



Alzheimer's
LOS ANGELES

Care Transitions Coaches
Alzheimer's Training

This training has been created by Alzheimer's Los Angeles. We would like to acknowledge the UCLA Health Services Research Program in Neurology and Partners in Care Foundation for their multi-year partnership and engagement in developing, implementing, and evaluating the Care Transitions Program for People with Alzheimer's Disease and Related Dementias after Hospitalization, supported by a grant from UniHealth Foundation, a non-profit philanthropic organization whose mission is to support and facilitate activities that significantly improve the health and well-being of individuals and communities within its service area. We also acknowledge Jewish Family Services, who participated in this training program.

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Learning objectives

- Distinguish between the stages of Alzheimer's disease
- Identify red flags of behavior changes that indicate risk for hospital readmission
- Increase knowledge of effective management of behavioral symptoms of Alzheimer's disease
- Utilize communication strategies to effectively coach caregivers about Alzheimer's

Training overview

DAY 1

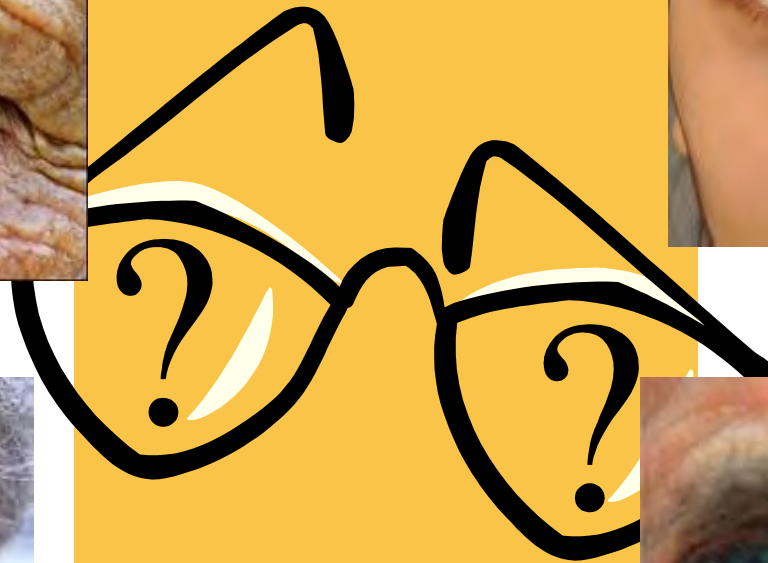
- Alzheimer's disease
- Cognitive, behavioral, and functional changes
- Stages of the disease
- Understanding baseline and when to call the doctor

Training overview

Day 2

- Transitioning from hospital to home
- Challenging behaviors
- *IDEA!*: A strategy to manage challenging behaviors
- Caring for the caregiver
- Community resources

Context of training: through the eyes of caregivers





Alzheimer's Disease

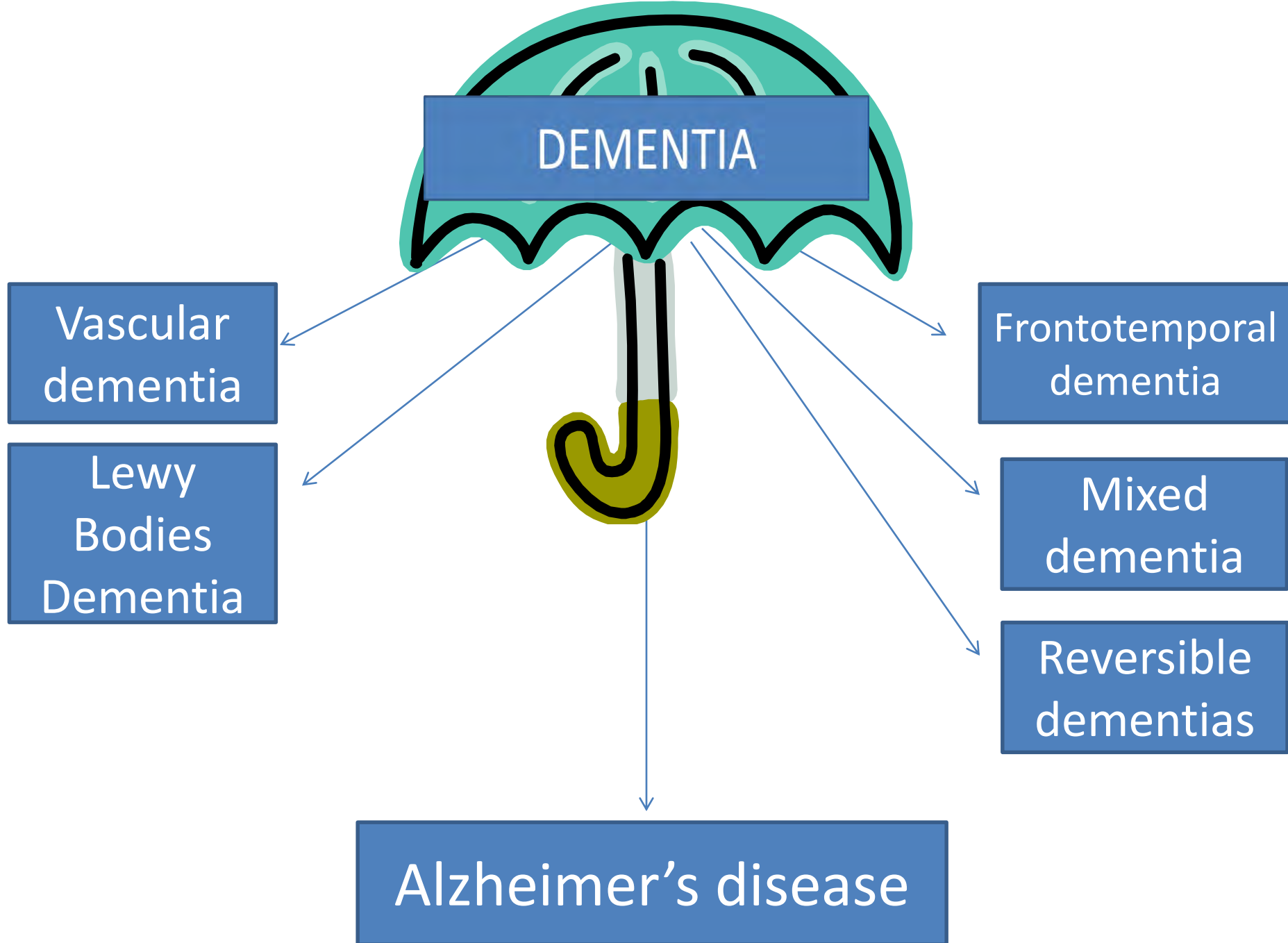




Video: Alzheimer's Disease Facts and Figures 2014



Video courtesy of Alzheimer's Association





Not everyone with dementia
has Alzheimer's disease

BUT

All people diagnosed with
Alzheimer's disease have a
form of dementia

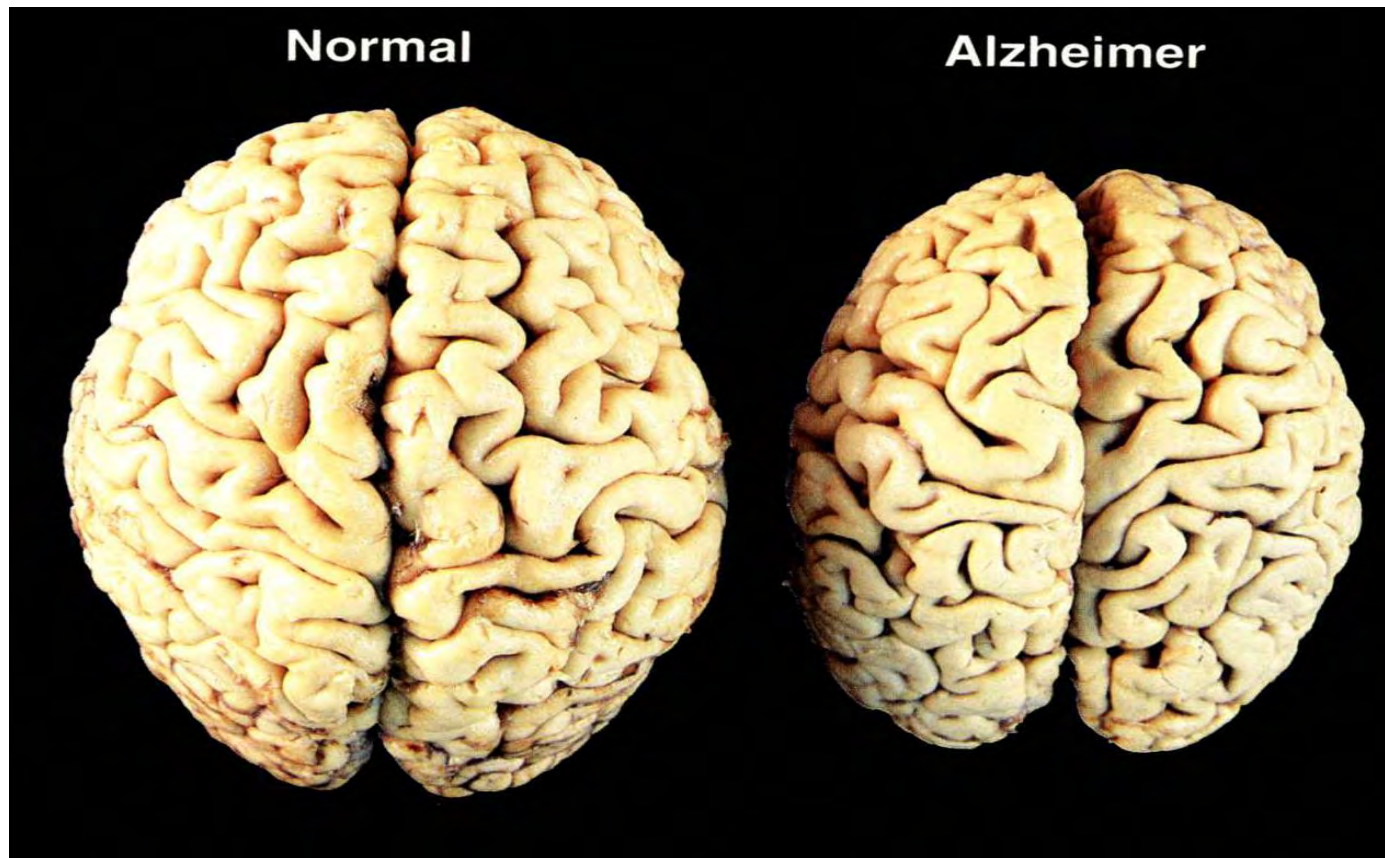


What is Alzheimer's disease?

- Most common form of dementia
- Neurocognitive disorder
- Must be diagnosed by physician
- Gradual onset
- Progressive
- Symptoms: memory impairment, problems with thinking and planning, behaviors
- Leads to death

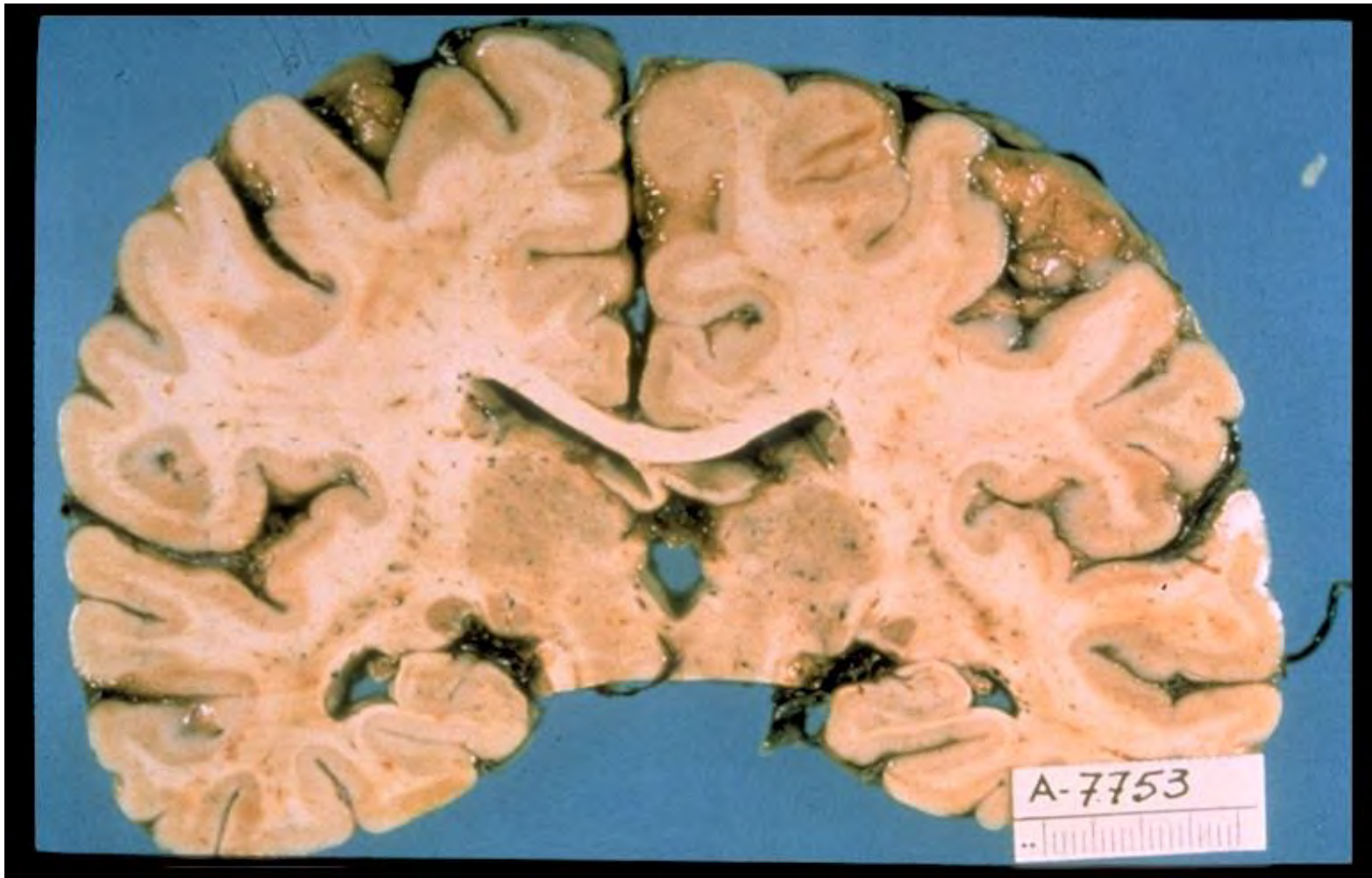


Healthy brain vs. brain with Alzheimer's



*Image appears courtesy of Dr. Richard E. Powers,
Director of the Alabama Bureau of Geriatric Psychiatry, alzbrain.org*

Normal brain



Alzheimer's brain





Video: What is Alzheimer's disease?





Cognitive, Behavioral, and Functional Changes

Changes caused by Alzheimer's

- Memory loss
- Disorientation
- Executive function/complex tasks
- Visual and spatial problems
- Language problems
- Behavioral symptoms
- Functional limitations

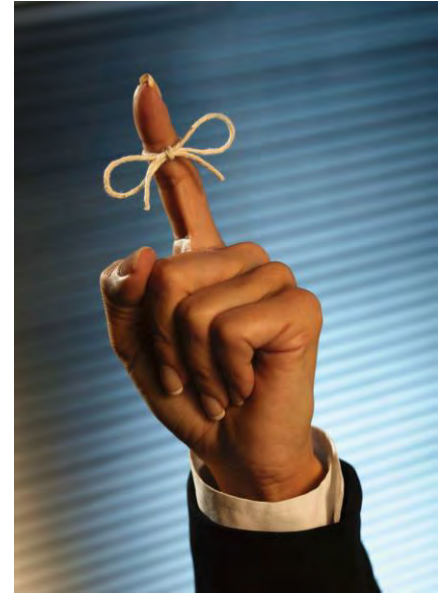
**Illness &
hospitalizations
can
worsen these**

Memory loss

- Short term
- Long term
- Repetitive questions

Adaptations:

- ✓ Allow person to share memories
- ✓ Do not correct
- ✓ Repeat, if necessary/answer repetitive questions
- ✓ People can “cover up” memory loss



Disorientation

- Person
- Place
- Time

Adaptations:

- ✓ A certain amount of reality orientation may be helpful in *earlier stages*
- ✓ Respect current reality of person and emotions he/she expresses



Complex tasks/executive function

- Problems planning, organizing, using judgment, and carrying out complex tasks
- Simple tasks can be complicated

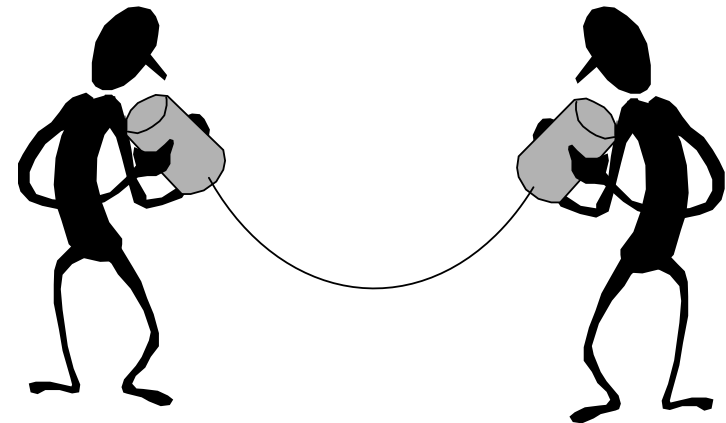
Adaptations:

- ✓ Break down directions one step at a time
- ✓ Provide help, but encourage independence
- ✓ Use simple and direct language
- ✓ Be sensitive to emotions



Common language problems

- Finding the right word/tip of the tongue
- Using native language
- Inability to speak
- Not understanding what someone else is saying



Common language problems

Adaptations:

- ✓ Use gentle tone
- ✓ Approach person from front
- ✓ Speak slowly and clearly
- ✓ Allow person time to respond
- ✓ Do not correct
- ✓ Pay attention to nonverbal communication



Loss of visual and spatial skills

- Eyes see, but brain unable to interpret and use judgment

Adaptations:

- ✓ Use cues to attract person to specific place
- ✓ Understand fear/discomfort
- ✓ Use glasses to maximize vision
- ✓ Pay attention to safety



Changes in behavior

Examples may include:

- Aggression
- Hallucinations
- Paranoia
- Disinhibition
- Saying “no” to care
- Sundowning

REMINF FAMILIES...
behaviors are *not*
on purpose
Behaviors are **part**
of the disease
process



Functional limitations

- Challenges with activities of daily living
- Assistance required
- In late stages, loss of bladder/bowel control and trouble swallowing

Adaptations:

- ✓ Provide assistance, but promote independence
- ✓ Use comforting and gentle touch
- ✓ Use assistive equipment as necessary





Activity: Through the eyes, head, and heart of a person with Alzheimer's

4 favorite
memories

3 most important
people in your life

2 things you love
to do

1 hope for your
future



Stages of the Disease

Remember...throughout all stages of the disease, **personhood** remains

Crazy



Incompetent



Dead already



Empty shell



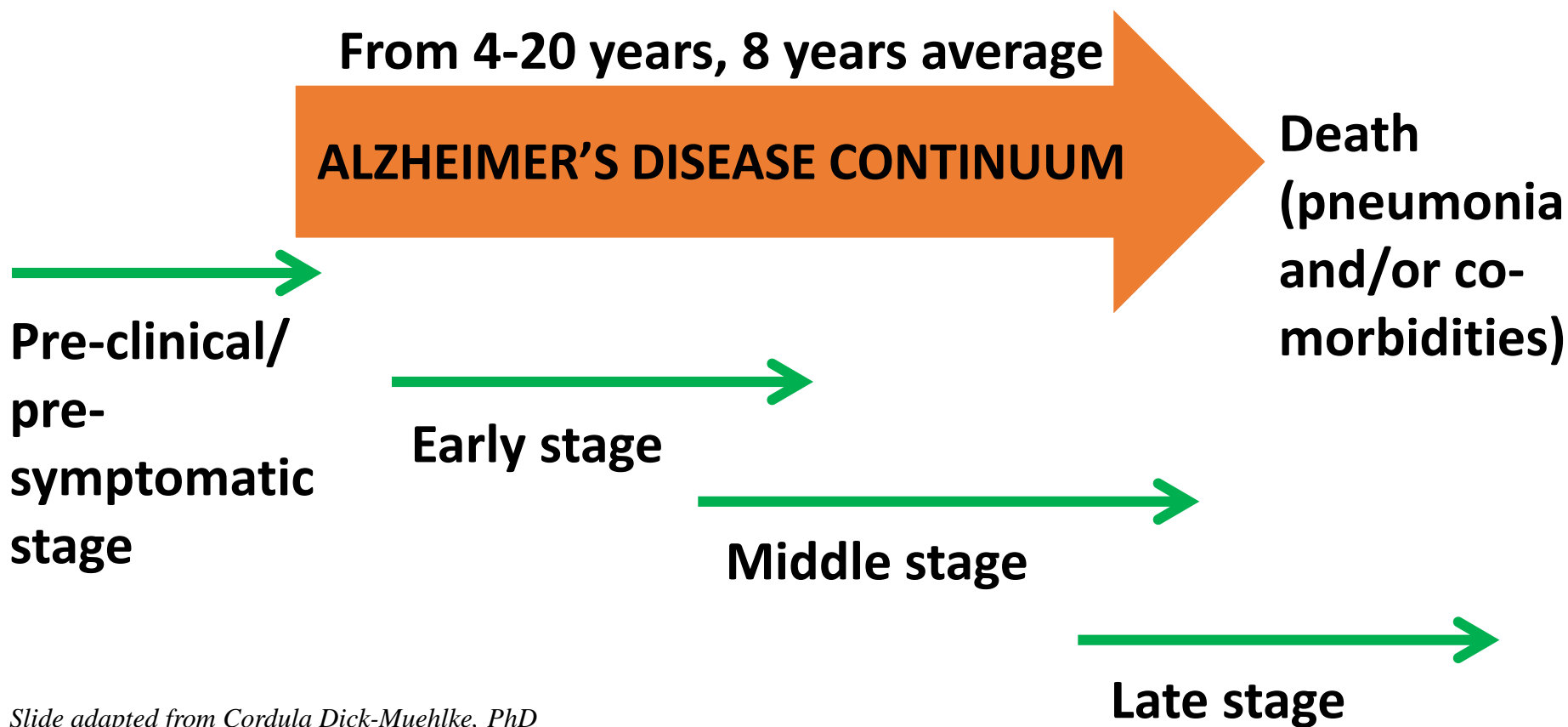
Unaware



Lost self



Alzheimer's disease progression



Slide adapted from Cordula Dick-Muehlke, PhD

Early stage Alzheimer's disease

- Insight into disease
- Many losses being experienced
- Depression
- Ability to make decisions/plan ahead



Early stage Alzheimer's disease

- Problems with memory and concentration
- Trouble finding the “right” word and/or remembering names
- Misplacing things
- Trouble organizing and planning (getting lost)



Early stage Alzheimer's disease

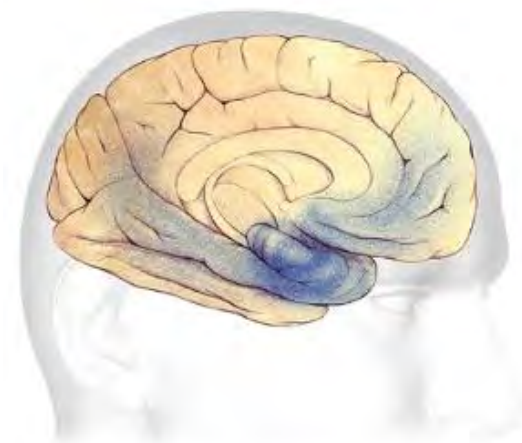
Caregivers may need to help with:

- Support and guidance
- Assistance with medications, cooking, finances, and getting lost
- Advanced planning



Middle stage Alzheimer's disease

Gaps in memory and thinking are noticeable, and individual begins to need help with day-to-day activities



Alzheimer's Association. Seven Stages of Alzheimer's.
http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

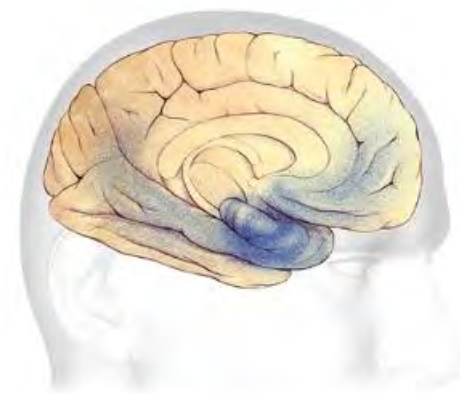
Middle stage Alzheimer's disease

- Memory and thinking problems more obvious
- Difficulty with communication
- Nonverbal communication retained
- Behavioral symptoms
- Greater assistance needed with day-to-day activities



Middle stage Alzheimer's disease

- Retention of social skills
 - Reports that everything is “fine”
 - Reports ability to bathe, cook, take medications, etc.
- Appears to be healthy to outsiders and to medical professionals



Middle stage Alzheimer's disease

Caregivers may need help with:

- Following hospital discharge instructions
- Not leaving person home alone
- Taking medications
- Bathing, dressing, eating, toileting, and other activities
- Making doctor's appointments and following instructions

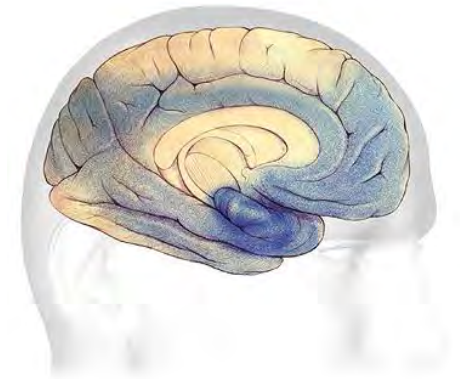


Video: HBO Documentary: The **Alzheimer's Project**



Late stage Alzheimer's disease

- Functional decline
- Assistance needed with day-to-day activities and personal care
- Brain hears, but unable to communicate with body what to do
- Unable to have a conversation
- Loss of bladder/bowel control
- Trouble swallowing





Questions caregivers may ask

- Each group will be given a question or statement that families often ask or say about Alzheimer's
- In small groups, come up with a simple response that is clear, easily understood, based on facts, and helpful



Questions caregivers may ask

- My sister said that mom remembers things from a long time ago—I don't think she has Alzheimer's.
- My mom doesn't have Alzheimer's—she just has dementia.
- My brother has Alzheimer's disease. Should I still ask for his opinion?
- What stage is my dad in?
- Grandma is confused, unable to do things, and has problems speaking. Is this Alzheimer's?



Understanding Baseline and When to Call the Doctor

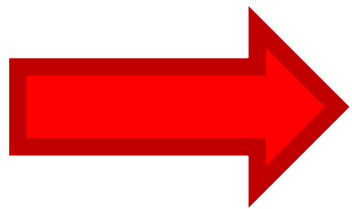




Remember that when someone has **Alzheimer's disease**, they may not be able to tell the caregiver that something is wrong. They may not be able to say that they are not feeling well.

What is “baseline?”

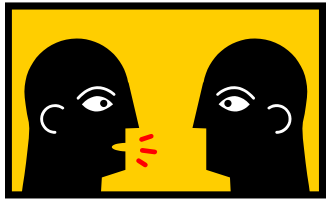
Baseline =
how a person USUALLY
thinks and acts



When someone has
Alzheimer's, thinking and
behavior can change, but it is
usually a slow change

What is “baseline?”

Caregivers need
to identify what is USUAL
for the person they care
for



Try saying...

When someone leaves the hospital and goes home, they may think or act differently for a while.

Try to think about how the person was *before* whatever happened that caused the hospitalization—**this is the person's baseline**. Write this down on page 6 of your Care Transitions Notebook.

Understanding “baseline”

Roger is a cheerful man who is very affectionate and has a high level of functioning. He is able to walk, go to the bathroom on his own, and eat meals that are prepared for him.





Understanding “baseline”

One day, Roger wakes up and is disoriented. He seems really irritated; you can see a look of anger on his face. Roger lashes out at his wife. He is also suddenly incontinent.

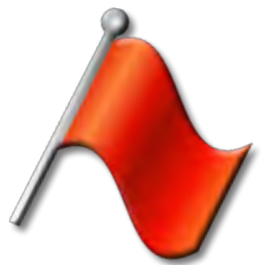




Understanding “baseline”

- Describe Roger's baseline
- Is there a change in baseline?
- Is there cause for concern?
- What would you tell Roger's wife to do?





Sudden and unusual changes

- Major change in memory or mood
- Increase in confusion
- Not knowing where he or she is, or what time it is
- Can't pay attention
- Aggression/violence
- Sudden incontinence
- Fever
- Seizure

Possible causes of sudden and unusual changes

- Delirium
- Infection
- Fever
- Dehydration
- Malnutrition
- Constipation
- Fatigue
- Pain/discomfort
- Medication reaction/interaction



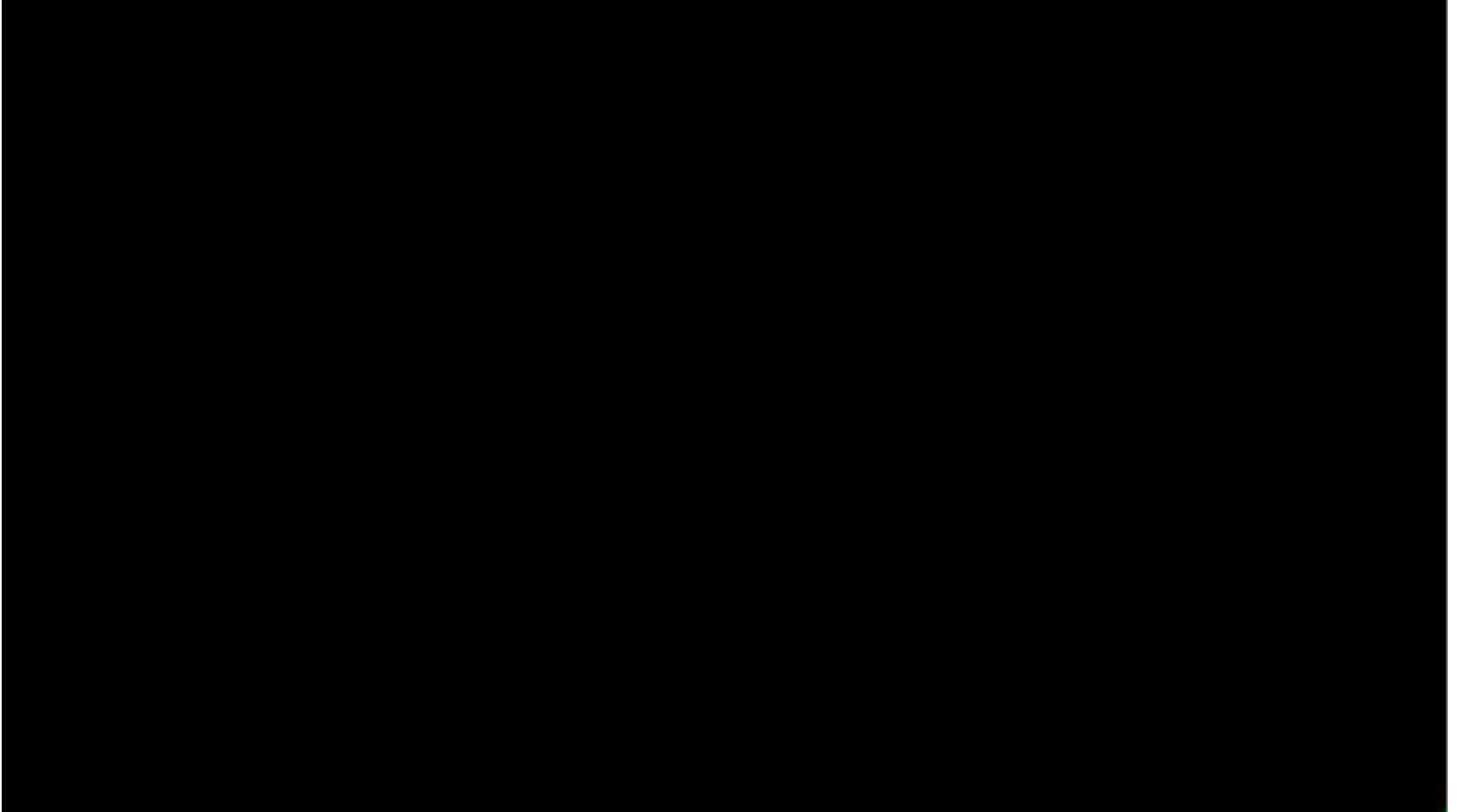
Delirium

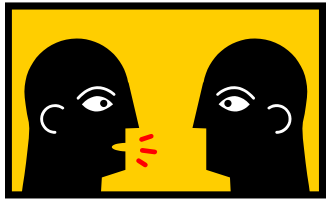


- Severe confusion
- Can develop over hours or days
- Person seems “out of it” and then can become alert again
- Changes in sleeping (intense dreams)
- Usually caused by an illness or reaction to medication
- Usually temporary and reversible
- Alert doctor



Video: Department of Veterans Affairs: Delirium Quiet and Excited





Try saying...

If you've seen any sudden and unusual changes, you should write them down on page 7 of your Care Transitions Notebook, and tell the doctor. The doctor should know about these concerns. Make sure to tell the doctor about baseline.

Remember...when someone has Alzheimer's...

- They may not be able to tell the caregiver that something is wrong or they do not feel well
- The caregiver will need to figure it out, based on the way the person is acting and thinking





Transitioning from Hospital to Home



Unique Adaptations

Medication
management

Shift in
environment

Home safety

Challenging
behaviors

Caregiver duties/
responsibilities change

Caregiver changes

Bouncing between hospital and home



Anonymous
September 2014

There were often “flare ups” of my grandma’s congestive heart failure (CHF). We spent the last year of my grandma’s life bouncing between hospitals and home. It was really hard, especially because no one actually dealt with the fact that she had **ALZHEIMER’S**. My grandma would be disoriented after each hospitalization; going home was confusing.

Bouncing between hospital and home

Anonymous
September 2014



Going home meant having a paid caregiver until things—more or less—returned to how they were before my grandma got sick. My grandma hated having strangers in the house. The caregivers did not know my grandma's routine and certainly did not know what was “normal” for her.

Bouncing between hospital and home

Anonymous
September 2014



Discharge instructions were confusing at best and completely infeasible to carry out at worse. Once home, there were new medications to take and my grandma was certainly not able to manage them. More than once she took my grandfather's medications instead of hers. Managing the CHF itself was really challenging too.

Bouncing between hospital and home

Anonymous
September 2014



How were the caregivers supposed to monitor weight gain when my grandma refused to get on the scale? The scale was scary. The caregivers struggled to put on pressure stockings because my grandma refused to have them put on. There was a lot of yelling and I'm not sure the caregivers understood that this was a manifestation of the disease—not my grandma being difficult.

Bouncing between hospital and home

Anonymous
September 2014

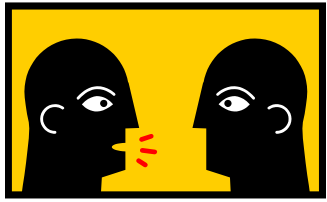


Sadly, it's not surprising that my grandma kept being hospitalized, over and over again. Better education and support would have really helped. I also think that having instructions and guidance that were *Alzheimer's specific* would have made a world of difference.

Medication management

- Person will need help taking medications; caregiver will need to administer
- Medications will need to be locked up so they are out of reach





Try saying...

Medications can be confusing,
especially after a hospitalization.
Do not rely on the person with
Alzheimer's to take his/her
medications.

You may want to talk to the doctor
about this.

Pain

- Person may not be able to tell caregiver that he/she is in pain
- Pain can go unnoticed or be mistaken for something else
- Pain is usually treatable



Warning signs of pain

PHYSICAL SIGNS

- Bruises
- Swelling
- Fever
- Vomiting
- Dry, pale gums
- Sores
- Pale, light skin tone or flushed, red skin tone



Warning signs of pain

NONVERBAL SIGNS

- Gestures/movements
- Spoken sounds
- Facial expressions

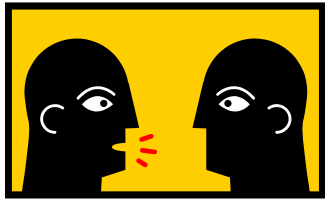


Warning signs of pain

CHANGES IN BEHAVIOR

- Increased anxiety
- Increased agitation
- Shouting
- New sleep problems





Try saying...

It can be hard to know if someone with Alzheimer's is in pain because he/she may not be able to say that he/she is in pain.

Let's look at page 9 of your Care Transitions Notebook. There is some information about how to recognize pain.

Have you noticed any of these signs of pain?

Home safety

- Person with Alzheimer's unable to know what is dangerous
- Keeping person relaxed and less confused can help reduce accidents



Home safety

- Never leave person home alone
- Caregiver needs to have someone “cover” for him/her if he/she needs to leave

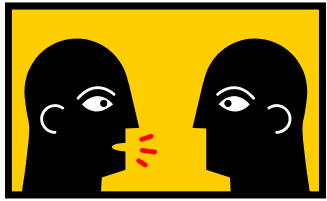


Home safety

Reduce risk for falls

- Keep rooms neat
- Keep things off the floor
- Remove small rugs/mats
- Use sturdy tables and chairs
- Use night light at night





Try saying...

If you look at page 10 in your Care Transitions Notebook, you will see a few simple tips on keeping the home safe.

Do you think you can do any of these?



Challenging Behaviors



Examples of challenging behaviors

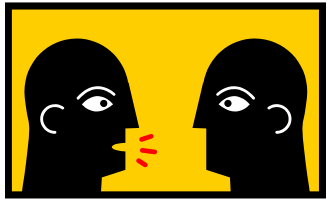
- Aggression
- Hallucinations
- Paranoia
- Disinhibition
- **Saying “no” to care**
- Sundowning



What challenging behaviors are NOT



- Not intentional
- Not trying to be difficult
- Not due to poor listening
- Caregivers should stop and remember disease process
- STOP before reacting



Try saying...

It can be frustrating to provide care to someone with Alzheimer's disease...when someone acts a certain way, it is because of the disease and not because they are trying to upset you.



S. GROSS

"It sort of makes you stop and think, doesn't it."

Effectively managing challenging behaviors will require caregivers to be detectives

What is the person communicating?

Why are they communicating this?

Is something wrong?

What does the person want or need?





IDEA!:

A Strategy to Manage
Challenging Behaviors



IDEA!

IDentify Behaviors
Identify problems

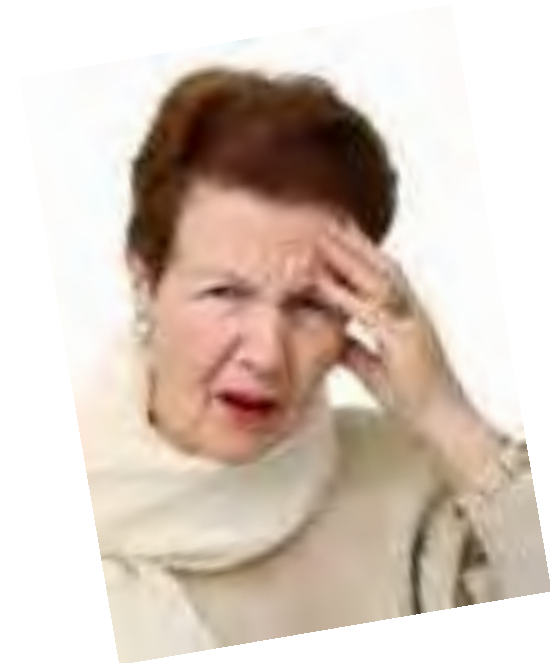
Educate Yourself
Understand the causes/triggers
Understand the meaning

Adapt
Problem solve



IDentify behaviors/problems

- ✓ What is the specific difficult/challenging behavior?
- ✓ Can the caregiver see the behavior?

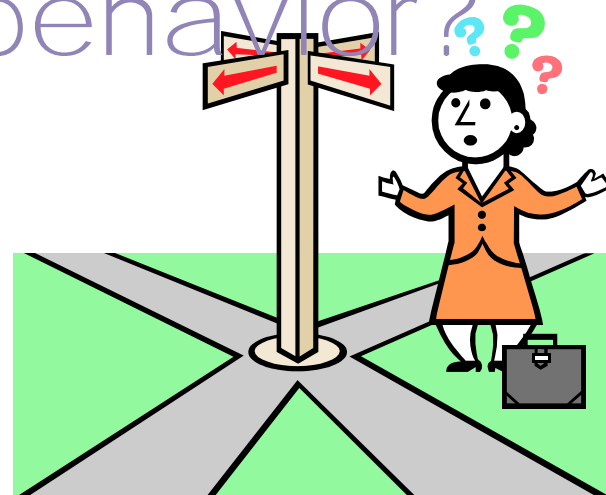


Educate yourself

Understand the causes/triggers

What is *causing* this behavior?

- ✓ Health
- ✓ Environment
- ✓ Task
- ✓ Communication



Educate yourself

Understand the health triggers

- ✓ Is the person taking a new medication?
- ✓ Is the person getting sick?
- ✓ Is the person in pain?



Rule out medical causes

Do not dismiss symptoms as “due to dementia”

New or worsening symptoms may be due to:

- ✓ Worsening of pre-existing medical or psychiatric illness
- ✓ Onset of new medical or psychiatric problem
- ✓ Medication interaction/side effects
- ✓ Delirium

Slide courtesy of Cordula Dick-Muehlke, PhD

Remember...

- ✓ When someone has a sudden and unusual change in the way he/she is acting or thinking, or has a medical condition that is getting worse, call the doctor
- ✓ Must know baseline to know if there is a change



Educate yourself

Understand the environmental triggers

- ✓ Is it too noisy?
- ✓ Is it too hot?
- ✓ Is the place unfamiliar?
- ✓ Is the lighting poor?





How would you feel if...

- You were cold and did not have a way to tell someone you wanted a jacket?
- You were being forced to take a shower in a cold bathroom?
- You looked in the mirror, did not recognize yourself, and thought that there was a stranger in the room?

Educate yourself

Understand the task triggers

- ✓ Is the task too hard?
- ✓ Are there too many steps?
- ✓ Is it something new and confusing?



Educate yourself

Understand the communication triggers

- ✓ Is it hard for the person to understand?
- ✓ Is it hard for the person to speak?



Educate yourself

Understand the meaning of the behavior

- ✓ Does the person feel like he/she is being treated like a child?
- ✓ Are there things that remind the person of something unhappy?
- ✓ Does the person feel a sense of insecurity, discomfort, or boredom?





What does it mean when...???

- What does it mean when someone says, “I want to go home”?
- What does “home” mean?
- How does the person feel when the caregiver says, “But mom, you *are* home.”
- What would be a better response to teach the caregiver?

Strategies not solutions



**Always pay
attention to
the person's
feelings**



- No one size fits all
- Try different things
- Caregiver can change; not the person with the disease
- Caregiver sets the tone





Distract or redirect by:

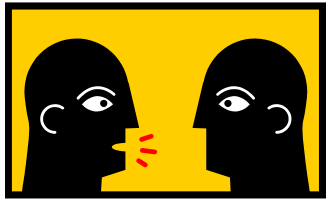
- Offering the person something he/she likes to eat
- Watching TV or listen to music
- Asking the person for his/her help with a simple activity
- Leading the person to a different room



Adapt

Address the cause/trigger:

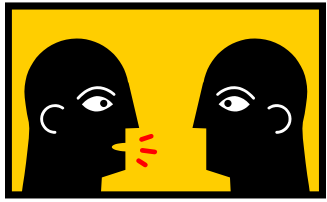
- Keep tasks and activities simple
- Find meaningful, simple activities
- Keep the home as calm and quiet as possible
- Speak slowly and gently
- Try not to say too much at one time
- **Don't argue**
- Comfort the person



Try saying...

It sounds like Mr./Ms. _____'s behaviors are challenging.

Perhaps I can offer some suggestions/tips that may help you. There is also information on page 11 of your Care Transitions Notebook on challenging behaviors.



Try saying...

You can try using *IDEA*! It's simple and easy, and can really help you break down what's going on so you find some techniques to help the situation.

Let's take a look at page 13 of your Care Transitions Notebook to learn about *IDEA*!



Using *IDEA*!

Juanita tells you that her father often gets agitated in the afternoon. Her dad wanders around, saying over and over again that he is looking for his daughter. He says that it is time for her to be home from school.





Using *IDEA*!

IDentify behaviors

- Wandering
- Asking for daughter





Using *IDEA*!

Educate Yourself: Understand the cause/trigger of the behavior

Happens in the afternoon/sundowning;
father is confused and disoriented;
father is bored/nothing to do





Using *IDEA*!

Educate Yourself: Understand the meaning of the behavior

Dad is anxious; responsibility as a parent





Using *IDEA*!

Adapt

- Increase illumination before sun goes down
- Tell dad that daughter will be home later and then distract/redirect
- Do something meaningful, like go for a walk
- Use a calm and gentle tone
- Be reassuring
- WHAT ELSE?





Caring for the
Caregiver



Importance of caregivers

- Knowledge of disease
- Management of challenging behaviors
- Ability to recognize red flag behaviors/medical issues



**Caregiver
knowledge,
skill, &
support**

- Minimize caregiver stress, fatigue, burnout, depression
- Decrease in unnecessary hospitalizations/readmissions
- Decrease/delay institutionalization
- Increase quality of life



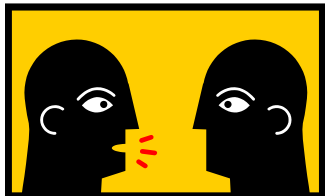
"Nobody ever asks 'How's Waldo?'"

Caregiver stress, depression, and fatigue

10 warning signs:

- 1) Denial
- 2) Anger
- 3) Social withdrawal
- 4) Anxiety
- 5) Depression
- 6) Exhaustion
- 7) Sleeplessness
- 8) Irritability
- 9) Lack of concentration
- 10) Health problems





Try saying...

Taking care of someone with Alzheimer's can be challenging and stressful. You may want to consider setting a goal for yourself to better help you manage and take care of yourself.

If you look at page 20 of your Care Transitions Notebook, there are some suggestions for personal goals.



Personal caregiver goal

Mary takes care of her mother. She reports that she has not slept well in a few days and is feeling overwhelmed.

She is exhausted. Before Mary's mom was hospitalized, Mary enjoyed going to church and spending time with her neighbors.





Personal caregiver goal

- ✓ What are your concerns?
- ✓ What would be an appropriate and realistic goal for Mary?
- ✓ How might you talk to Mary about this goal?



Caregiver support

Referrals and support for caregivers:

- Support groups
- Identify support systems
- Self-care
- Respite
- Caregiver education

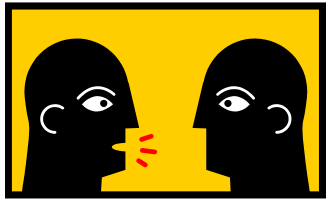




Caregiver referral

- ✓ What might be an appropriate referral for Mary?
- ✓ How might you suggest a referral to Mary?
- ✓ What can you say to her?





Try saying...

It sounds like there are many challenges at home. Let's look at page 21 of your Care Transitions Notebook to go over information on getting support.



Community Resources



Alzheimer's Greater Los Angeles

- Website www.alzheimersla.org
- Helpline 844.HELP.ALZ | 844.435.7259
- Social Work Support and consultation



Alzheimer's Greater Los Angeles

- Family caregiver education; psycho-educational classes
- Early stage services
- Support groups



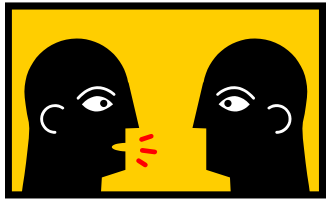
Multiple
languages

Medic Alert®

- 24-hour nationwide emergency response service
- Activates community support network to reunite family

*Wandering
is always a
potential
risk*





Try saying...

Alzheimer's Los Angeles is a non-profit organization that specializes in memory loss. Perhaps speaking to someone at Alzheimer's Los Angeles may be helpful.

Thank you

Jennifer Schlesinger, MPH, CHES

Director, Professional Training and Healthcare Services

Alzheimer's Los Angeles

jschlesinger@alzheimersla.org

844.HELP.ALZ | 844.435.7259



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844.HELP.ALZ
AlzheimersLA.org



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