



## October, November, December 2013

October 16 Training

### FACING THE CHALLENGES OF ALZHEIMER'S

Presented by David Hoppe, Family Services Director,  
Alzheimer's Association of Colorado

#### A CHALLENGE THAT IS GROWING WITH AN AGING POPULATION

Currently, over 5 million Americans are living with Alzheimer's disease (AD). By 2025, the number of people age 65 and older with Alzheimer's is estimated to reach 7.1 million, a 40% increase from the 5 million affected today. By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent, slow or stop the disease.

Alzheimer's disease is the sixth leading cause of death in the United States. Nearly one in every three seniors who dies each year has Alzheimer's or another dementia. **It is the only cause of death among the top 10 in America without a way to prevent it, cure it or even slow its progression.** Deaths from Alzheimer's increased 68% between 2000 and 2010, while deaths from other major diseases, including the number one cause of death (heart disease), decreased.

Alzheimer's disease is an irreversible, progressive brain disease that slowly

destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. Scientists do not yet fully understand what causes Alzheimer's disease, but it has become increasingly clear that it develops because of a complex series of events that take place in the brain over a long period of time. It seems likely that damage to the brain starts a decade or more before problems become evident. Alzheimer's disease is the most common cause of dementia among older people.

Alzheimer's disease is only one type of dementia, accounting for 7 out of 10 cases. Families and caregivers, in particular, are faced with tough, heartbreaking challenges dealing with this disease. Alzheimer's and other forms of dementia also present a myriad of challenges to law enforcement, Adult Protective Services, and other public agencies that serve older adults.

Sources: [2013 Alzheimer's Disease Facts and Figures](#) (Alzheimer's Association); [Alzheimer's Disease Fact Sheet](#), [Alzheimer's Disease Education and Referral \(ADEAR\) Center](#).

[REGISTER HERE](#) FOR THE NEXT FREE CCERAP TRAINING OCTOBER 16:

#### TRAINING DETAILS

- Wednesday, October 16, 2013
- Registration: 8:30 am
- Training: 9:00 am - 11:00 am
- Aurora City Hall, City Council Chambers
- 15151 E. Alameda Pkwy, Aurora, CO

Training begins at 9:00 am

(no refreshments are allowed in the City Council Chambers)

**Continuing education: 2 CLE's & POST units (applied for) 2 hours recertification for ombudsman training**

Directions to Training:

- I-225 to Alameda Ave.
- East on Alameda about 1/2 mile to Chambers Rd.
- Left on Chambers Road 1 block
- Left into City Hall parking lot
- Parking garage is available on west side or park in lot on east side

**All CCERAP trainings and materials are FREE.**

**REGISTER HERE BY EMAIL [ccerap@comcast.net](mailto:ccerap@comcast.net). Provide name, title, organization, email and phone number.**

CCERAP provides trainings at no cost, thanks to financial support from the Older Americans Act, disseminated by the Colorado Department of Human Services, State Unit on Aging.

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# THE STAGES OF ALZHEIMER'S

**STAGE 1:** No impairment, normal functioning.

**STAGE 2:** Very mild cognitive decline (may be normal age-related memory lapses).

**STAGE 3:** Mild cognitive decline. Early stage Alzheimer's disease can be diagnosed in some but not all individuals with associated symptoms.

**STAGE 4:** Moderate cognitive decline, diagnosable early-stage AD. An informed medical interview will detect clear deficiencies in memory, decreased capacity to perform complex tasks, reduced memory of one's personal history and tendency to withdraw socially or from mentally challenging situations.

**STAGE 5:** Moderate severe cognitive decline (mid-stage AD). Major gaps in memory and deficits in cognitive functioning emerge. Assistance with activities of daily living becomes essential. Very common facts such as current address and telephone number cannot be recalled upon medical examination, confusion about place and time, simple math difficult, retaining knowledge about self is lost and individual usually needs assistance with toileting and eating.

**STAGE 6:** Severe cognitive decline; can be severe, moderate or mid-stage AD upon diagnosis. Memory loss accelerates, personality changes emerge and more intense help with activities of daily living are needed. Wandering is common in this stage of the disease.

**STAGE 7:** Very severe cognitive decline; severe or late stage AD. This is the final stage of the disease; individuals lose their ability to respond to their environment, the ability to speak and ultimately, the ability to control movement.

Source: [Colorado State Alzheimer's Disease Plan](#) (December 2010)

The caregiving associated with Alzheimer's disease is often resource intensive, particularly once the disease has progressed to stages five through seven. (National Center on Elder Abuse)

## THE CHALLENGE OF KNOWING: OBVIOUS AND NOT SO OBVIOUS SIGNS OF ALZHEIMER'S

Identifying Alzheimer's or other forms of dementia in the early stages can be confusing. Some signs are more subtle than others. Alzheimer's symptoms are also typically as unique as the individuals themselves. But early diagnosis is highly desirable for managing this disease.

It would be easy to just assume these are issues of aging. And while it is true that advancing age is the highest risk factor for Alzheimer's, **AD is decidedly different than the natural aging process.**

### SOME OF THE MORE OBVIOUS SIGNS INCLUDE:

- Delusions, such as accusing people of stealing
- Hallucinations
- Not remembering the names of close family members
- Speaking to relatives that are no longer alive

### LESS OBVIOUS SIGNS INCLUDE:

- Difficulty finding the right words during communication
- Fear of going out in public, or at night
- More and more frequent short-term memory loss
- Agitation and/or mood swings
- Poor judgment
- Misplacing things
- Repetitive speech
- Depression and/or withdrawal
- Lack of motivation
- Less attention to personal hygiene
- Trouble sleeping

Look for the behaviors that are very unlike the person. If they were always good at certain familiar tasks, like paying the bills on time, and are suddenly having financial mishaps, this is a warning. If they are misplacing items, and you are the one finding them in strange places (keys in the freezer), you need to take action.

If families, caregivers and professionals are unsure of certain behaviors, the Alzheimer's Association has a hotline available 24/7 (800.272.3900) to answer questions.

# THE CHALLENGE FOR CAREGIVERS

*“Caregiving is an inadequate term...it’s really LOVE-giving. You essentially need to be willing to give unconditional love to the person that’s suffering from Alzheimer’s.”*

Mark Shriver

As people with Alzheimer’s and other forms of dementia become increasingly dependent on others, caregivers experience many challenges in keeping their loved one at home. At some point, it may become unsafe to leave loved ones with dementia at home alone, as they may wander and get lost, fall or neglect to take care of themselves. Given that people with dementia can live for a period of several years to over a decade, the physical, emotional and economic tolls of providing care can truly become great.

Identifying financial costs of dementia has been challenging. People with Alzheimer’s and other dementias are typically older and often have multiple medical conditions, such as stroke and depression, diseases commonly co-occurring with dementia. It is also difficult to capture the national costs of family-provided or other informal care. However, some estimates show that the cost of caring for those with Alzheimer’s and other dementias may total \$203 billion or more in 2013, increasing to \$1.2 trillion (in today’s dollars) by mid-century. In 2012, 15.4 million caregivers provided more than 17.5 billion hours of unpaid care valued at \$216 billion. Eighty percent of care provided in the community is provided by unpaid caregivers.

## **ALZHEIMER’S AND DEMENTIA AS A RISK FACTOR FOR ABUSE**

Although the vast majority of family caregivers care for their loved ones with dignity, respect and compassion, the daily 24/7 struggle can lead to highly stressful situations. Elders

*Because of sensationalized news stories, many people assume that most cases of the abuse or neglect of Alzheimer’s or dementia victims takes place in long-term care facilities. Recent studies have established the troubling fact that most cases of abuse of Alzheimer’s and dementia victims actually take place in the family home setting.*

with dementia are thought to be at greater risk of abuse and neglect than those of the general elderly population. In the moderate to severe stages of dementia, people can fail to recognize their loved ones, have difficulty in walking and taking medications, and experience troubling behavioral problems such as wandering, hallucinations and delusions. These behaviors can be a tremendous burden on caregivers.

Caregiving for someone with dementia greatly elevates the risk for abuse: caregivers can suffer from anxiety, depression, lack of social contacts, perceived burden, and poor emotional status. In addition, those they are caring for may exhibit behaviors, which exacerbate the situation: psychological aggression and physical assault behaviors. The Journal of Gerontology reports that in one US study, 20% of caregivers expressed fears that they would become violent with the people they were caring for. Caregivers reported verbal abuse (60%), neglect (14%) and physical abuse (5-10%).

## **Help for Caregivers**

The Alzheimer’s Association and the federal government provide helpful tips for caregivers. (See local and national “Resources” on page 8.)

# THE CHALLENGE FOR FIRST RESPONDERS

Alzheimer's disease and related dementias are community problems, especially when a person with Alzheimer's is missing. Searches are exhaustive, expensive, and often have tragic endings.

***One researcher estimated that an average search-and-rescue operation lasts about 9 hours and costs approximately \$1,500 per hour.***

According to an FBI Law Enforcement Bulletin, public safety first responders, including law enforcement personnel, regularly deal with individuals exhibiting Alzheimer's disease symptoms, such as confusion, disorientation, or wandering. Persons with the condition often cannot ask for or even may not recognize that they need help. They could walk or drive for hours, unaware of the passage of time or their own disorientation. These individuals also can become easy targets for predators. While other missing persons, such as children, hunters, or hikers, may try to assist authorities looking for them, people with Alzheimer's who are wandering might actively and unconsciously attempt not to be found by searchers.

Each year, an estimated 125,000 people with Alzheimer's or other dementias leave the safety of their homes and families and are unable to find their way back. According to the National Alzheimer's Association, 6 out of 10 persons with Alzheimer's will wander at some time during its progression. Approximately half of wanderings lead to injury if the individual is not found within 24 hours.

*Source: "Awareness of Alzheimer's Disease", Robert Schaefer and Julie McNiff, FBI Law Enforcement Bulletin, October 2011.*

The use of technology has reduced the risk of wandering and may ensure a safe return if wandering occurs. Several years ago, the Colorado Alzheimer's Coordinating Council (CACC) recommended increased visibility and utilization of locator devices and programs to mitigate the risks associated with wandering. Several commercial products are available; caregivers can learn of specific locator devices from their local chapter of the Alzheimer's Association.

## EFFECTIVE INTERACTIONS FOR FIRST RESPONDERS

When an individual with Alzheimer's disease has gone missing or finds himself/herself in a difficult situation, it is often a first responder's job to diffuse the situation and/or provide required supervision and protective services.

### DO:

- Introduce yourself, explain you are there to help
- Remain calm, smile, and use a friendly voice
- Speak slowly and ask simple questions
- Check for a tracking device or Medic Alert ID
- Change the topic to something pleasant if the person becomes agitated
- Provide security and comfort (i.e. blanket, water, or someplace to sit)

### DO NOT:

- Don't take comments personally
- Don't correct the person
- Don't approach from behind without warning
- Don't argue
- Don't touch without asking/explaining
- Don't repeat a question too many times as it may provoke agitation

*Source: International Association of Chiefs of Police*

## DRIVING

Diminished ability to drive also poses a risk to the individual with Alzheimer's disease as well as a public safety risk. Currently, the Colorado Department of Motor Vehicles has the authority to cancel, deny or deny reissuance of a license for several reasons, including the inability to operate a motor vehicle because of physical or mental incompetence.

The written medical opinion of a licensed physician, physician's assistant or optometrist may be used for the renewal, suspension, revocation or cancellation of drivers' licenses. Signs of unsafe driving may include:

- Forgetting how to locate familiar places
- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Becoming angry or confused while driving

[At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving](#), a guide to help people with dementia and their families.

## Legal and Financial Planning for People With Alzheimer's Disease

This fact sheet offers information and advice about legal and financial planning for people with Alzheimer's disease. Because people with AD may lose the ability to think clearly and participate in decision making, advance planning for health care and financial arrangements is critical. When possible, advance planning should take place soon after a diagnosis of early AD, when the person can participate in discussions. This tip sheet discusses the different kinds of advance directives, the types of professionals who can help with advance planning, general advice for advance planning, resources for low-income families, and steps for getting one's affairs in order.

**Available from Alzheimer's Disease Education and Referral (ADEAR) Center. (800- 222-2225).**

## Can Alzheimer's Be Diagnosed Online?

Recently a panel of geriatricians, human-computer interaction specialists, neuropsychologists, and neuroethicists from the University of British Columbia evaluated 16 freely accessible online tests for Alzheimer's disease. The panel focused specifically on scientific validity and reliability, human-computer interaction features, and ethics-related factors. Their findings showed that these tests were not valid and potentially harmful. They found that the tests were "fraught with ethical issues, including commercial conflicts of interest, confidentiality, and consent." The overall message was to NOT use these tests, "as they have the potential to harm a vulnerable population and negatively impact their health".

Source: "Online Tests for Alzheimer's, 'Invalid, Potentially Harmful' ", *Medscape*, July 17, 2013.

# THE CHALLENGE OF MANAGING MONEY AND AVOIDING SCAMS

People with Alzheimer's disease often have problems managing their money. **In fact, money problems may be one of the first noticeable signs of the disease.** Early on, a person with Alzheimer's may be able to perform basic tasks, such as paying bills, but may have problems with more complicated tasks, such as balancing a checkbook. As the disease gets worse, a person may try to hide financial problems to protect his or her independence. Or, the person may not realize that he or she is losing the ability to handle money matters.

Trouble counting change, paying for a purchase, calculating a tip, balancing a checkbook, or understanding a bank statement may be cause for concern. The person may be afraid or worried when he or she talks about money. Signs to watch for:

- Unpaid and unopened bills
- Lots of new purchases on a credit card bill
- Strange new merchandise
- Missing money, either cash or from an account

## ALZHEIMER'S AND DEMENTIA AS RISK FACTORS FOR FINANCIAL EXPLOITATION

People with AD also may be victims of financial abuse or "scams" by dishonest people. There can be telephone, mail, e-mail, or in-person scams. Sometimes, the person behind the scam is a "friend" or family member.

## SCAMS CAN TAKE MANY FORMS, SUCH AS:

- Identity theft
- Get-rich-quick offers
- Phony offers of prizes or home or auto repairs
- Health scams such as ads for unproven memory aids
- Insurance scams
- Threats

## HERE ARE SOME SIGNS THAT THE PERSON WITH ALZHEIMER'S IS NOT MANAGING MONEY WELL OR HAS BECOME A VICTIM OF A SCAM:

- The person seems afraid or worried when he or she talks about money.

- Money is missing from the person's bank account.
- Signatures on checks or other papers don't look like the person's signature.
- Bills are not being paid, and the person doesn't know why.
- The person's will has been changed without his or her permission.
- The person's home is sold, and he or she did not agree to sell it.
- Things that belong to you or the person with AD, such as clothes or jewelry, are missing from the home.
- The person has signed legal papers (such as a will, a power of attorney, or a joint deed to a house) without knowing what the papers mean.

## TREATMENT SCAMS

Unfortunately, many people will try to take advantage of those with Alzheimer's or other dementia by offering outlandish claims for a treatment or cure. To avoid this, families and caregivers should learn as much as possible about Alzheimer's and other dementias. With good information, they can determine if a treatment has merit or is bogus. Look out for:

- Outlandish claims
- Exaggerated language
- Undocumented testimonials
- Emphasis to buy "right away"

## CLINICAL TRIALS

When a truly effective treatment or a cure is found, the news will come from a reliable source and will be readily available. New treatments are being tested in clinical trials. A health care provider specializing in neurodegenerative diseases may have information about a local clinical trial or specialized research.

**["Participating in Alzheimer's Disease Clinical Studies and Trials"](#)** is a helpful fact sheet from the Alzheimer's disease Education and Referral Center within the National Institute on Aging.

The **[Alzheimer's Association's TrialMatch](#)** is a free, easy-to-use clinical studies matching service that connects individuals with Alzheimer's, caregivers, healthy volunteers and physicians with current studies. Call 800-272-3900 or visit **[alz.org/trialmatch](http://alz.org/trialmatch)**.

## WHERE TO FIND HELP

### COLORADO RESOURCES

Alzheimer's Association Colorado  
455 Sherman Street, Suite 500  
Denver, CO 80203

#### 24/7 Helpline

Contact for information, referral and support:  
Telephone: 1.800.272.3900  
TDD: 1.866.403.3073  
E-mail: info@alz.org

#### Local Colorado Chapters of the Alzheimer's Association:

2315 Bott Avenue  
Colorado Springs, CO 80904  
719-266-8773

455 Sherman Street, #500  
Denver, CO 80203  
303-813-1669

701 Camino del Rio, #321  
Durango, CO 81301  
970-259-0122

415 Peterson Street  
Fort Collins, CO 80524  
970-472-9798

2232 N. 7th Street, Unit B1  
Grand Junction, CO 81501  
970-256-1274

3001 8th Avenue, Suite 100  
Evans, CO 80620  
970-392-9292

4104 Outlook Blvd, Bldg B  
Pueblo, CO 81008  
719-544-5720

#### [Colorado Leaders in Dementia Care](#)

The **Alzheimer's Association** is committed to helping service providers improve their knowledge and skills, build stronger teams and deliver better care to people with dementia and their families. Organizations that have completed Leaders in Dementia Care training are listed by county in Colorado.

#### [Colorado State Alzheimer's Disease Plan: A Roadmap for Alzheimer's Disease Caregiving and Family Support Policies](#)

December 1, 2010

A report presenting the findings and recommendations of the Colorado Alzheimer's Coordinating Council (CACC) concerning the increasing incidence of Alzheimer's disease in Colorado, focusing on the state's current public and private capacity to address the care and service needs of individuals and families affected by Alzheimer's. The report also makes recommendations for improvements to the current system in light of Colorado's rapidly aging population.

### NATIONAL RESOURCES

#### [Webinar Series on Alzheimer's Disease and Tools for Caregiving](#)

The Administration for Community Living, the Administration on Aging and the American Bar Association have developed a webinar series on legal issues and Alzheimer's disease. The four webinars cover legal issues of people with Alzheimer's disease and their caregivers. The webinars were designed to help ensure that people with Alzheimer's have their dignity, safety, and rights maintained by providing a unique training opportunity to legal and aging professionals. Although these webinars were shown earlier this year, they can be archived from the Administration for Community Living.

## WHERE TO FIND HELP CONT.

### ■ **Alzheimer's Association**

National Office  
225 N. Michigan Ave., Fl. 17  
Chicago, IL 60601  
24/7 Helpline: 1-800-272-3900

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

The Alzheimer's Association provides supportive programs and services to help people with Alzheimer's and their caregivers deal with the disease and its impact on their lives. Each chapter in their nationwide network offers five core services listed below. In addition, some chapters offer special programs such as assistance to individuals with Alzheimer's who live alone, people living with early-onset Alzheimer's, rural and/or multicultural outreach, care coordination services, and training programs for families and professionals.

### **Core programs**

- Information and referral
- Care consultation
- Support groups
- Safety services
- Education

### ■ **[Alzheimer's Disease Education and Referral Center](#)** (ADEAR)

800-222-2225

Information Specialist 800-438-4380

This is a service of the National Institute on Aging, a division of the National Institute of Health. The ADEAR website provides helpful information for families such

as "Caring for a Person with Alzheimer's Disease". Also guidelines on how to find help, updates on the latest research, federal initiatives, understanding Alzheimer's disease, caregiving, planning ahead (health, legal and financial issues).

### ■ **[2013 Alzheimer's Disease Facts and Figures](#)**

is a statistical resource for US data related to Alzheimer's and other dementias. It addresses prevalence, mortality, caregiving and use and costs of care and services. Published by the Alzheimer's Association.

### ■ **[Alzheimers.gov](#)**

This is an official US government website managed by the US Department of Health and Human Services, providing information on treatment options, how to pay and plan, caregiving assistance, finding help and fighting Alzheimer's.

### ■ **Family Caregiver Alliance**

[www.caregiver.org](http://www.caregiver.org)

690 Market Street, Suite 600

San Francisco, CA 94104

Telephone: 415-434-3388

A national information center and a pioneer in the development of caregiver services.

### ■ **["Preventing Elder Abuse by Family Caregivers"](#)**

National Center on Elder Abuse, March 2002

*Information for this newsletter was adapted from the following sources:*

*2013 Alzheimer's Disease Facts and Figures*

*Alzheimer's Association, Colorado Chapter*

*Alzheimer's Disease Education and Referral (ADEAR) Center*

*Alzheimer's Disease Fact Sheet, National Institute of Health*

*Alzheimer's Foundation of America*

*Colorado State Alzheimer's Disease Plan (December 2010)*

*Dementia SOS: Colorado's Dementia News and Resource Center*

*FBI Law Enforcement Bulletin, October 2011*

*International Association of Chiefs of Police Alzheimer's Initiatives*

*The National Center on Elder Abuse Research Brief: People with Dementia*

## Colorado Coalition for Elder Rights and Abuse Prevention Steering Committee

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*Colorado Coalition for Elder Rights and Abuse Prevention  
programs are available to all without discrimination.*

**Helen Davis**, Coordinator and Newsletter Editor, [ccerap@comcast.net](mailto:ccerap@comcast.net)

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- Updated Fraud and Scam Alerts
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- Links to Organizations Serving and Advocating for the Elderly
- Aging Resources
- Additional Articles and Information on Powers of Attorney

For more information or to subscribe to the CCERAP newsletter,  
contact Helen Davis, Coordinator by e-mail at [ccerap@comcast.net](mailto:ccerap@comcast.net).

CCERAP has discontinued its 800 telephone number. Please visit our website for the most recent information.

*Promoting statewide understanding of elder/adult abuse and the rights and protections  
available to elder and at-risk adults.*