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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
Alzheimer’s disease

Brain conditions:

- Vascular dementia
- Lewy Bodies Dementia
- Frontotemporal dementia
- Mixed dementia
- Reversible dementias
Did you know?

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
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

REMIND 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

<table>
<thead>
<tr>
<th>4 favorite memories</th>
<th>3 most important people in your life</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 things you love to do</td>
<td>1 hope for your future</td>
</tr>
</tbody>
</table>

Alzheimer’s LOS ANGELES
Stages of the Disease
Remember...throughout all stages of the disease, **personhood remains**

- Crazy
- Incompetent
- Dead already
- Lost self
- Empty shell
- Unaware
Alzheimer’s disease progression

From 4-20 years, 8 years average

ALZHEIMER’S DISEASE CONTINUUM

Pre-clinical/pre-symptomatic stage

Early stage

Middle stage

Late stage

Death (pneumonia and/or co-morbidities)

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

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.
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.
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
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.
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.
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
Warming 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?
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
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.
“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/trigger
- 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
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 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
Adapt

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

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
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!
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
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.
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](http://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
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

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