

A Caregiver's Guide to Managing Your Dementia/Alzheimer's Patient



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MEDICAL SUPPLIES FOR CARE AT HOME SINCE 1957

Objectives for this Webinar

- List three types of behaviors common to dementia and strategies to address them.
- Give three tips for communicating with someone with dementia.
- Identify two common feelings caregivers experience when responsible for someone with dementia.
- Name an organization that offers resources for caregivers of people with dementia.

Dementia: Is this Dementia and What Does it Mean?

Introduction

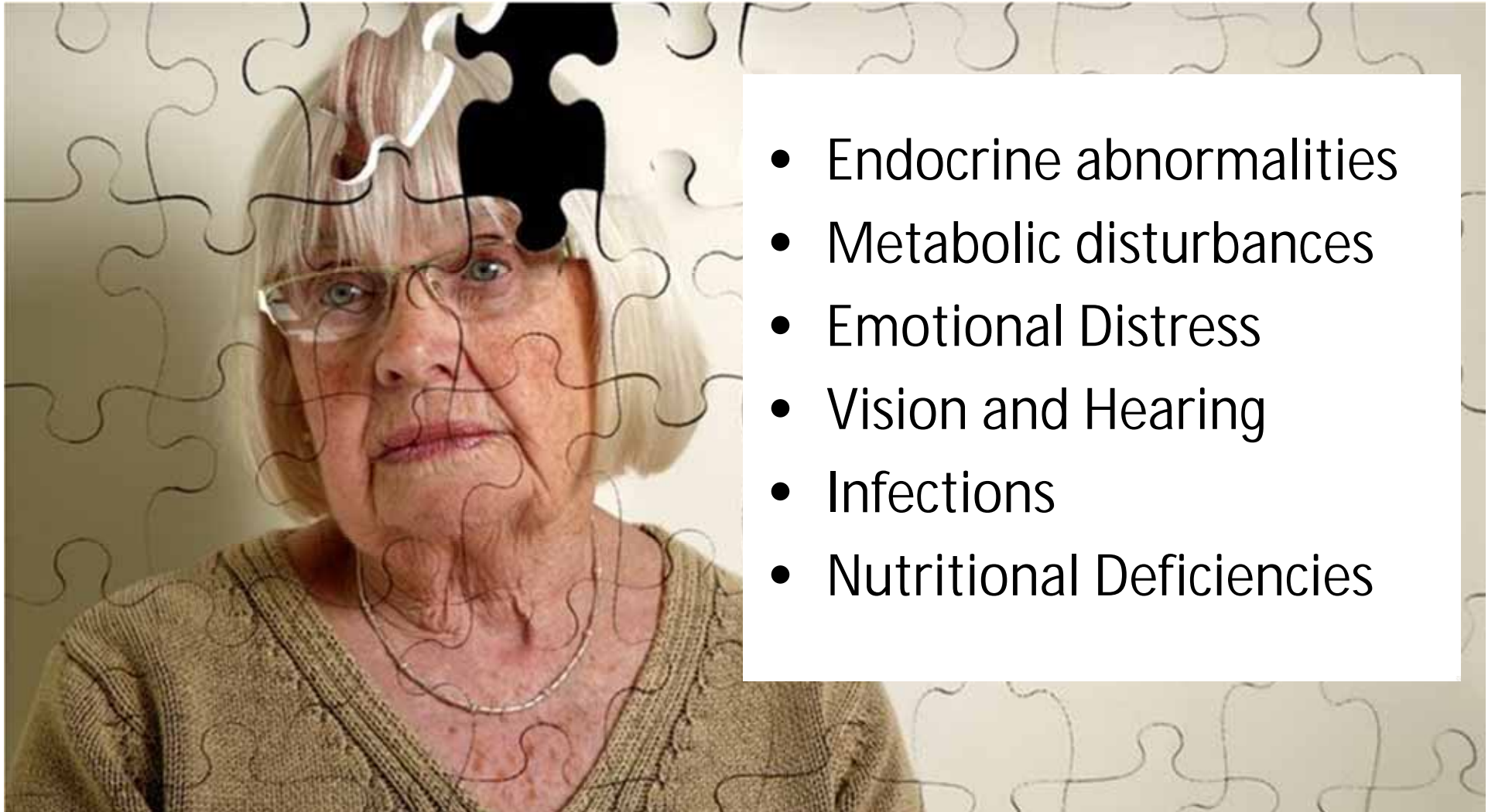
- **Importance of Obtaining a Diagnosis for Dementia**
 - ✓ The diagnosis of dementia requires a complete medical and neuropsychological evaluation.
 - ✓ The process is first to determine if the person has a cognitive problem and how severe it is.
 - ✓ The next step is to determine the cause in order to accurately recommend treatment and allow patients and caregivers to plan for the future.



Reversible Dementias

- Deteriorating intellectual capacity may be caused by a variety of diseases and disorders in older persons. An illness and/or a reaction to medication may cause a change in mental status.

Reversible Dementias



- Endocrine abnormalities
- Metabolic disturbances
- Emotional Distress
- Vision and Hearing
- Infections
- Nutritional Deficiencies

Degenerative (Irreversible) Dementias

The following are the most common degenerative dementias:

- Alzheimer's disease
- Ischemic Vascular Dementia
- Frontotemporal Dementia (FTD)
- Creutzfeldt-Jakob Disease
- Parkinson's Dementia
- Progressive Supranuclear Palsy (PSP)
- Normal Pressure Hydrocephalus (NPH)
- Huntington's disease (HD)
- Mixed Dementias

Communicating about Dementia with Health Care Providers



- Good communication with the primary care provider affects the well-being of the person with dementia as well as the well-being of the caregiver.
- Establishing a good working relationship with primary care physician helps ensure good care and ongoing support
- It is important that your concerns are taken seriously, and you are treated with respect and dignity.



Your Role as a Caregiver

- Safety-proofing the home, learning behavior management techniques and addressing legal and financial matters are important steps families can take to manage dementia, and resources are available to help.

- Every family is different.

Ten Tips for Communicating with a Person with Dementia



We aren't born knowing how to communicate with a person with dementia—but we can learn.

- 1 Set a positive mood for interaction.
- 2 Get the person's attention.
- 3 State your message clearly.
- 4 Ask simple, answerable questions.
- 5 Listen with your ears, eyes and heart.

Ten Tips for Communicating with a Person with Dementia



We aren't born knowing how to communicate with a person with dementia—but we can learn.

- 6 Break down activities into a series of steps.
- 7 When the going gets tough, distract and redirect.
- 8 Respond with affection and reassurance.
- 9 Remember the good old days.
- 10 Maintain your sense of humor.

Handling Trouble Behavior



 **We cannot change the person.**

Try to accommodate the behavior, not control the behavior.

- For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

*Remember that we **can change our behavior** or the physical environment.*

- Changing our own behavior will often result in a change in our loved one's behavior.



Things to Remember about Behavior



- ✓ Check with the doctor first.
- ✓ Behavior has a purpose.
- ✓ Behavior is triggered.
- ✓ Get support from others.

The following is an overview of the
most common dementia-associated behaviors
with suggestions that may be useful in handling them.

Dementia-associated behaviors

WANDERING

- ✓ Make time for regular exercise
- ✓ Consider installing new locks that require a key
- ✓ Try a barrier like a curtain or colored streamer to mask the door
- ✓ Place a black mat or paint a black space on your front porch
- ✓ Add “child-safe” plastic covers to doorknobs
- ✓ Consider installing a home security system or monitoring system
- ✓ Put away essential items
- ✓ Have your relative wear an ID bracelet
- ✓ Tell neighbors about your relative’s wandering behavior



Dementia-associated behaviors

INCONTINENCE

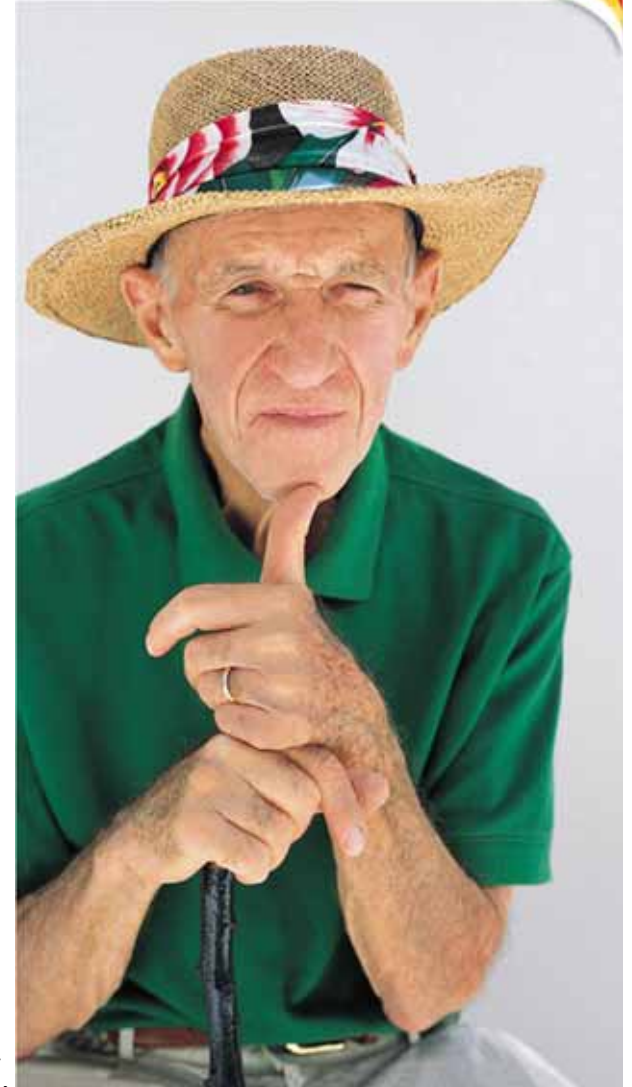
- ✓ Establish a routine for using the toilet
- ✓ Schedule fluid intake
- ✓ Use signs (with illustrations) to indicate which door leads to the bathroom
- ✓ Use a commode
- ✓ Incontinence products
- ✓ Use easy-to-remove clothing



Dementia-associated behaviors

AGITATION

- ✓ Reduce noise, clutter or the number of persons in the room.
- ✓ Maintain structure by keeping the same routines.
- ✓ Reduce caffeine intake, sugar.
- ✓ Try gentle touch, soothing music, reading or walks to quell agitation.
- ✓ Keep dangerous objects out of reach.
- ✓ Allow the person to do as much for himself as possible
- ✓ Acknowledge the confused person's anger
- ✓ Distract the person with a snack or an activity.



Dementia-associated behaviors



REPETITIVE SPEECH OR ACTIONS (PERSEVERATION)

- ✓ Provide plenty of reassurance and comfort, both in words and in touch.
- ✓ Try distracting with a snack or activity.
- ✓ Avoid reminding them that they just asked the same question.
- ✓ Don't discuss plans with a confused person until immediately prior to an event.
- ✓ You may want to try placing a sign on the kitchen table, such as, "*Dinner is at 6:30*" to remove anxiety and uncertainty about anticipated events.
- ✓ Learn to recognize certain behaviors.

Dementia-associated behaviors

PARANOIA

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling.

- ✓ Help them look for the “missing” object and then distract them into another activity. Try to learn where the confused person’s favorite hiding places are for storing objects, which are frequently assumed to be “lost.” Avoid arguing.
- ✓ Take time to explain to other family members and home-helpers that suspicious accusations are a part of the dementing illness.



Dementia-associated behaviors

SLEEPLESSNESS/SUNDOWNING

- ✓ Restlessness, agitation, disorientation and other troubling behavior in people with dementia often get worse at the end of the day.
- ✓ Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.



Dementia-associated behaviors

SLEEPLESSNESS/SUNDOWNING

- ✓ Watch out for dietary culprits, such as sugar, caffeine and some types of junk food.
- ✓ Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*. Perhaps take a stroll outdoors, play a simple card game or listen to soothing music together.
- ✓ Nightlight



Dementia-associated behaviors

SLEEPLESSNESS/SUNDOWNING

- ✓ As a last resort, talk to the doctor about medication to help the agitated person relax and sleep. Sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.




Caregiver Considerations

SLEEP

It's essential that you, the caregiver, get enough sleep.

If your loved one's nighttime activity keeps you awake, consider asking a friend or relative, or hiring someone, to take a turn so that you can get a good night's sleep. Catnaps during the day also might help.

A photograph of a bedroom. In the foreground, there is a bed with white linens and a green pillow. To the left of the bed is a wooden chair with a yellow cushion. In the background, there is a window with a white frame and a small table with a plant and some books. The room is brightly lit.

Sleep is not a luxury,
it's a **NECESSITY**.

Caregiver Considerations

BATHING

People with dementia often have difficulty remembering “good” hygiene.

- Think historically of your loved one’s hygiene routine – what did she/he prefer?
- If your loved one has always been modest, enhance that feeling by making sure doors and curtains are closed.



Caregiver Considerations



BATHING

Never leave a person with dementia unattended in the bath or shower.

If hair washing is a struggle, make it a separate activity.

If bathing in the tub or shower is consistently traumatic, a towel bath provides a soothing alternative.




Additional Problem Areas

- Hallucinations may occur as the dementia progresses
- Sexually inappropriate behavior
- Verbal outbursts
- Remember, this behavior is caused by the disease



Emotional Side of Caregiving

- 
- Caregivers are often reluctant to admit to negative feelings.
 - If you don't deal with ALL of your emotions, they will get your attention!

Emotional Side of Caregiving



If only we were perfect, we would not feel . . .

Ambivalence

Anger

Anxiety

Boredom

Crankiness/Irritability

Depression/Sadness

Disgust

Embarrassment

Fear

Grief/Loss

Guilt

Impatience

Jealousy

Lack of Appreciation

Loneliness

Resentment

The Stresses of Caregiving



- Caring for an individual with dementia can be challenging and, at times, overwhelming.
- Frustration is a normal and valid emotional response.
- When you are frustrated, it is important to distinguish between *what is* and *what is not within your power to change*.

The Critical Step: Asking for Help



You cannot take on all the responsibilities of caregiving by yourself.
It's important to know...

*When
to say
"Yes"*



*When
to say
"No"*

Self-care to Prevent Frustration



Fact Sheet:

[Taking Care of YOU: Self-Care for Caregivers](#) offers additional information.

See the hand-outs section.



- While it may be difficult to find time to focus on yourself and your needs, it is very important that you do so to prevent frustration and burnout.

Self-care



3 STEPS for taking better care of YOU

1. Make Time for Yourself
2. Take Care of Yourself
3. Seek Outside Support

Recommended Reading

Bathing Without a Battle

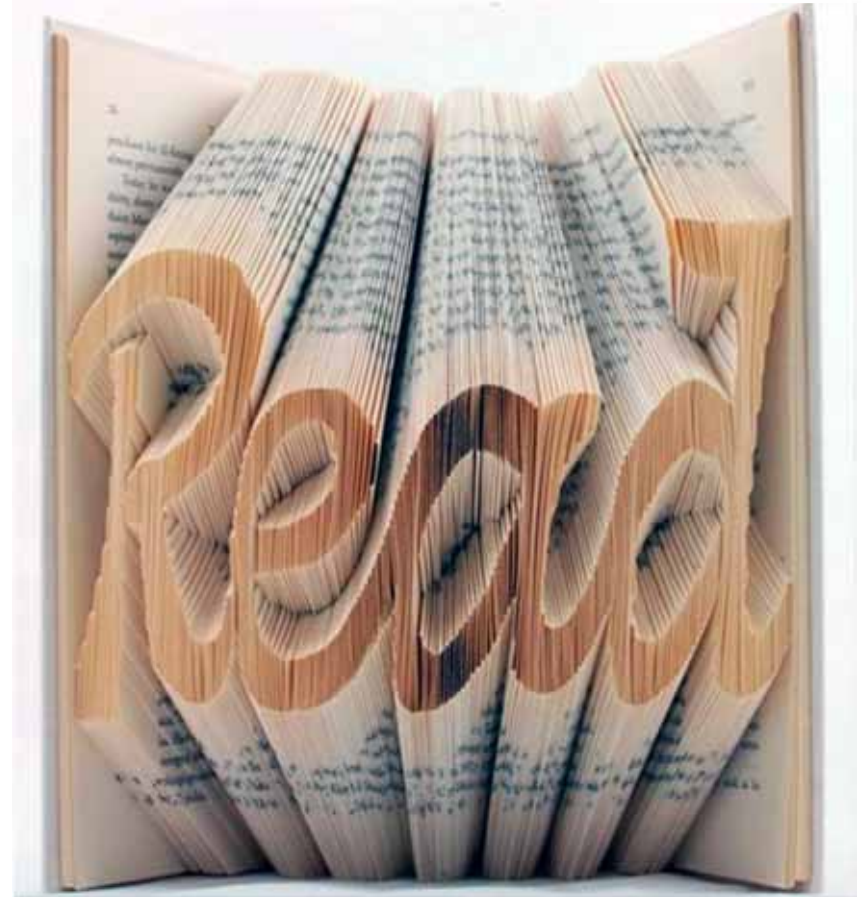
Ann Louise Barrick, Joanne Rader, Beverly Hoeffler y Philip Sloane, Springer Publishing, 2002

36 Hour Day: Family Guide to Caring for People who have Alzheimer's Disease, Related Dementias and Memory Loss

Johns Hopkins Press Health Book, 2011

Steps to enhancing communications: Interacting with persons with Alzheimer's disease

Alzheimer's Association, 2012



Recommended Reading

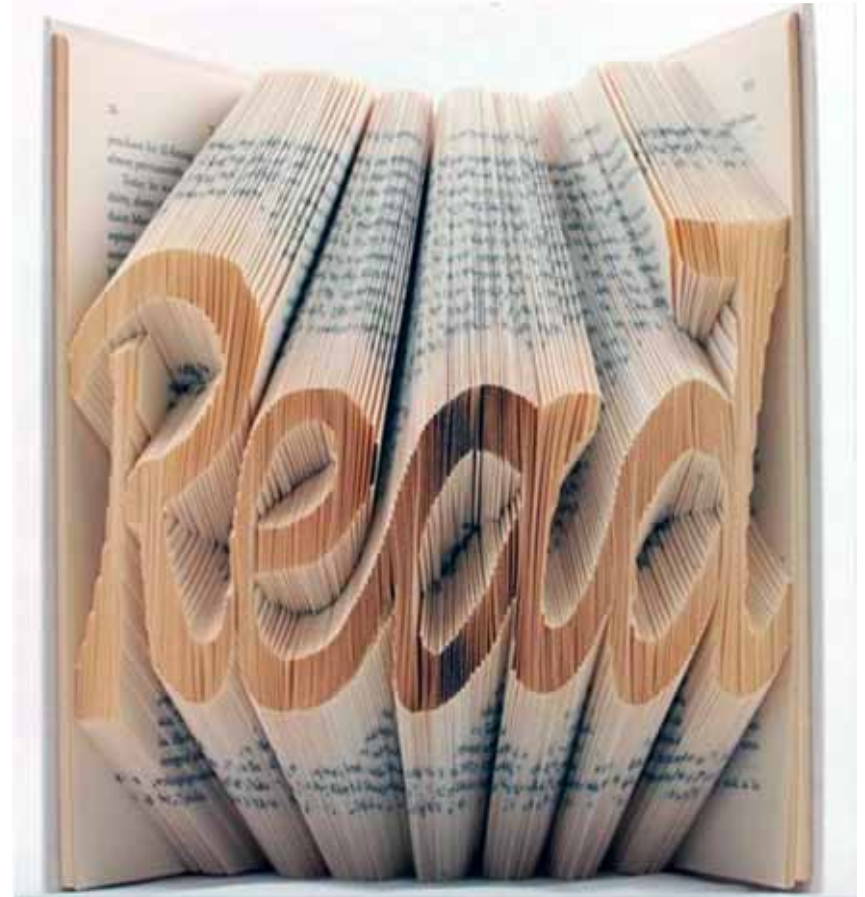
The Validation Breakthrough: Simple Techniques for Communicating with People with Alzheimer's-Type Dementia Naomi Feil, Health Professions Press, Baltimore, MD, 2nd Edition, 2002

Understanding Difficult Behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses A. Robinson, B. Spencer y L. White, Eastern Michigan University, Ypsilanti, MI, 2001

The Forgetting. Alzheimer's: Portrait of an Epidemic
David Shenk, 2001, Random House, New York, NY.

Alzheimer's Disease: Unraveling the Mystery,
Anne Brown Rodgers
2003, ADEAR (Alzheimer's Disease Education & Referral Center, a service of the National Institute on Aging), Silver Spring, M.D.

Caregiving at Home
William Leahy, M.D., 2005, Hartman Publishing Inc. and William Leahy, M.D., 8529 Indian School Road NE, Albuquerque, NM 87112, (505) 291-1274.



RESOURCES



Family Caregiver Alliance (FCA)

seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

caregiver.org



RESOURCES



All **FCA Fact Sheets** are available online at
www.caregiver.org/fact-sheets

- *Caregiver's Guide to Understanding Dementia Behaviors*
- *Dementia, Caregiving and Controlling Frustration*
- *Taking Care of YOU: Self-Care for Family Caregivers*

Organizations



Family Caregiver Alliance: *National Center on Caregiving*

Website: www.caregiver.org

E-mail: info@caregiver.org

Family Care Navigator:
www.caregiver.org/family-care-navigator

Alzheimer's Disease Education and Referral (ADEAR) Center

This service of the National Institute on Aging offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and research related to Alzheimer's disease.

www.nia.nih.gov/alzheimers

Organizations



Eldercare Locator

This service of the Administration on Aging offers information about and referrals to respite care and other home and community services offered by state and Area Agencies on Aging.

<http://www.eldercare.gov/>

Alzheimer's Association Safe Return Program

A nationwide program that identifies people with dementia who wander away and returns them to their homes. For a registration fee, families can register their loved one in a national confidential computer database. They also receive an identification bracelet or necklace and other identification and educational materials.

<http://www.alz.org/safetycenter>



Special thanks to the Family Caregivers Alliance
for assisting with the development of this program.

Additional information is available at:

www.caregiver.org



Questions?



Questions not answered during the live webinar
will be answered via email.

About this Webinar



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