / Prowers /  
Pueblo / Rio Grande / Saguache **FAX: (970) 493-1571**

# Questions



# Alzheimer's Association

We're here. All day, every day.

**24/7 Helpline: 800.272.3900**

[alz.org](http://alz.org)