Alzheimer's
LOS ANGELES

Dementia Care Specialist Training

Effectively Working with Patients and Families to Improve Care

This training program is supported, in part, by grant numbers 90DS2002-01-00 and 90DS2017-01-00, from the Administration on Aging, U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201; the California Department of Aging; The Allergan Foundation; and The Rosalinde and Arthur Gilbert Foundation. Grantees undertaking projects under government or foundation sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living, California Department of Aging, or other funders' policies.

Learning Objectives

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Learning Objectives

At the conclusion of this training, you will:

- Describe hallmark symptoms of Alzheimer's disease and related dementias (ADRD)
- Demonstrate correct use of a cognitive screening tool
- Summarize the components of the *IDEA!* behavior management strategy
- Describe the importance of identifying, assessing, and supporting family caregivers
- Demonstrate ability to develop care plans for people with ADRD and/or their caregivers
- Describe the importance of making appropriate referrals to home- and community-based services (HCBS)

What are We Tackling Today?

- Dementia-Capable Healthcare
- Fundamentals of Cognitive Impairment, Dementia, and Alzheimer’s Disease
    - Potential Warning Signs
    - Defining Dementias and Alzheimer’s Disease
    - Disease Progression
    - Risk Factors
- Screening/Detection and Diagnosis
    - AD8 Screening Tool
- Alzheimer’s Clinical Care Guideline

Dementia-Capable Healthcare

Alzheimer's
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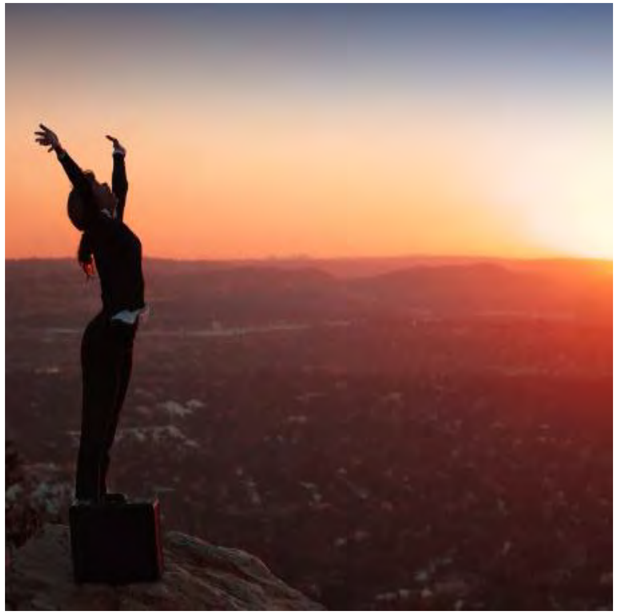
Dementia Care Specialist

Why do you want to be a Dementia Care Specialist?



Criteria for Moving a Member to a Dementia Care Specialist

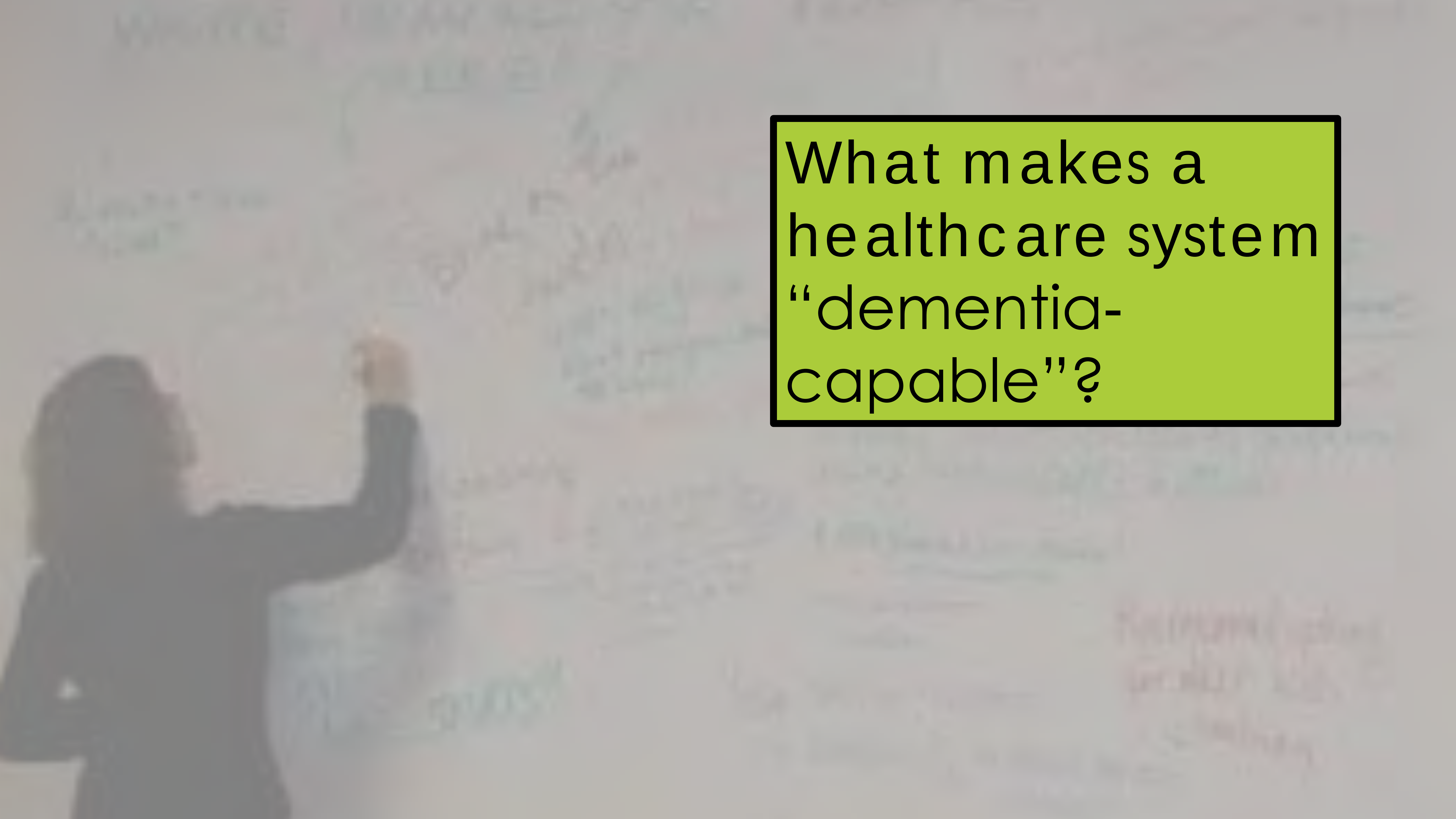
- The member does not have a caregiver
- The member is unable to follow a care manager's recommendations
- The member's caregiver has knowledge deficits about Alzheimer's disease and related dementias
- The member has behavioral or mood disturbances

Criteria for Moving a Member to a Dementia Care Specialist

- Difficulty managing chronic medical conditions that are complicated by Alzheimer's
- Difficulty managing medication regimen

Criteria for Moving a Member to a Dementia Care Specialist

- Difficulty completing ADLs
- Healthcare utilization concerns (i.e. multiple ER visits in the last year or difficulty attending appointments)



What makes a healthcare system “dementia-capable”?

Video: Building Systems of Healthcare for People with Dementia

https://www.youtube.com/watch?v=fdQ4Tv5L7Gc

Running time: 1 minute 49 seconds

Dementia-Capable Systems of Care

(1) Timely detection of dementia

- ☐ Assessments include trigger questions for cognitive impairment
- ☐ Adoption of a validated cognitive screening tool
- ☐ Integration of results into electronic health record (EHR)
- ☐ Protocol for diagnosis if screen is positive
- ☐ Documentation of diagnosis

Dementia-Capable Systems of Care

(2) Person- and family-centered care plans

- ☐ Identification of family caregiver
- ☐ Documentation of caregiver in EHR
- ☐ Adoption of validated caregiver assessment tool
- ☐ Integration of caregiver education
- ☐ Adoption of best practice care plans
- ☐ Respite provided to caregivers

Dementia-Capable Systems of Care

(3) Seamless access to dementia-specific community-based services

- ☐ Provision of services and supports to patients and caregivers
- ☐ Adoption of direct referral program (*ALZ Direct Connect*) to connect families to education and support services

PART I

Fundamentals of Cognitive Impairment, Dementia, and **Alzheimer's Disease**

Introduction

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Video: Alzheimer's and Dementia

Statistics 2018 ALZLA

https://www.youtube.com/watch?v=ok0iJCS1rn4

Running time: 1 minute 36 seconds

Alzheimer’s Disease in the United States

1in10
people age 65 and older has Alzheimer’s

5.7
million people have Alzheimer’s

6th
leading cause of death

1in3
people age 85 and older has Alzheimer’s

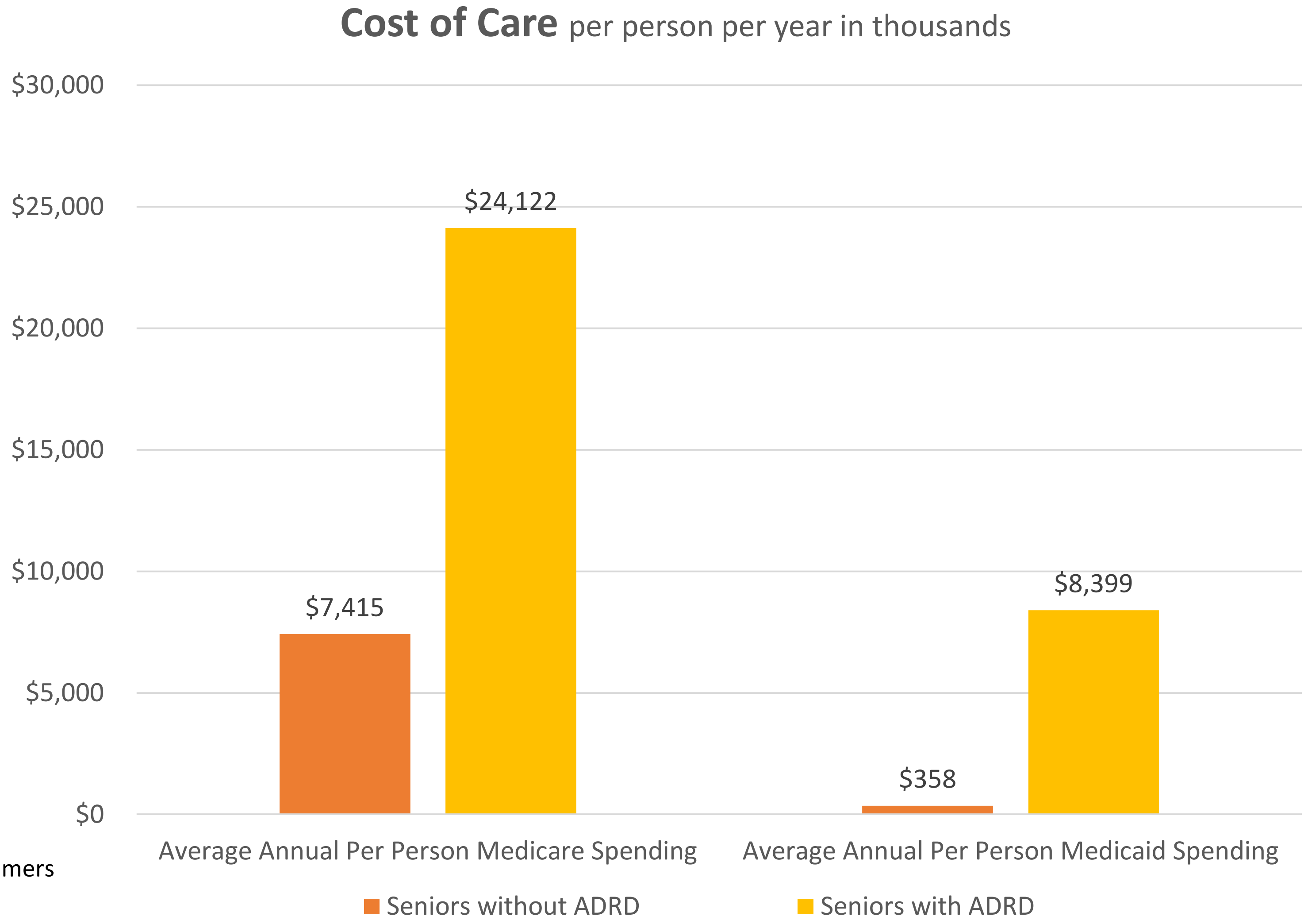
a new case every
65
seconds

16.1
million unpaid caregivers

Alzheimer’s Association.
2018 Alzheimer’s Disease
Facts and Figures.
Alzheimer’s & Dementia,
2018;14(3)367-429

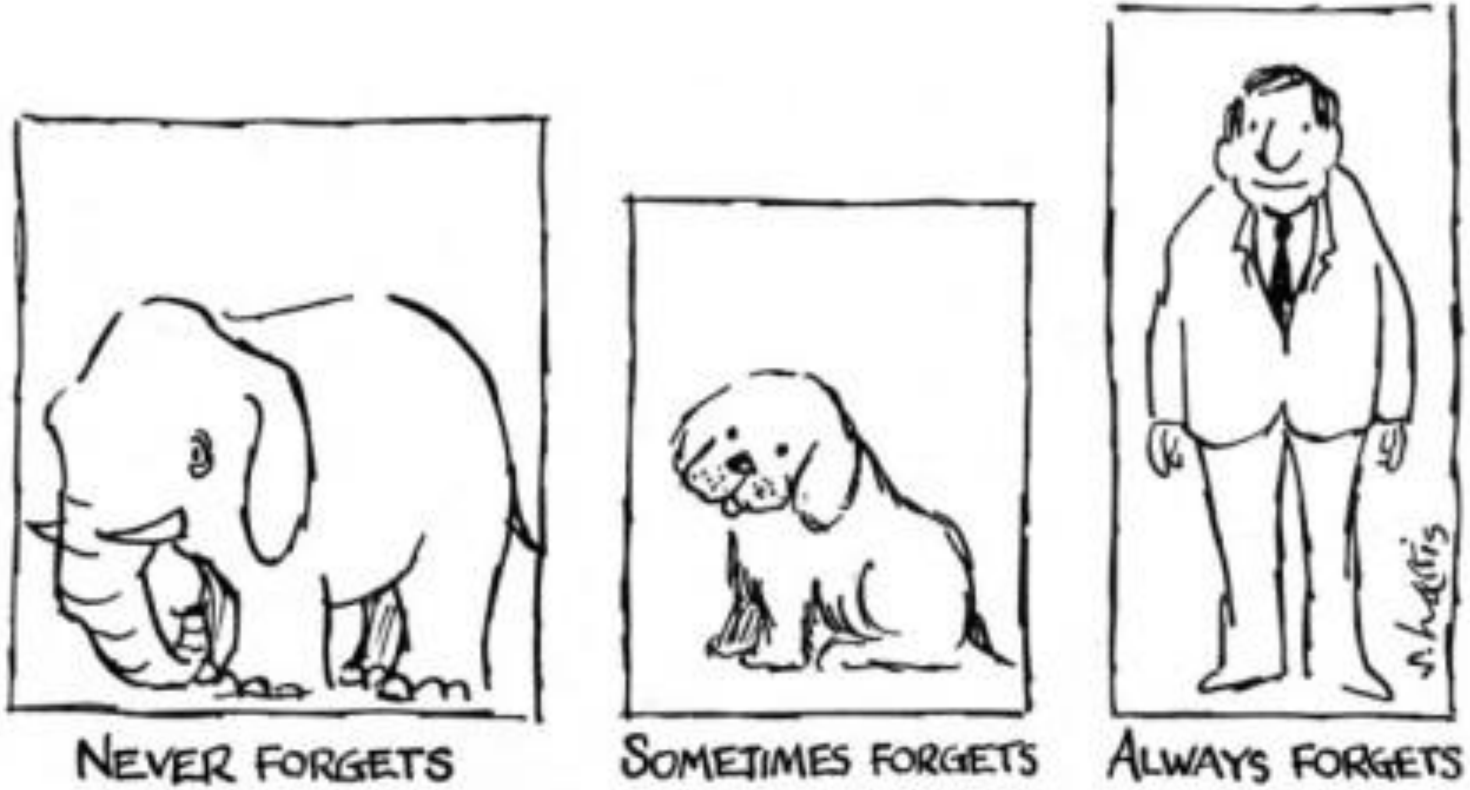
Implications for Health Care

- Average per-person **Medicare** spending for those with ADRD is **three times higher** than for those without these conditions
- The average per-person **Medicaid** spending for seniors with ADRD is **23 times higher** than average per-person Medicaid spending for all other seniors



Alzheimer's Association. 2018 Alzheimer's Disease Facts and Figures. Alzheimers Dementia 2018;14(3):367-429.

Age-Related Memory Loss & Potential Warning Signs


NEVER FORGETS
SOMETIMES FORGETS
ALWAYS FORGETS
s. harris

Why Recognize Warning Signs?

Why is it important that care managers and others on the team members recognize potential warning signs of cognitive impairment?

Normal Aging

- Slower thinking, but intelligence remains stable
- Some difficulties finding the right word
- Mild decrease in short-term memory
- Changes in senses
- Difficulty paying attention
- Slower processing

Normal Aging

Alzheimer's is *not* a normal part of aging. Typical age-related changes can include:

Missing a monthly payment

Losing things from time to time

Sometimes forgetting a word

Making a bad decision once in a while

Forgetting the day and remembering it later

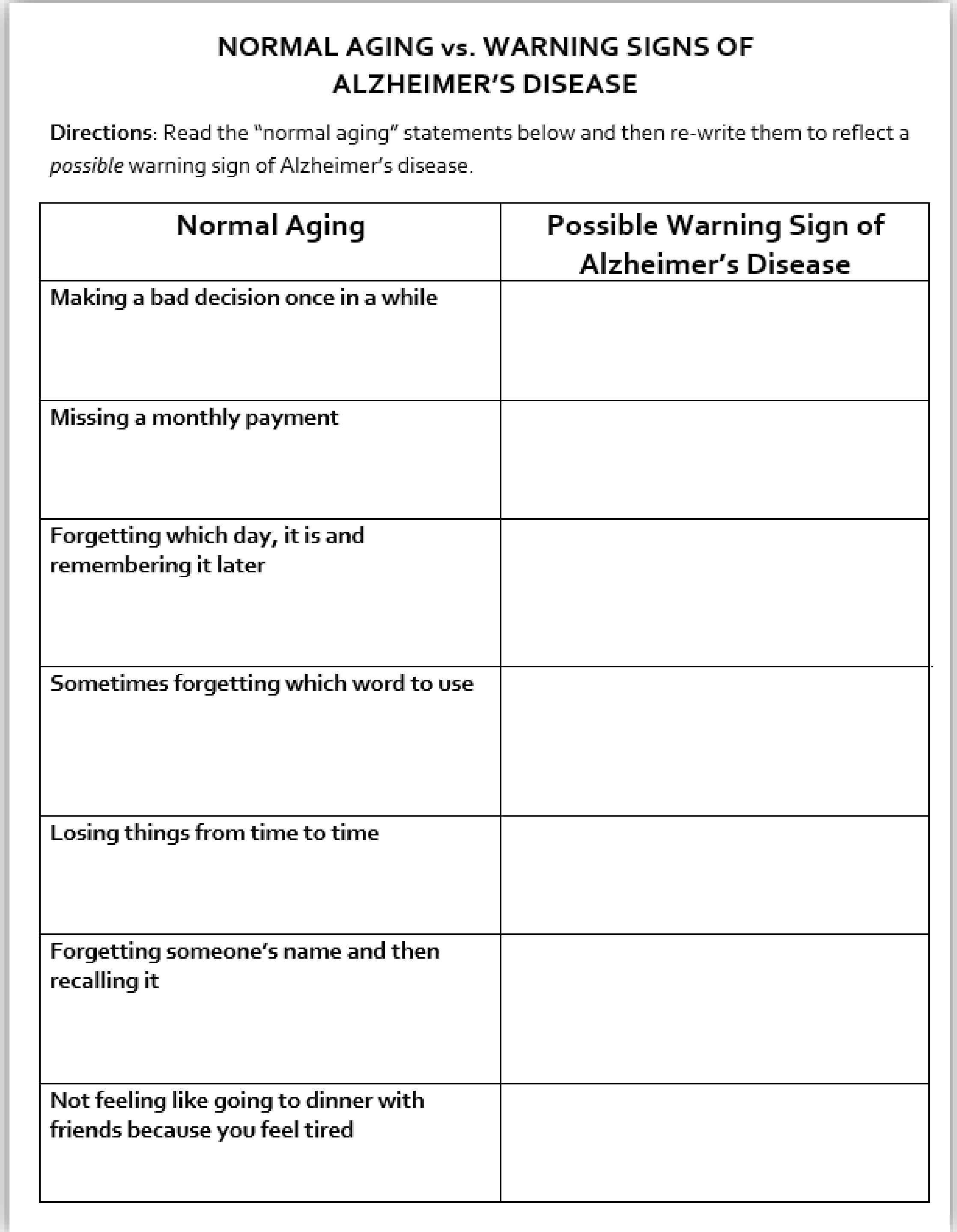
Early Signs of Alzheimer's Disease

1. Feeling less able to do day to day activities
2. Difficulty or trouble managing finances and paying bills
3. Misplacing or losing things more often
4. Increasing anger, anxiety, or sadness
5. Trouble with reading, writing, and conversations

Early Signs of Alzheimer's Disease

6. Repeating questions or stories
7. Withdrawing from family, friends, or social activities
8. Getting lost on familiar roads or paths
9. Needing more reminders to stay organized
10. Hearing that others have concerns about changes in memory or behavior

Activity: Normal Aging vs. Possible Warning Sign of Alzheimer's Disease



NORMAL AGING vs. WARNING SIGNS OF ALZHEIMER'S DISEASE

Directions: Read the "normal aging" statements below and then re-write them to reflect a *possible* warning sign of Alzheimer's disease.

Normal Aging	Possible Warning Sign of Alzheimer's Disease
Making a bad decision once in a while	
Missing a monthly payment	
Forgetting which day, it is and remembering it later	
Sometimes forgetting which word to use	
Losing things from time to time	
Forgetting someone's name and then recalling it	
Not feeling like going to dinner with friends because you feel tired	

Dementia

Lens on Alzheimer's

On each post-it, write a word that is commonly used to describe a person who has Alzheimer's

Stigma and Labeling

Empty shell

Disease of the "old"

Dead already

Lost self

Crazy

Unaware

Burden

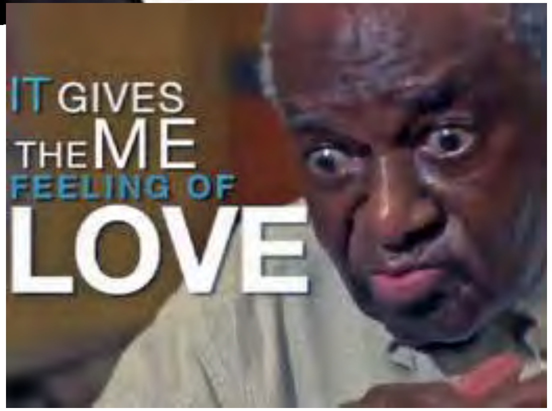
The Many Faces of Dementia Moving Beyond Stereotypes

Abilities

Preferences

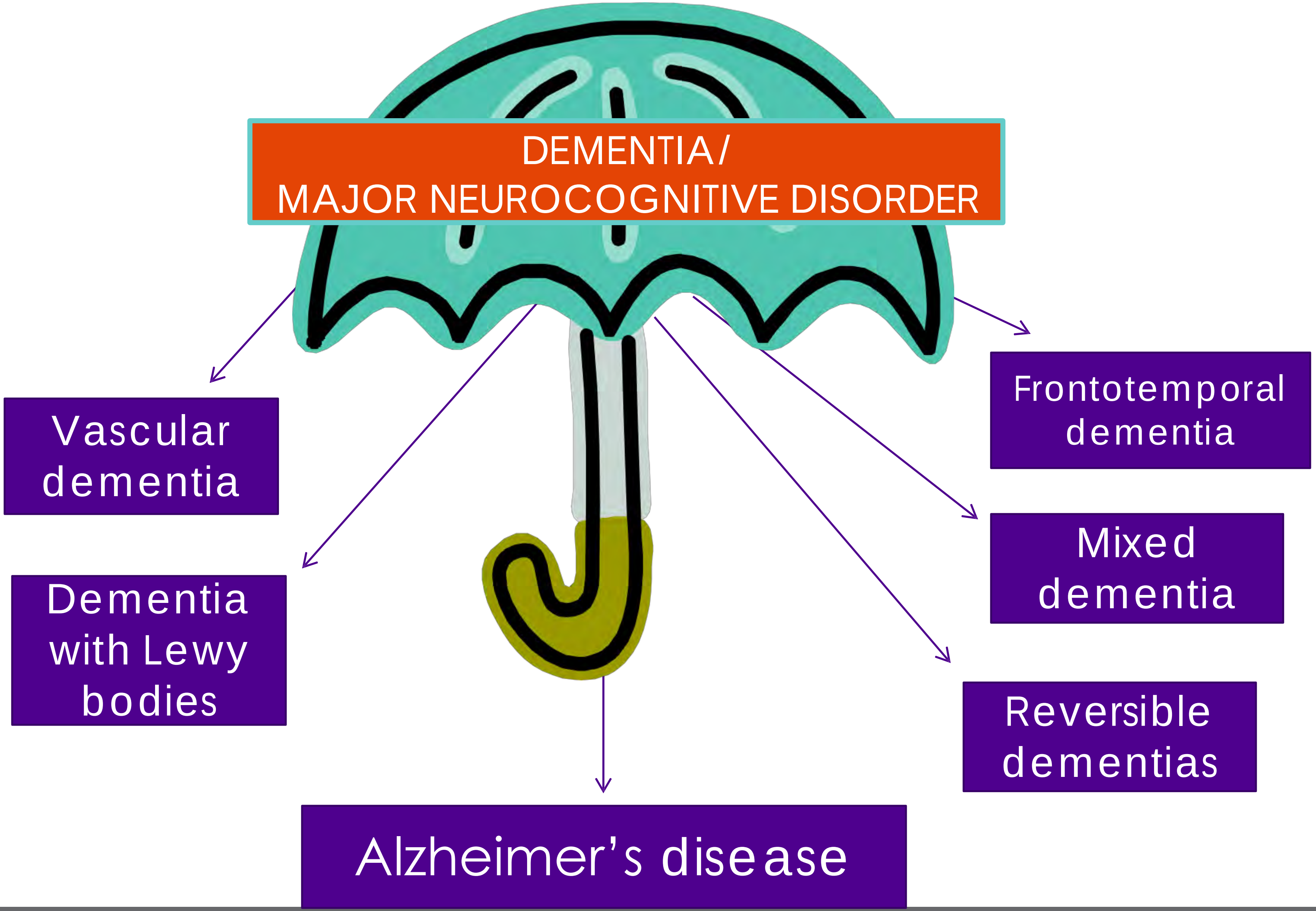
Strengths

Unique



Values

Strong opinions



DEMENTIA/
MAJOR NEUROCOGNITIVE DISORDER

Vascular dementia

Dementia with Lewy bodies

Alzheimer's disease

Frontotemporal dementia

Mixed dementia

Reversible dementias

Major Neurocognitive Disorder DSM-5

- Previously known as dementia
- Significant cognitive decline from a previous level of performance in one or more cognitive domains
- Cognitive deficits interfere with independence in everyday activities

DSM-5 Definition

What is Vascular Dementia?

- Interrupted blood flow to the brain; often caused by stroke
- Changes in thinking can occur suddenly or worsen gradually
- Common early signs include:
  - Trouble with planning and judgment
  - Uncontrollable laughing or crying
  - Difficulty with attention
  - Difficulty with speech
- Other symptoms can vary widely, including disorientation and loss of vision

National Institute on Aging, 2015. Alzheimer's Disease Education and Referral Center. Retrieved from https://www.nia.nih.gov/alzheimers/vascular-dementia-resource-list January 19, 2016.

Vascular Dementia

Educate families:

- Doing things that can prevent stroke may be helpful in reducing further vascular damage
- Exercise, healthy eating, not smoking, regular check ups with doctor
- Importance of accessing medical care for co-existing conditions (diabetes, high BP)

What is Frontotemporal Dementia?

- Begins at a younger age
- Progresses more rapidly than Alzheimer's disease
- First symptoms are usually personality changes and disorientation

When John was about 61 years old, his partner, David, started noticing some distinct and concerning changes in John's personality and behavior. John would not change his clothes unless David put out clean clothes for him to wear. John was using excessive profanity, saying racial slurs, and was socially disinhibited. John would urinate in the presence of his family. This embarrassed David. David felt that John was doing all of this intentionally.

Frontotemporal Dementia

Educate families:

- Disease often manifests behaviorally
- Behaviors are not intentional
- Families may have misconception that the way a person acts or things he/she says are a reflection of how the person always felt

What is Dementia with Lewy Bodies?

- Wide variations in attention and alertness
- May include:
  - Hallucinations
  - Tremors
  - Rigidity
- Potential for adverse reaction to anti-psychotic medications

Angie is 78 years old. She has a history of falls and has trouble with her gait.

She has fluctuations in alertness, activity level, mood, and speech.

Angie is sometimes very oriented and sometimes lacks attention and alertness.

Angie has visual hallucinations that include someone signing, dancing, and talking to her.

Dementia with Lewy Bodies

Educate families:

- Antipsychotic medications should be avoided due to adverse reactions
- Memory problems may not be noticeable in early stages; visual hallucinations more common

What is Mixed Dementia?

- Alzheimer’s disease and another type of dementia can co-exist
- Researchers think this occurs with almost 50% of people who have Alzheimer’s disease

Potentially Reversible Causes of Dementia

- Depression, delirium
- Emotional disorders
- Metabolic disorders (i.e. hypothyroidism)
- Eye and ear impairments
- Nutritional (i.e. B12 deficiency)
- Tumors
- Infections
- Alcohol, drugs, medical interactions

Alzheimer's Association. *The Basics*.

Alzheimer's Disease

Did You Know?

Not everyone with dementia has Alzheimer's disease

BUT

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

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

What is Alzheimer's Disease?

Most common form of dementia

Neurocognitive disorder

Must be diagnosed by physician

Onset is gradual

Progressive

Symptoms: memory impairment, problems with thinking and planning, and behaviors which interfere with daily life

Leads to death

National Institute on Aging, 2015. Alzheimer's Disease Education and Referral Center. Retrieved from https://www.nia.nih.gov/alzheimers/dementia-resource-list January 19, 2016.

Alzheimer’s Disease

Educate families:

- Beyond memory
- Gradual progression; no cure
- Sudden and unusual changes can be sign of acute condition
- People experience disease differently, but problem-solving strategies can be useful to all

Healthy Brain vs. Brain with Alzheimer's

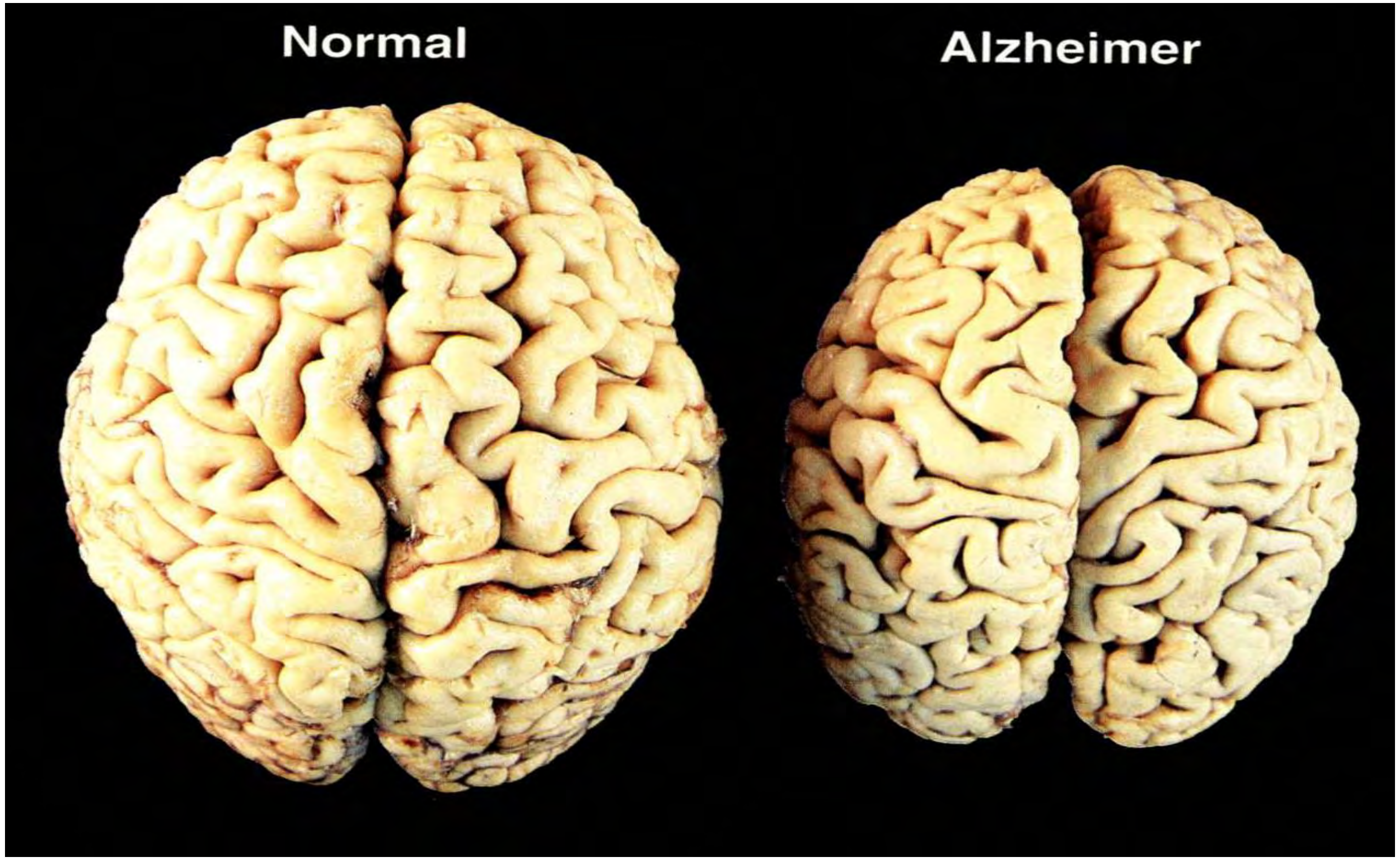
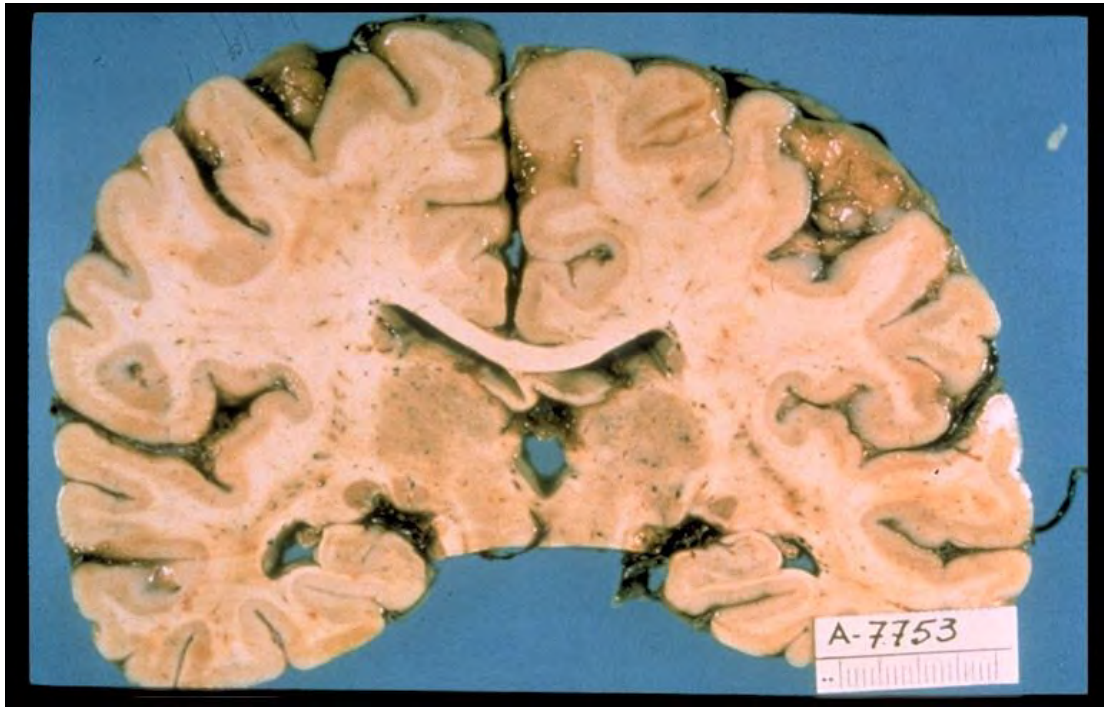


Image appears courtesy of Dr. Richard E. Powers,
Director of the Alabama Bureau of Geriatric Psychiatry, alzbrain.org



Healthy Brain

Brain with Alzheimer’s

Video: What is Alzheimer’s Disease?

https://www.youtube.com/watch?v=7_kO6c2NfmE&t=61s

Running time: 3 minutes 14 seconds

Myth vs. Fact

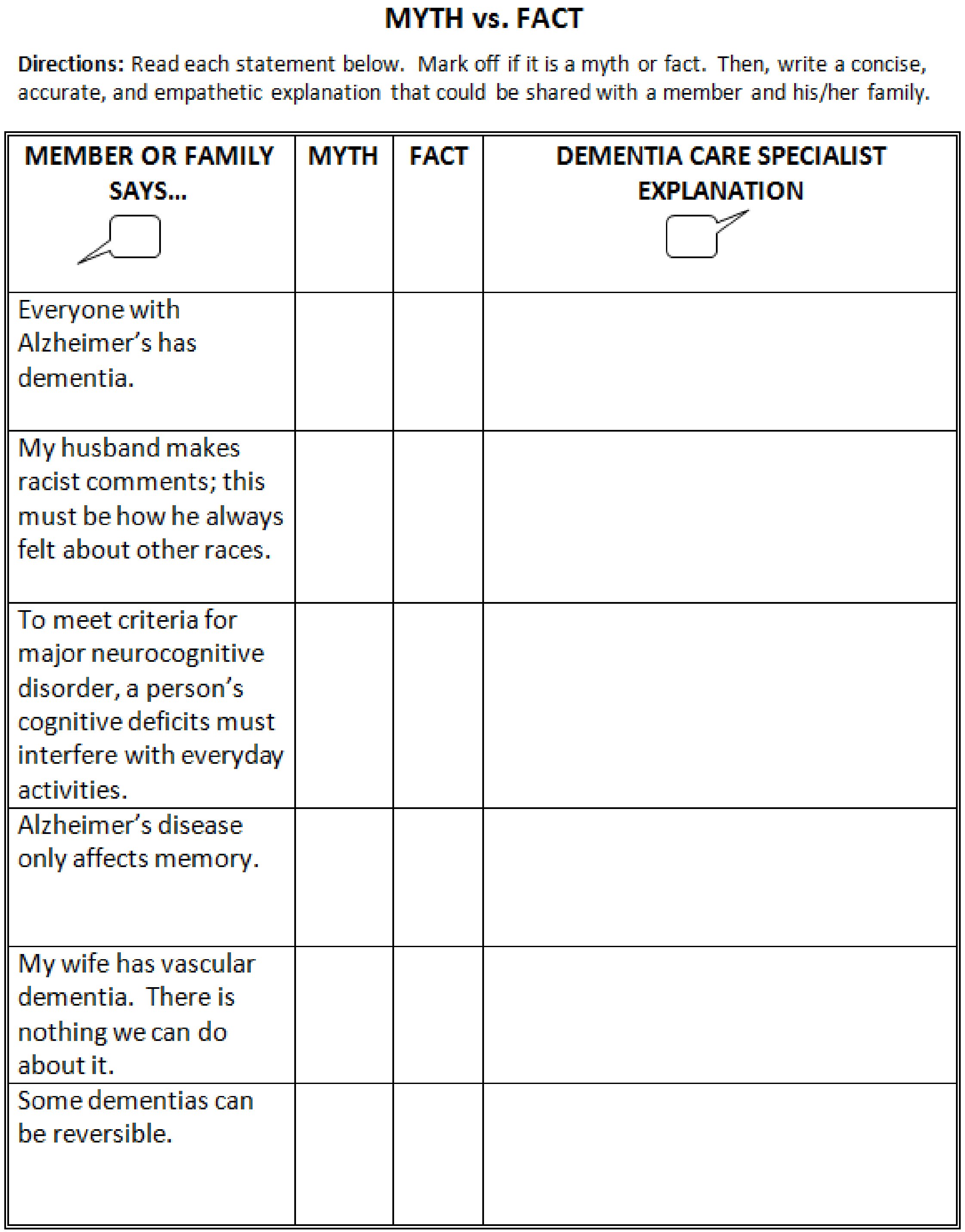
It is important that members have correct information about Alzheimer's.

Explain to the member if his/her statement is a myth or fact.

Explain why.

Be concise, accurate, & culturally sensitive

Myth vs. Facts



MYTH vs. FACT

Directions: Read each statement below. Mark off if it is a myth or fact. Then, write a concise, accurate, and empathetic explanation that could be shared with a member and his/her family.

MEMBER OR FAMILY SAYS…	MYTH	FACT	DEMENTIA CARE SPECIALIST EXPLANATION
Everyone with Alzheimer's has dementia.			
My husband makes racist comments; this must be how he always felt about other races.			
To meet criteria for major neurocognitive disorder, a person's cognitive deficits must interfere with everyday activities.			
Alzheimer's disease only affects memory.			
My wife has vascular dementia. There is nothing we can do about it.			
Some dementias can be reversible.			

Disease Progression

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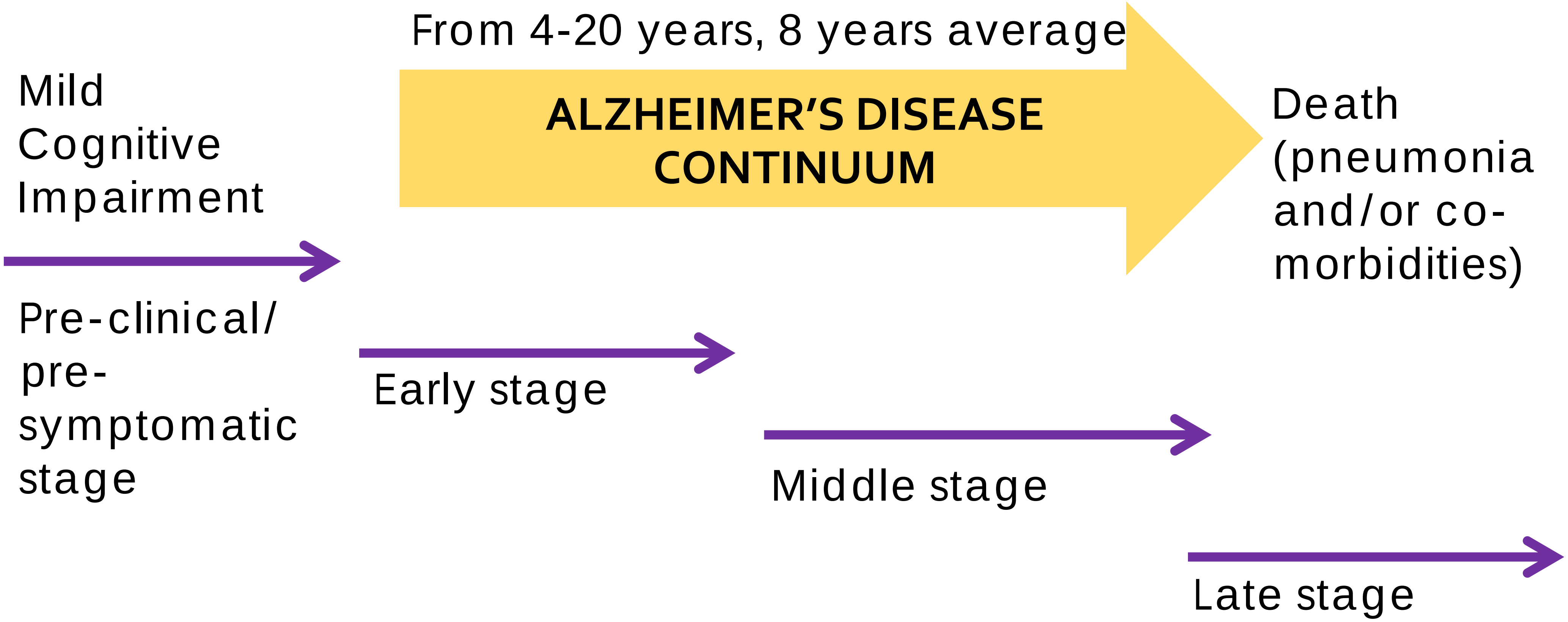
Alzheimer’s Disease Progression



From 4-20 years, 8 years average

ALZHEIMER’S DISEASE CONTINUUM

Mild Cognitive Impairment

Pre-clinical/ pre-symptomatic stage

Early stage

Middle stage

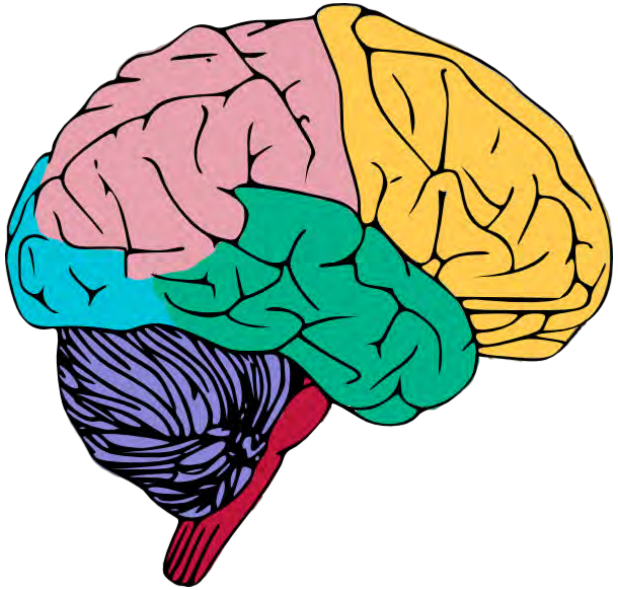
Late stage

Death (pneumonia and/or co-morbidities)

Slide courtesy of Cordula Dick-Muehlke, PhD

Domains Affected by Alzheimer's

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



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 & planning (getting lost)

Video: The Unspoken Impact of Dementia

https://www.youtube.com/watch?v=z15-0xZTng4

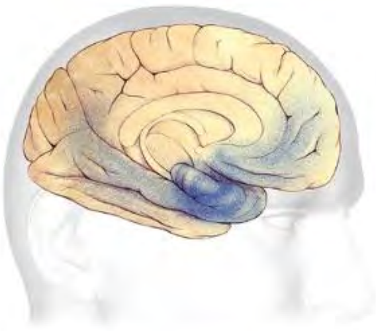
Alzheimer's Australia, 2014

Running time: 4 minutes 2 seconds

Middle Stage Alzheimer's Disease

- Memory & thinking problems more obvious
- Difficulty with communication
- Nonverbal communication retained
- Behavioral symptoms
- Greater assistance needed with day-to-day activities
- More caregiver involvement

Middle Stage Alzheimer's Disease



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

Video: HBO Documentary: The Alzheimer’s Project

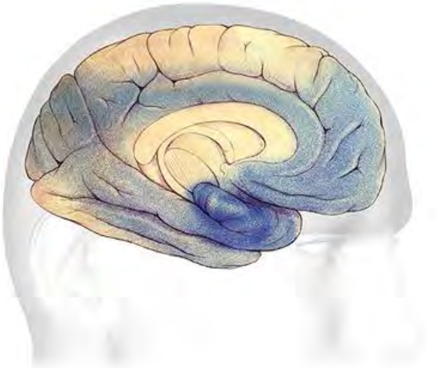
https://www.hbo.com/documentaries/the-alzheimers-project-caregivers

Running Time: 3 minutes

*Note: The video clip was manually extracted

Late Stage Alzheimer's Disease

- Functional decline
- Assistance needed with day-to-day activities & 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



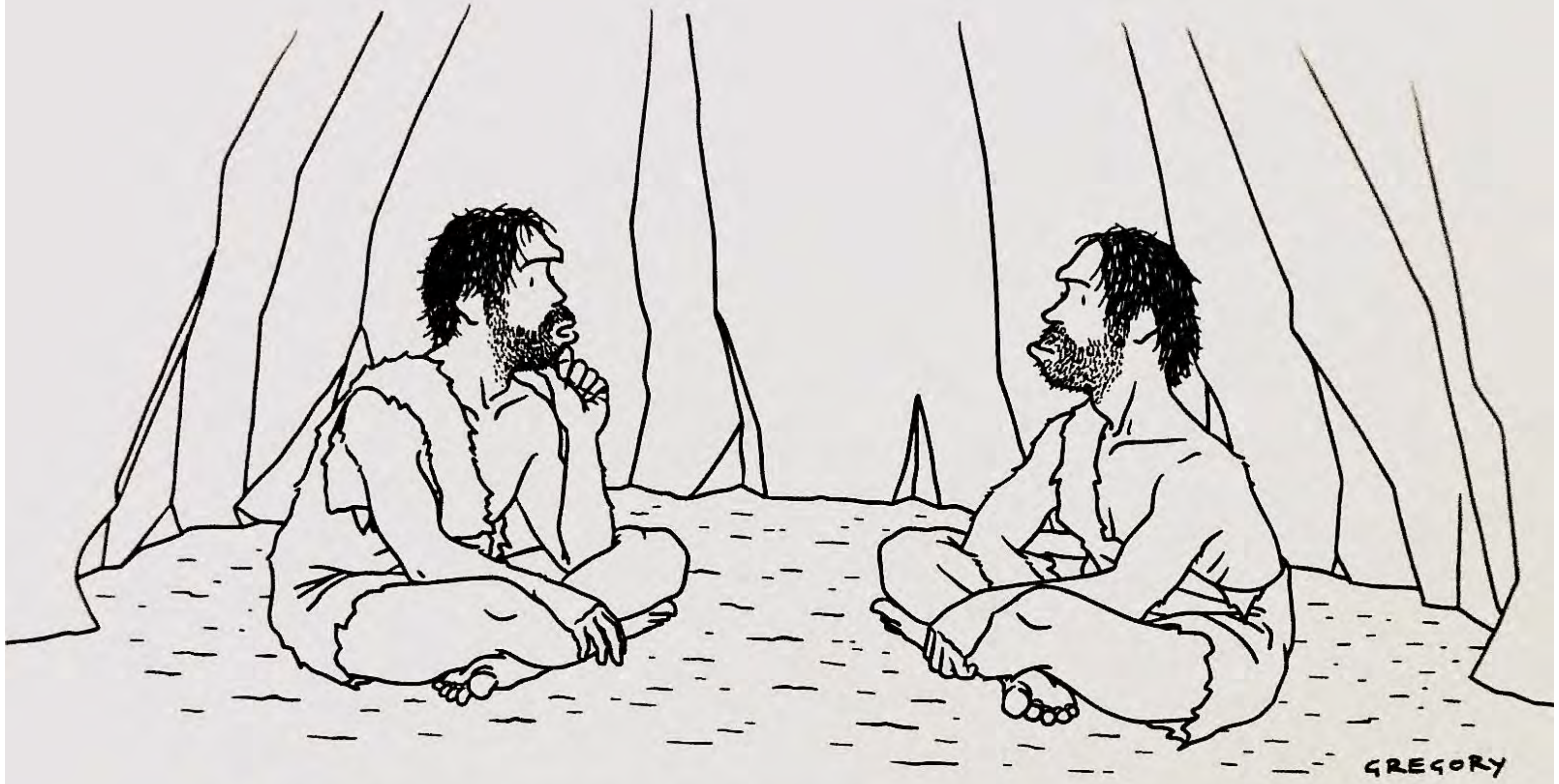
Trish is unable to recognize family members and often calls for her mom who is deceased. Trish's speech is fragmented; it's often difficult to understand her. Trish is confined to a chair or her bed. She needs help with eating and toileting. Chewing and swallowing are challenging. Trish regularly dozes during the day. She is often asleep.

Disease Continuum

Instructions

- You will receive a card that has a description on it
- Find the stage of Alzheimer's that best corresponds to the description
- Everyone will line up in the order that best represents the progression of the disease
- Feel free to talk to your colleagues and discuss
- In some cases, there is no "right" or "wrong" answer

Risk Factors



"Something's just not right—our air is clean, our water is pure, we all get plenty of exercise, everything we eat is organic and free-range, and yet nobody lives past thirty."

Major Risk Factors for Alzheimer's Disease

- Age
- Family history
- Genetics
- Head injury
- Heart-brain connection
- General healthy aging

Heart-Brain Connection

- Evidence links brain health to heart health
- Factors that increase risk of cardiovascular disease are associated with higher risk of developing ADRD
  - Smoking
  - Obesity
  - Diabetes
  - High cholesterol
  - Hypertension

Alzheimer's Association, *2014 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia, Volume 10, Issue 2*

Screening and Diagnosis

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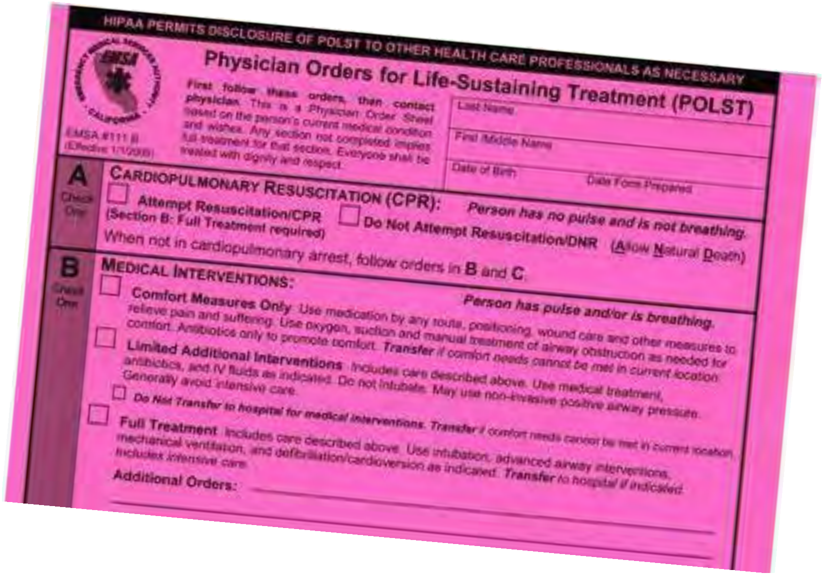
Why Get a Diagnosis?

There is no cure for Alzheimer's disease so why get a diagnosis?

Importance of Diagnosis

- Ability to plan ahead
- Preferences for care/medical decisions
- Legal/financial planning
- Living options/long-term care



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 1/1/2009)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name

First/Middle Name

Date of Birth   Date Form Prepared

A Check One

CARDIOPULMONARY RESUSCITATION (CPR): ***Person has no pulse and is not breathing.***

☐ **Attempt Resuscitation/CPR (Section B: Full Treatment required)** ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B Check One

MEDICAL INTERVENTIONS: ***Person has pulse and/or is breathing.***

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Do Not Transfer to hospital for medical interventions. Transfer*** *if comfort needs cannot be met in current location.*

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated.* Includes intensive care.

Additional Orders: ______

Importance of Diagnosis

- Optimize disease management
- Management of co-existing conditions
- Care coordination and care planning
- Drug and non-drug treatments
- Medication review
- Safety
- Anticipate issues/head off crises
- Participation in clinical studies

Importance of Diagnosis

- Support for person with disease and family
- Linking to home and community-based organizations (faith-based organizations)
- Education, support services, and programs

Trinity had some concerns about her cognition, but thought they were just signs of aging. By the time Trinity was diagnosed with dementia, the disease was rather progressed. Her children had different ideas about the best course of care for her. Some of her children thought she should remain at home with a caregiver and others wanted to place her in a nursing home. The siblings had bitter arguments about how to care for mom.

Cultural/Ethnic Barriers

Compared to whites, ethnic minorities are less likely to get a diagnosis, and when they do, it is often in the later stages of the disease.

Why?

Chin AL, et al. Alzheimer Dis Assoc Disord. 2011 Jul-Sep. Diversity and disparity in dementia: the impact of ethnoracial differences in Alzheimer disease.

Diverse Communities' Views of Dementia

- Normal aging (not a disease process)
- Cognitive issues may be expected and dismissed as normal
- Associated with mental illness, craziness, madness

Stigma

- Stigma
- Shame
- Humiliation
- Diagnosis may be seen as shaming family for doing something wrong/causing disease
- Poor reflection on family and family lineage

Omar is Pakistani. He is showing early signs of dementia. His family speaks English and Urdu. Dementia is directly translated into Urdu as "insanity" or of "unsound-mind."

How might this meaning **affect Omar's family and** feelings of shame or stigma?

Use of Formal Healthcare Services

- Unaware of available services
- Do not know how to gain access to services

Use of Formal Healthcare Services

- Distrust in care providers
- Lack of professionals with cultural and linguistic expertise & sensitivity
- Linguistic barriers
- Limited information at appropriate literacy level

Detection

- Complaints/ family observations
- Screening (AD8)
- Annual Wellness Visit
- Health Risk Assessment

Diagnosis

- PCP rules out reversible causes
- Referral for full diagnostic evaluation
- Document in medical record

Disease management/ care planning

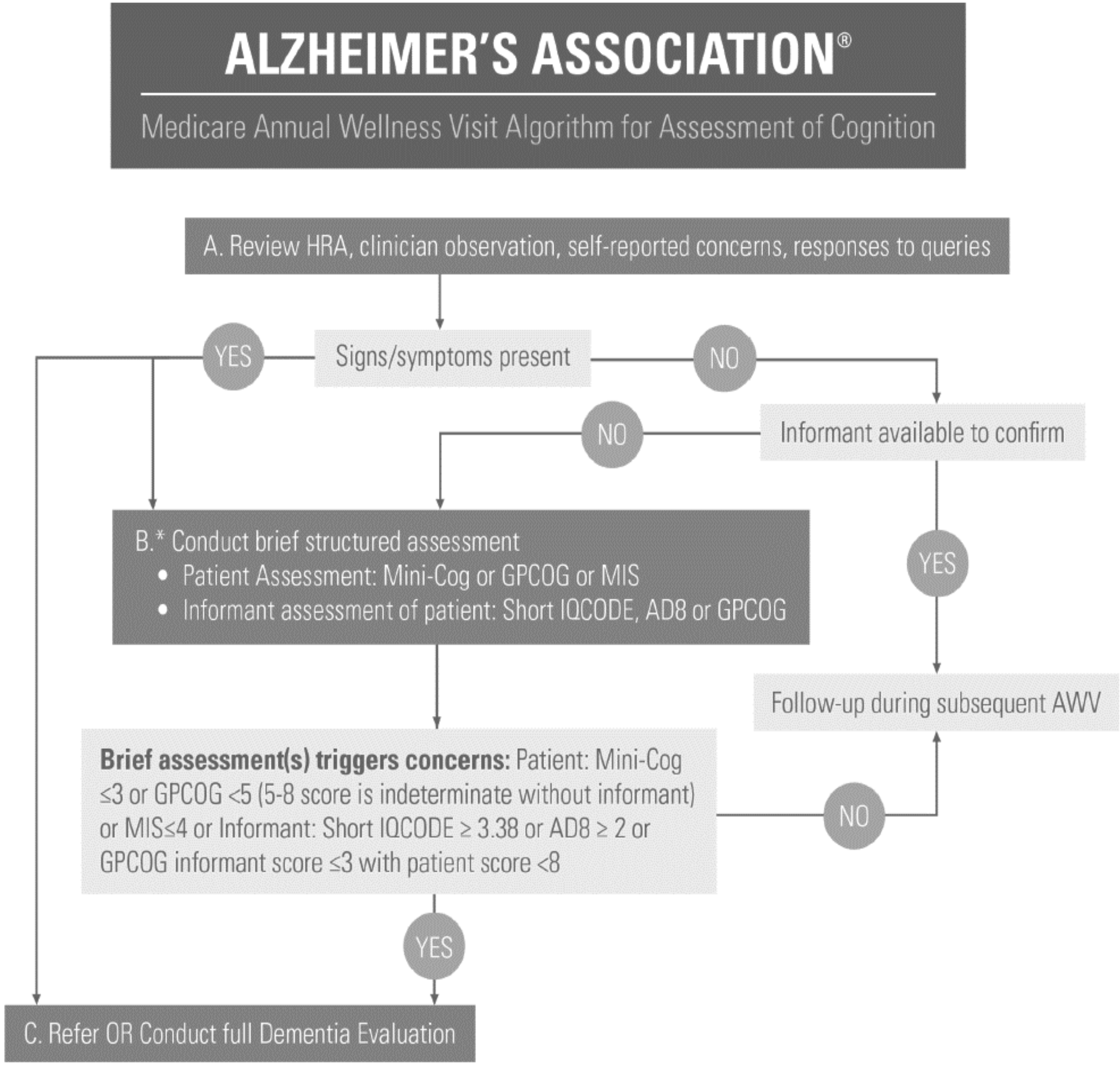
- Ongoing assessment
- Care plans
- Treatment
- Patient/family education/support
- Legal considerations
- Link to community resources

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

- Complaints/ family observations
- Screening (AD8)
- Annual Wellness Visit
- Health Risk Assessment

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



ALZHEIMER'S ASSOCIATION®

Medicare Annual Wellness Visit Algorithm for Assessment of Cognition

A. Review HRA, clinician observation, self-reported concerns, responses to queries

Signs/symptoms present

YES

NO

Informant available to confirm

NO

YES

B.* Conduct brief structured assessment

- Patient Assessment: Mini-Cog or GPCOG or MIS
- Informant assessment of patient: Short IQCODE, AD8 or GPCOG

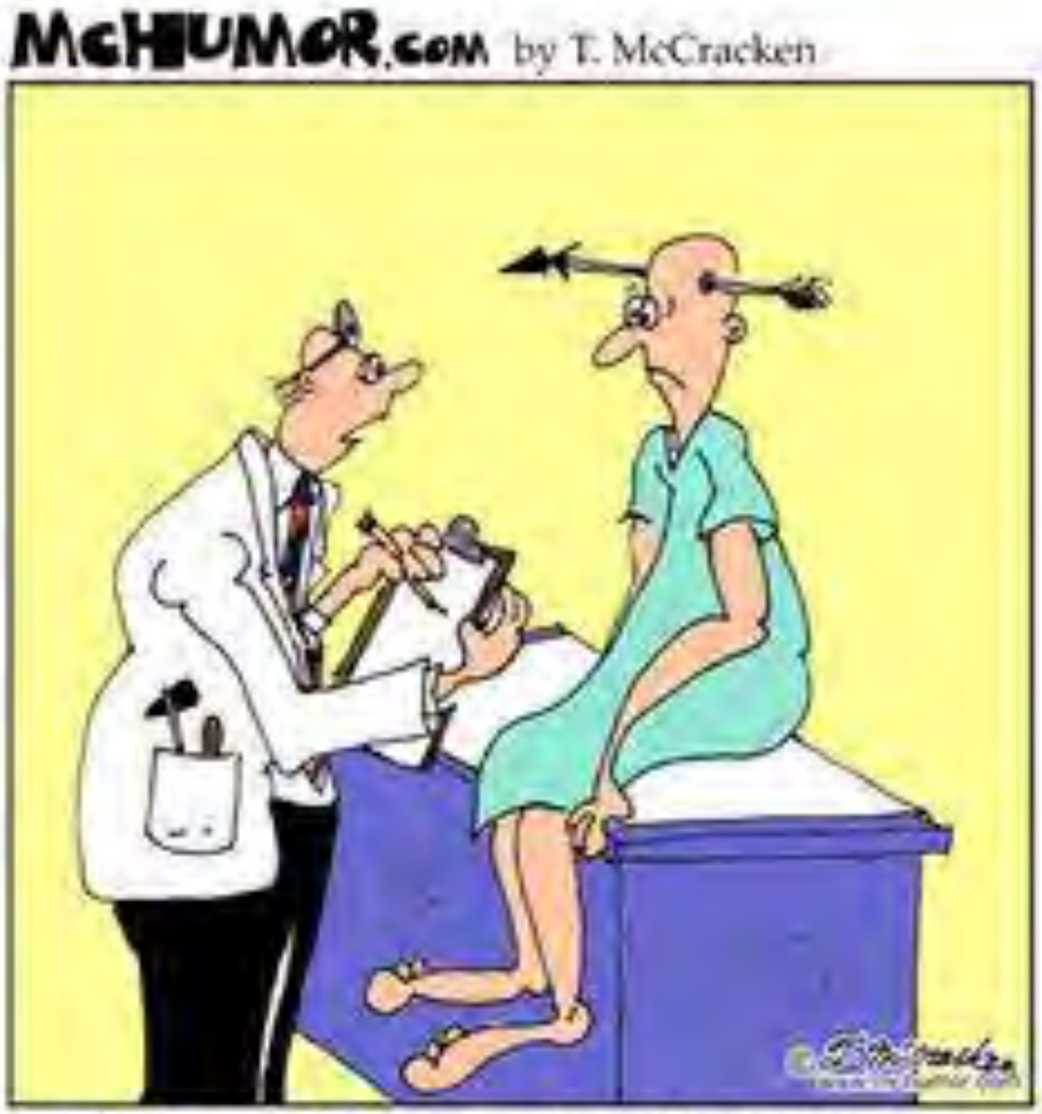
Follow-up during subsequent AWV

Brief assessment(s) triggers concerns: Patient: Mini-Cog ≤3 or GPCOG <5 (5-8 score is indeterminate without informant) or MIS≤4 or Informant: Short IQCODE ≥ 3.38 or AD8 ≥ 2 or GPCOG informant score ≤3 with patient score <8

NO

YES

C. Refer OR Conduct full Dementia Evaluation



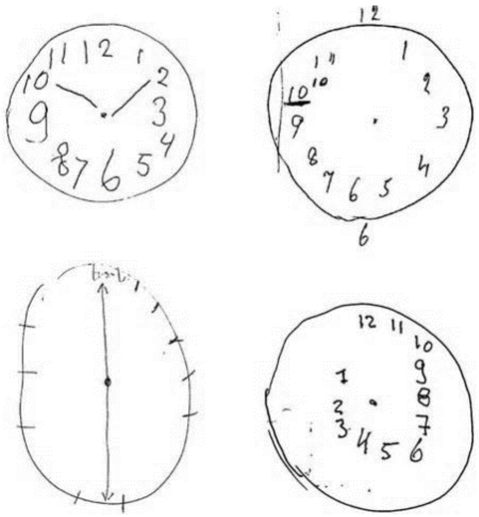
"Off hand, I'd say you're suffering from an arrow through your head, but just to play it safe, I'm ordering a bunch of tests."

Taking Complaints Seriously

- Member and/or family presents "complaints" about memory loss or cognitive impairment
- Cognitive screen administered
- Results to PCP or specialist for diagnostic workup

Cognitive Screening Tools

- Several validated screening tools
- Involve member and family ("informant")
- Counseling before and after screen
- Screening tools do not diagnose dementia; they may indicate a need for further assessment



AD8 Dementia Screening Interview

AD8 Dementia Screening Interview

Patient ID#:__________

CS ID#:___________
Date:___________

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. **Daily** problems with thinking and/or memory			
TOTAL AD8 SCORE			

Adapted from Galvin JE et al, The AD8, a brief informant interview to detect dementia, Neurology 2005:65:559-564

Detection: Using the AD8 Screening Tool

- Validated screening tool
- Use with patient or "informant"
- Introduce screening:

  "I am going to ask you some questions to help better plan for your care/your relative's care."
- Administer screening

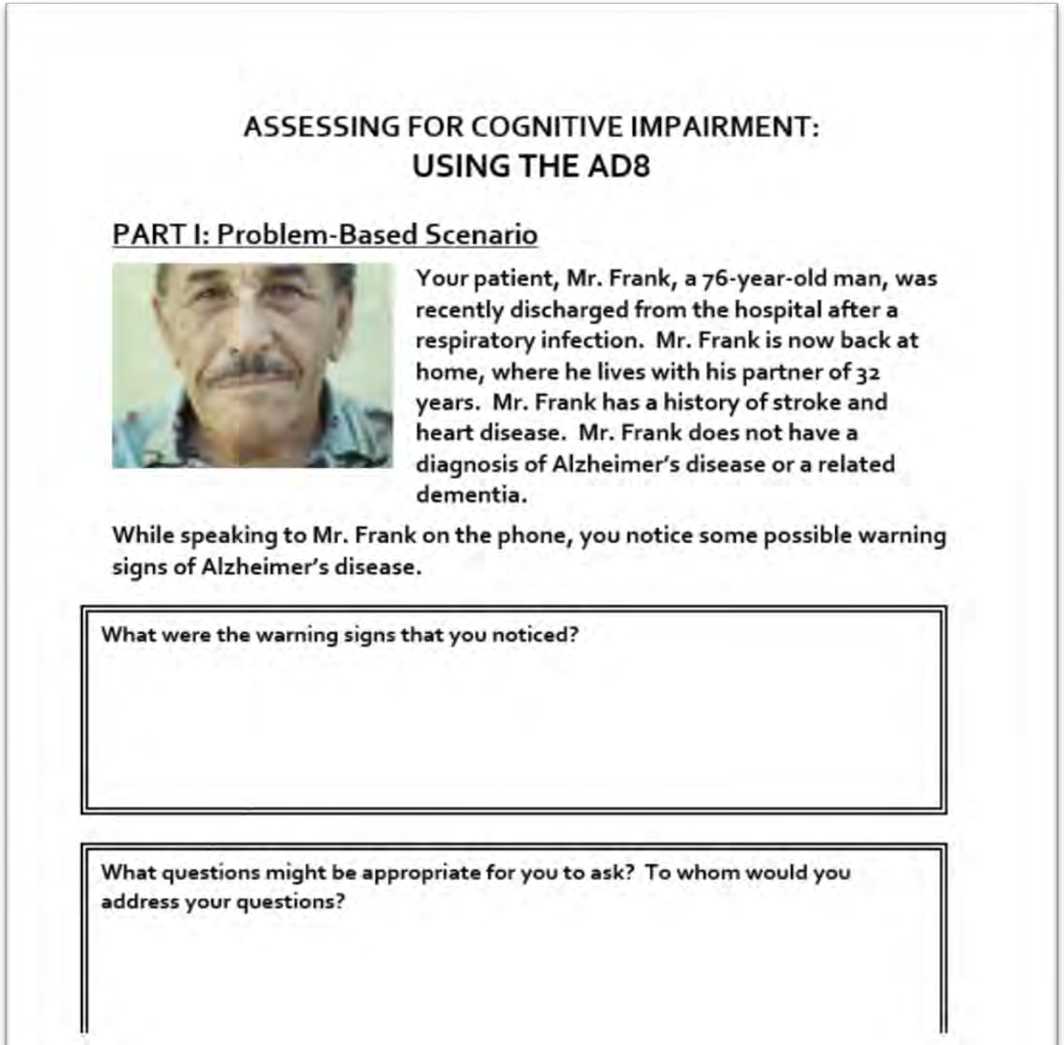
Detection: Using the AD8 Screening Tool

- Read each statement aloud
- Add up the sum of the number of items marked "Yes, a change"
- Keep in mind that the AD8 does not diagnose dementia; it may indicate a need for further assessment
- Based on clinical findings, use the following cut points:
  - 0-1: Normal cognition
  - 2 or greater: Cognitive impairment is likely to be present

Using the AD8: Practical Tips

- In addition to AD8, ask patient and/or caregiver, “has a doctor or other healthcare professional ever said that you have or think the person has Alzheimer’s disease or some other form of dementia?”
- Make referral to primary care provider for diagnostic workup

Activity: Assessing for Cognitive Impairment: Using the AD8



ASSESSING FOR COGNITIVE IMPAIRMENT:
USING THE AD8

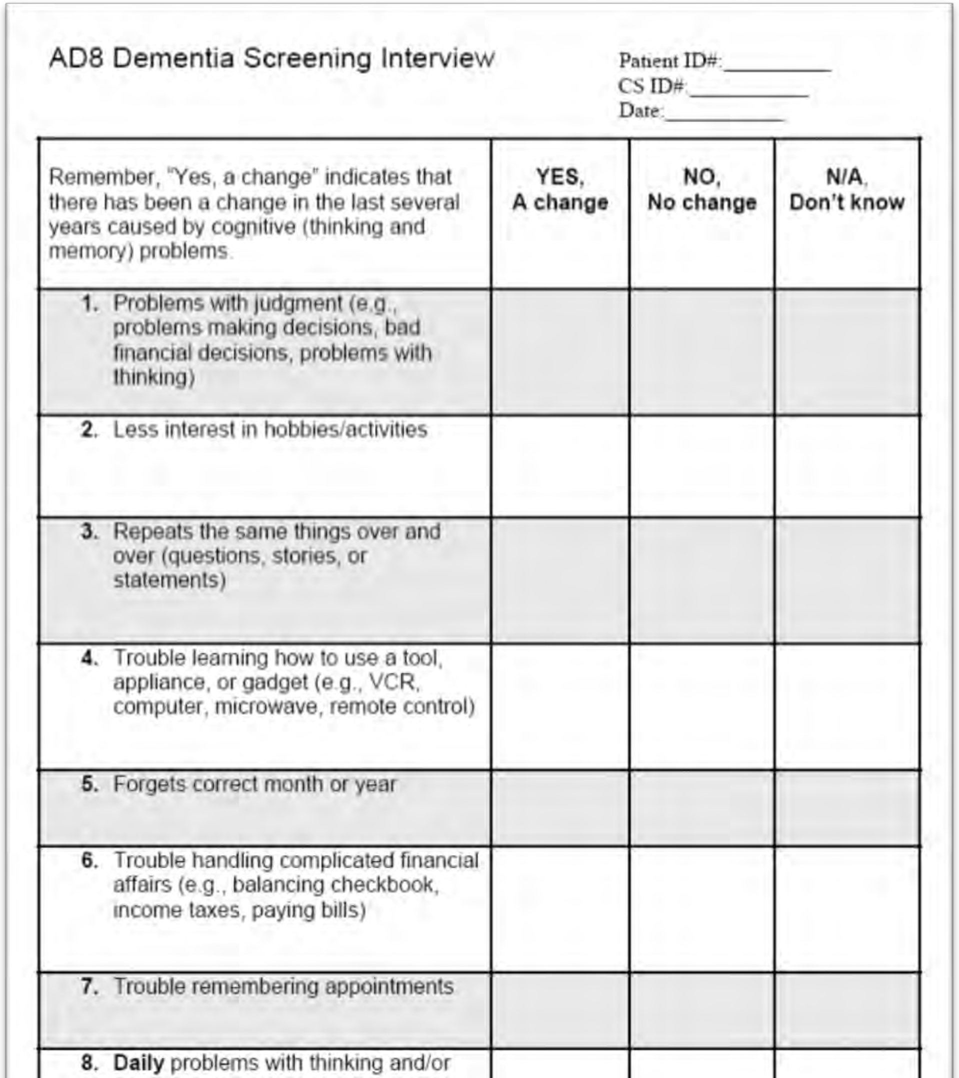
PART I: Problem-Based Scenario

Your patient, Mr. Frank, a 76-year-old man, was recently discharged from the hospital after a respiratory infection. Mr. Frank is now back at home, where he lives with his partner of 32 years. Mr. Frank has a history of stroke and heart disease. Mr. Frank does not have a diagnosis of Alzheimer's disease or a related dementia.

While speaking to Mr. Frank on the phone, you notice some possible warning signs of Alzheimer's disease.

What were the warning signs that you noticed?

What questions might be appropriate for you to ask? To whom would you address your questions?



AD8 Dementia Screening Interview

Patient ID#:__________
CS ID#:__________
Date:__________

Remember, "Yes, a change" indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.	**YES, A change**	**NO, No change**	**N/A, Don't know**
1. Problems with judgment (e.g., problems making decisions, bad financial decisions, problems with thinking)			
2. Less interest in hobbies/activities			
3. Repeats the same things over and over (questions, stories, or statements)			
4. Trouble learning how to use a tool, appliance, or gadget (e.g., VCR, computer, microwave, remote control)			
5. Forgets correct month or year			
6. Trouble handling complicated financial affairs (e.g., balancing checkbook, income taxes, paying bills)			
7. Trouble remembering appointments			
8. Daily problems with thinking and/or			

Process for Communicating AD8 with Provider

What process is in place to communicate the results of the AD8 to the primary care provider or to a specialist?

- PCP rules out reversible causes
- Referral for full diagnostic evaluation
- Document in medical record

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Alzheimer’s Diagnosis

- Medical history
- Mental status evaluation
- Physical examination
- Neurological examination
- Laboratory tests
- Brain scans/images
- Psychiatric evaluation
- Interviews with family/caregiver

Documented Diagnosis

Why is it important that a diagnosis of Alzheimer's disease or a related dementia is documented in the medical record and disclosed to the member and family?

Documentation

- Appropriate medical care
- Coordinated care
- Care planning
- Appropriate referrals to home and community-based services

Impact on Medical Care

Primary Care Providers

- Consideration to medical and non-medical interventions/treatments
- Better management of co-existing conditions
- Avoid treatments for wrong conditions
- Counsel about safety issues
- Appropriate care planning

Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Impact on Medical Care

Emergency Department

- Member may be poor historian
- Unnecessary tests ordered
- Non-optimal decisions about discharge
- Poor care transitions
- Importance of family

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Impact on Medical Care

Hospital

- Delirium
- Fall risk
- Elopement
- Dehydration risk
- Inadequate food intake
- Resistance to care
- New incontinence
- Loss of functional abilities
- Importance of family

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Impact on Medical Care

Specialists

- Avoid provision of treatments that may worsen cognition
- Multiple medications
- Lack of ability to monitor co-existing conditions

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

Detection

Diagnosis

Disease management/ care planning

- Ongoing assessment
- Care plans
- Treatment
- Patient/family education/support
- Legal considerations
- Link to community resources

K Maslow and SM Ling. Medicare Annual Wellness Visit as Springboard to Detection of Cognitive Impairment, Diagnosis, and Post-Diagnosis Support Presentation. The Gerontological Society of America. January 2014 Webinar.

2017 Alzheimer's
Clinical Care
Guideline is a
care plan
roadmap

2017 Alzheimer's
Clinical Care Guideline

Alzheimer's* Clinical Care Guideline

ASSESSMENT
Understand (or Know) the Patient

Address the Patient Directly
- Confirm, disclose and document the diagnosis in the patient record.
- Identify the patient's culture, values, primary language, literacy level, and decision-making process.
- Identify the primary caregiver and assess the adequacy of family and other support systems, paying attention to the caregiver's own mental and physical health.

Monitor and Reassess Changes

Upon sudden changes or significant decline, and at least annually, conduct and document the following:
- Ability to manage finances and medications, as well as daily functions, including feeding, bathing, dressing, mobility, toileting and continence;
- Cognitive status, using a valid and reliable instrument, e.g., MoCA (Montreal Cognitive Assessment), AD8 (Ascertian Dementia 8) or other tool;
- Comorbid medical conditions, which may present with sudden worsening in cognition and function or changes in behavior, and could complicate management of dementia;
- Emotional, behavioral and/or mood symptoms;
- Medications, both prescription and non-prescription, for appropriate use and contraindications; and
- Adequacy of home environment, including safety, care needs, and abuse and/or neglect.

CARE PLAN
Beneficial Interventions

Disease Management
- Discuss the progression and stages of the disease.
- Evaluate and manage comorbidities in context of dementia and prognosis.
- Consider use of cholinesterase inhibitors, N-Methyl-D-aspartate antagonist, and other medications, if clinically indicated, to slow cognitive decline.
- Promote and refer to social services and community support.

Treat Emotional, Behavioral and/or Mood Symptoms
- First consider non-pharmacologic approaches such as counseling, environmental modification, task simplification, activities, etc.
- Consult with or refer to mental health professionals as needed.
- IF non-pharmacological approaches prove unsuccessful, THEN use medications targeted to specific emotions, behaviors or moods, if clinically indicated. Note, many medications carry an FDA black box warning and side effects may be serious, significant or fatal.

Evaluate Safety Issues
- Discuss driving, wandering, firearms, fire hazards, etc. Recommend medical identification for patients who wander.

Document Goals of Care
- Explore preferred intensity of care to include palliative care and end-of-life options such as hospice.
- Provide information and education on advance health care directives, Do Not Resuscitate Orders, Physicians Orders for Life Sustaining Treatment, Durable Power of Attorney and other documents.

Promote Healthy Living
- Discuss evidence in support of modifiable risk factors, e.g., regular physical activity and diet/nutrition.

Refer to Clinical Studies
- If interested, advise patient and family of opportunities to participate in research.

EDUCATION AND SUPPORT
Engage with the Community

Connect with Social and Community Support
- Involve the patient directly in care planning, treatment decisions and referrals to community resources.
- As the disease progresses, suggest appropriate home and community-based programs and services.
- Link the patient and caregiver to support organizations for culturally appropriate educational materials and referrals to community and government resources.

For statewide patient and family resources, link to:
California Department of Public Health, Alzheimer's Disease Program (916) 552-9900
cdph.ca.gov/programs/Alzheimers/Pages/default.aspx
Check for local services in your area.

Alzheimer's LOS ANGELES | 844.HELP.ALZ
AlzheimersLA.org

IMPORTANT CONSIDERATIONS
Time Sensitive Issues

Advance Planning
- Discuss the importance of basic legal and financial planning as part of the care plan and refer for assistance.

Capacity Evaluations
- Assess the patient's decision-making capacity and determine whether a legal surrogate has been or can be identified.
- Consider literacy, language and culture in assessing capacity.

Elder Abuse
- Monitor for evidence of and report all suspicions of abuse (physical, financial, sexual, neglect, isolation, abandonment and/or abduction) to Adult Protective Services, Long-Term Care Ombudsman or the local police department, as required by law.

Driving
- Report the diagnosis of Alzheimer's disease in accordance with California law.

Eligibility for Benefits
- Patients diagnosed with early-onset Alzheimer's disease may be eligible for Social Security compassionate allowance.
- Other benefits may include Department of Veterans Affairs or long-term care insurance coverage under existing policies.

2017, rev. 4 *This guidance may apply to other forms of dementia as well as mild cognitive impairment. California Department of Public Health

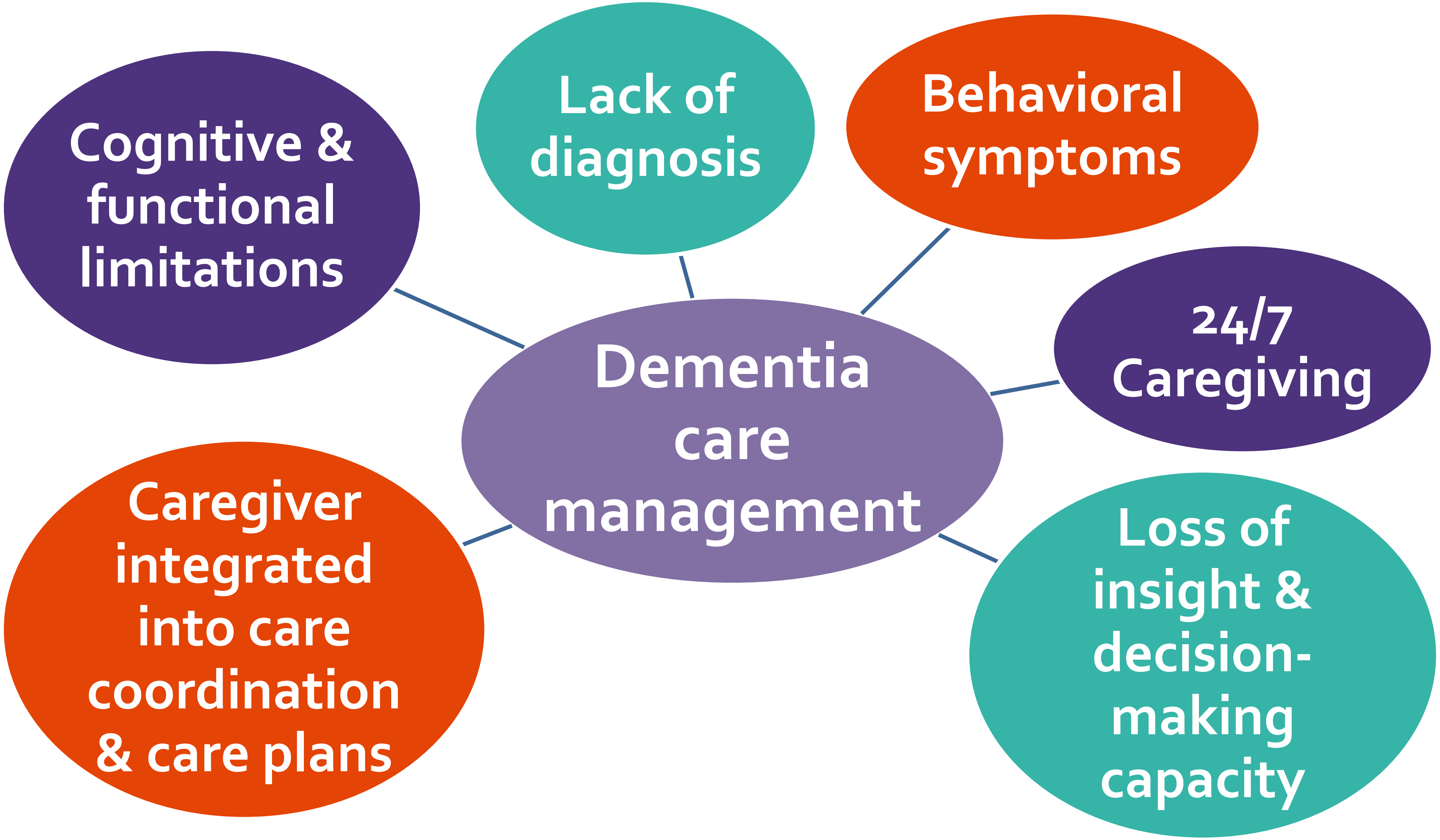
PART II

Practical Dementia Care Management

What are We Tackling Today?

- Management of Alzheimer’s Disease and Related Dementias
    - Mandatory Reporting: Elder Abuse/Driving
    - Medication Management
    - Co-Existing Conditions
    - Safety
    - Behavioral Symptoms/*IDEA!*

What Makes Dementia Care Management Unique?



Dementia care management

Cognitive & functional limitations

Lack of diagnosis

Behavioral symptoms

24/7 Caregiving

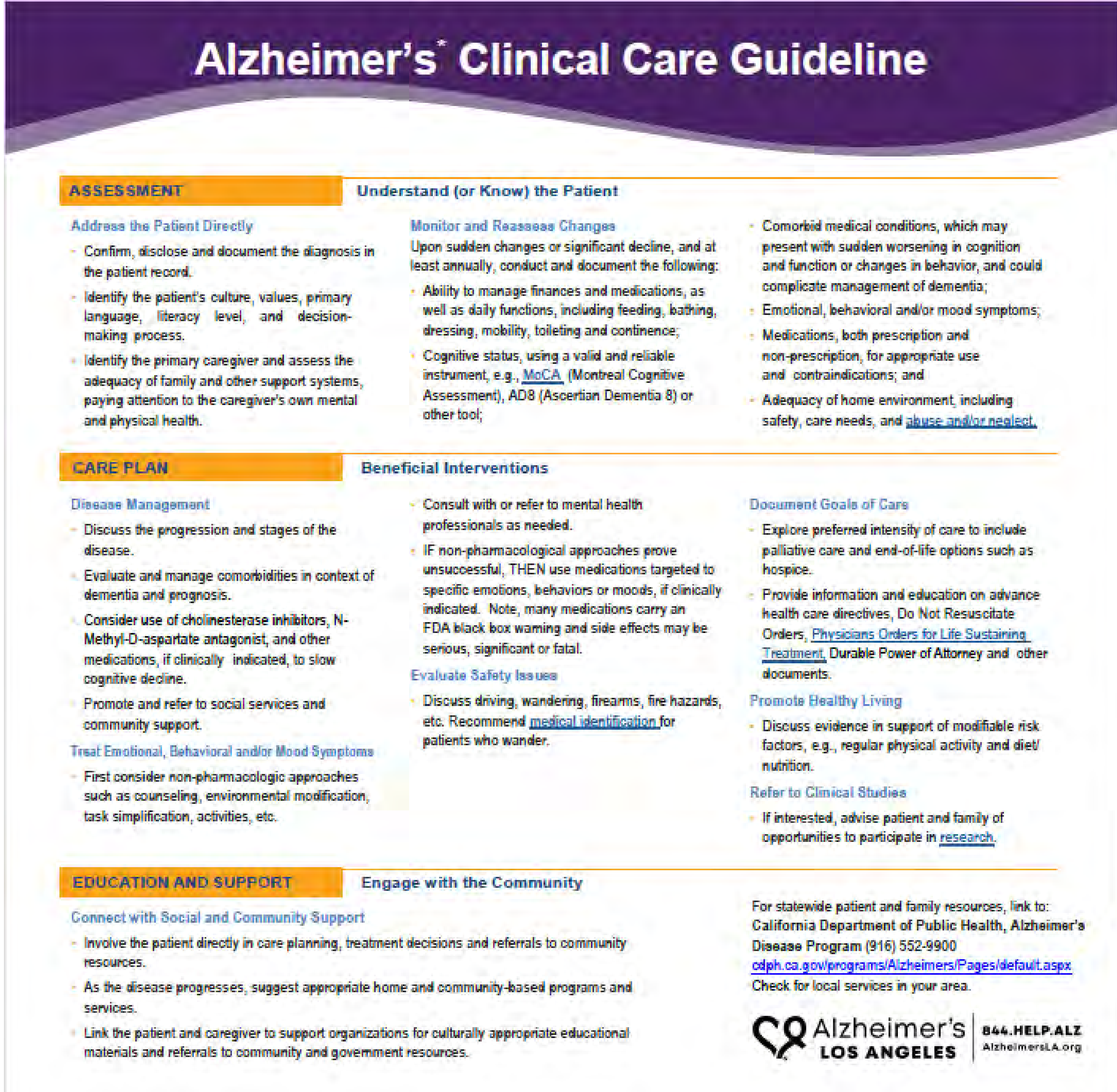
Loss of insight & decision-making capacity

Caregiver integrated into care coordination & care plans

Management of **Alzheimer's** Disease and Related Dementias

Alzheimer's
LOS ANGELES

Alzheimer's Clinical
Care Guideline



Alzheimer's* Clinical Care Guideline

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- Emotional, behavioral and/or mood symptoms;
- Medications, both prescription and non-prescription, for appropriate use and contraindications; and
- Adequacy of home environment, including safety, care needs, and abuse and/or neglect.

CARE PLAN — Beneficial Interventions

Disease Management

- Discuss the progression and stages of the disease.
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Refer to Clinical Studies

- If interested, advise patient and family of opportunities to participate in research.

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- Involve the patient directly in care planning, treatment decisions and referrals to community resources.
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Alzheimer's LOS ANGELES
844.HELP.ALZ
AlzheimersLA.org

Mandatory Reporting: Elder Abuse and Driving

Alzheimer's
LOS ANGELES

Elder Abuse

- As many as 1 in 10 older adults, and 1 in 2 people with dementia, are victims of elder abuse
- For every reported case of elder abuse, there are 23 that go unreported
- 70-90% of perpetrators of elder abuse are family members, loved ones, or caregivers
- Reporting helps link families to needed services
- Victims of elder abuse are two times more likely to be hospitalized than other seniors

Ageless Alliance at http://agelessalliance.org Dong and Simon. (2013). JAMA, 173(10), 911-917.

Who are Mandated Reporters?

Any person who has assumed full or intermittent responsibility for the care or custody of an elder or dependent adult, whether or not he or she receives compensation

Health practitioners are mandated reporters of elder abuse

Welfare and Institutions Code Section 15630-15632

What Must Be Reported?

Abandonment

Isolation

Neglect

Physical abuse

Financial abuse

Self Neglect

(deficits in physical self-care, medical care, health and safety hazards, and/or malnutrition)

Abduction

Welfare and Institutions Code Section 15630-15632

Raj and Ana have been married for over 40 years. Raj is Ana's primary caregiver.

Ana's dementia is very progressed. She is unable to follow simple instructions and is slow in completing tasks like dressing and eating.

Raj loves Ana very much, but often gets frustrated and is sometimes forceful with her. Recently, Raj grabbed Ana when helping her get dressed and pushed her down. He left marks on her arms. He also shoved food into Ana's mouth because she was eating so slowly.

Is this abuse? Why or why not?

Robert is Mary's second husband. Mary has Alzheimer's and Robert takes care of her.

Robert never really liked Mary's children or extended family. Robert has cut Mary off from her children, extended family, and friends. He does not allow anyone to come over to visit and does not pass Mary the phone when her children call. Robert does not take Mary out of the house.

Is this abuse? Why or why not?

Michael's son, Erik, is his paid IHSS caregiver. Michael is in the mid stage of Alzheimer's. He is unable to make phone calls, has a history of wandering and getting locked out of the house, and once left the stove on.

Erik says that he cares for his dad during the day, but he is working outside of the home. He is also taking Michael's social security income and using it for his personal expenses.

Is this abuse? Why or why not?

Why Report Elder Abuse?

- It is the LAW. Failure to report, or impeding or inhibiting a report…is a misdemeanor, punishable by county jail, a fine, or both
- Helps connect families to support services
- Improves quality of life
- Can reduce hospitalizations

Welfare and Institutions Code Section 15630-15632

Reporting Driving

In California, physicians and surgeons are required to report a patient with Alzheimer's disease and dementia to the local health officer, in writing. Reports must include the name of the patient, date of birth, and address.

Health and Safety Code Section 103900

Video: HBO: The Alzheimer’s Project

https://www.hbo.com/documentaries/the-alzheimers-project-caregivers

Running Time: 3 minutes 11 seconds
*Note: The video clip was manually extracted

Medication Management

"Time for your morning medication...
and I understand you haven't been
eating very much."

Overarching Principles/Aims

- Minimize overall number of medications
- Minimize number of times in a day medications are given
- Identify best time(s) of day for member to take medications
- Monitor for effects, side effects, and adverse reactions
- Review medications regularly with the doctor

Alzheimer's Considerations

- As disease progresses, cannot rely on person to take medications
- Caregiver needs to make sure medications are properly administered
- Do not leave person home alone with medications
- Lock up medications

Keep medications out of reach; lock up for safety

Alzheimer's Considerations

- Sudden and unusual changes in cognition or behavior can be a sign of an adverse reaction
- Watch for medication reactions or interactions
- Refusing to take medications complicates medication management

Helping Caregivers Manage Medications

- Instruct families how to monitor for potential adverse effects
- Assess members' and caregivers' ability to adhere to medication regimen
- Simplify and use adherence aids
- Encourage caregivers to write down ALL questions to ask doctor/pharmacist; talk to doctor/ pharmacist

CDC's Noon Conference. *Medication Adherence*. March 27, 2013. www.cdc.gov/primarycare/materials/medication/docs/medication-adherence-01ccd.pdf
B. Williams. The Ups and Dows of Psychotropic Meds in Older Adults.

Questions to Encourage Asking Doctor/Pharmacist

- Can pills be crushed?
- Can all pills be taken at the same time?
- Are herbal remedies safe to take?
- Will supplements interact with the medication?
- Other???

May's daughter puts her mom's pills in a pill box and then leaves them on the counter for her mom to take. May's daughter sets an alarm to remind her mom when to take her pills.

Sometimes, May's daughter returns home from work and finds a pill still in the pill box or finds a pill on the floor.

What would you suggest to May's daughter, given that she has to go to work?

Co-Existing Conditions

"I would go to the doctor, but I can't afford to take on any new conditions at this time."

People with Dementia Have Multiple Co-Existing Conditions

- 60% hypertension
- 26% coronary heart disease
- 25% stroke
- 23% diabetes

Bynum JP. Characteristics, Costs, and Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis: Report 1. Dartmouth Institute for Health Policy and Clinical Care (2009).

Monitoring & Managing Co-Existing Conditions

- Loss of cognitive ability to understand multiple conditions and disease management
- Difficulty attending follow-up medical appointments/visits
- Less ability to express symptoms, leading to delays in seeking treatment
- Caregiver must learn techniques to manage co-existing conditions

Monitoring & Managing Co-Existing Conditions

- Consideration for care and treatment preferences
- How aggressive should treatments be? Will they cause distress? Will it be possible to adhere to instructions?
- How many medications will be prescribed? Will they be taken correctly?
- Should consideration be given to palliative care?

More Tests…What For?

Anonymous
August 12, 2014

"I would have done just about anything to prolong my grandma's life; however, when you know someone has Alzheimer's, you ask yourself if certain procedures are necessary anymore. My grandma resisted medical interventions when she was well, so I doubted she would have wanted a colonoscopy at mid-stage Alzheimer's to see if she had colorectal cancer. Seriously, how would I, her caregiver, have even been able to get her to drink the Colyte? It's hardly palatable when you *know* why you need to drink it. And the subsequent diarrhea? She could hardly wipe herself after regular bowel movements. It's not like she had the cognitive ability to understand all of this nor did she have the functional ability to manage it. And, if she had been diagnosed with cancer, then what?"

A Dementia-Informed Lens

- ***It's not business as usual***
- Need to think differently about how to manage care
- Creative approaches may be needed
- Special instructions may be needed
- Caregivers may need additional training and support

Managing Co-Existing Conditions with a Dementia-Informed Lens

Congestive heart failure	Challenge of dementia	Potential adaptation strategies for caregiver
Monitoring weight	- Person refuses to go onto scale - Person is unsteady when going onto scale	- Try weighing person when he/she is more relaxed - Make weighing an activity - Grab bars near scale
Taking diuretic	- Cannot rely on patient to take medication - More toileting needs; person unable to use bathroom independently - Person is up at night	- Caregiver administers medication - Caregiver assists with toileting; consider toileting schedule - Talk to doctor about taking medication in morning so person is not up at night
Compression stockings	- Person refuses to wear stockings - Person gets aggressive when caregiver tries to put on stockings	- Elevate feet instead - Speak to doctor about alternatives to compression stockings

Managing Co-Existing Conditions with a Dementia-Informed Lens: *Your Turn*

In groups of 4-5, consider a co-existing condition that you work with patients to manage.

- How would dementia affect the management of this condition? Be specific.
- Consider how you would modify your disease management instructions given the dementia. What could be done differently? Be creative and realistic.

Safety

Safety Considerations

- Home safety
- Never leave person home alone
- Wandering
- Driving

Video: The Alzheimer's Caregiver-Janice Crenwelge on her Husband's Wandering

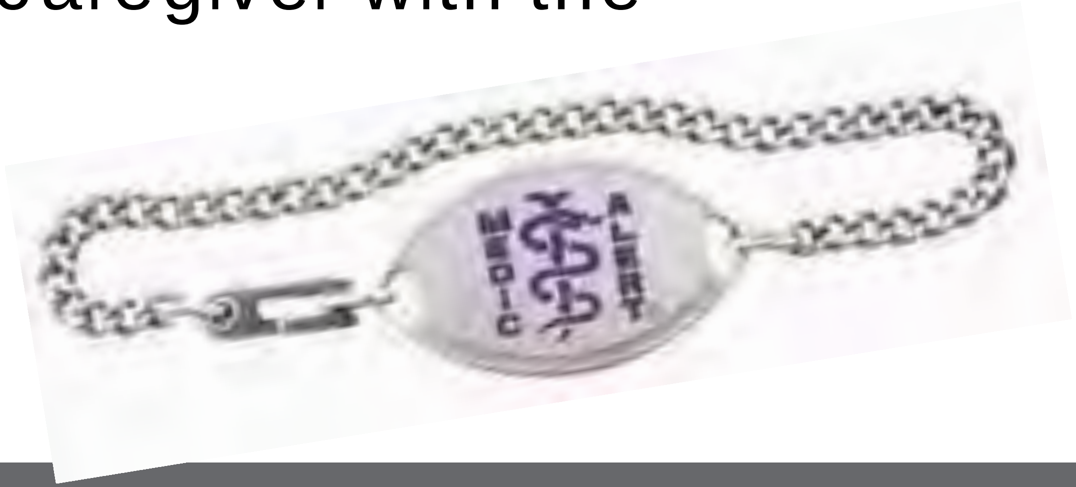
https://www.youtube.com/watch?v=wOAEJAtfTWU

Running Time: 1 minute 14 seconds

Medic Alert®

- 24-hour nationwide emergency response service
- Activates community support network to reunite family member/caregiver with the person who wandered

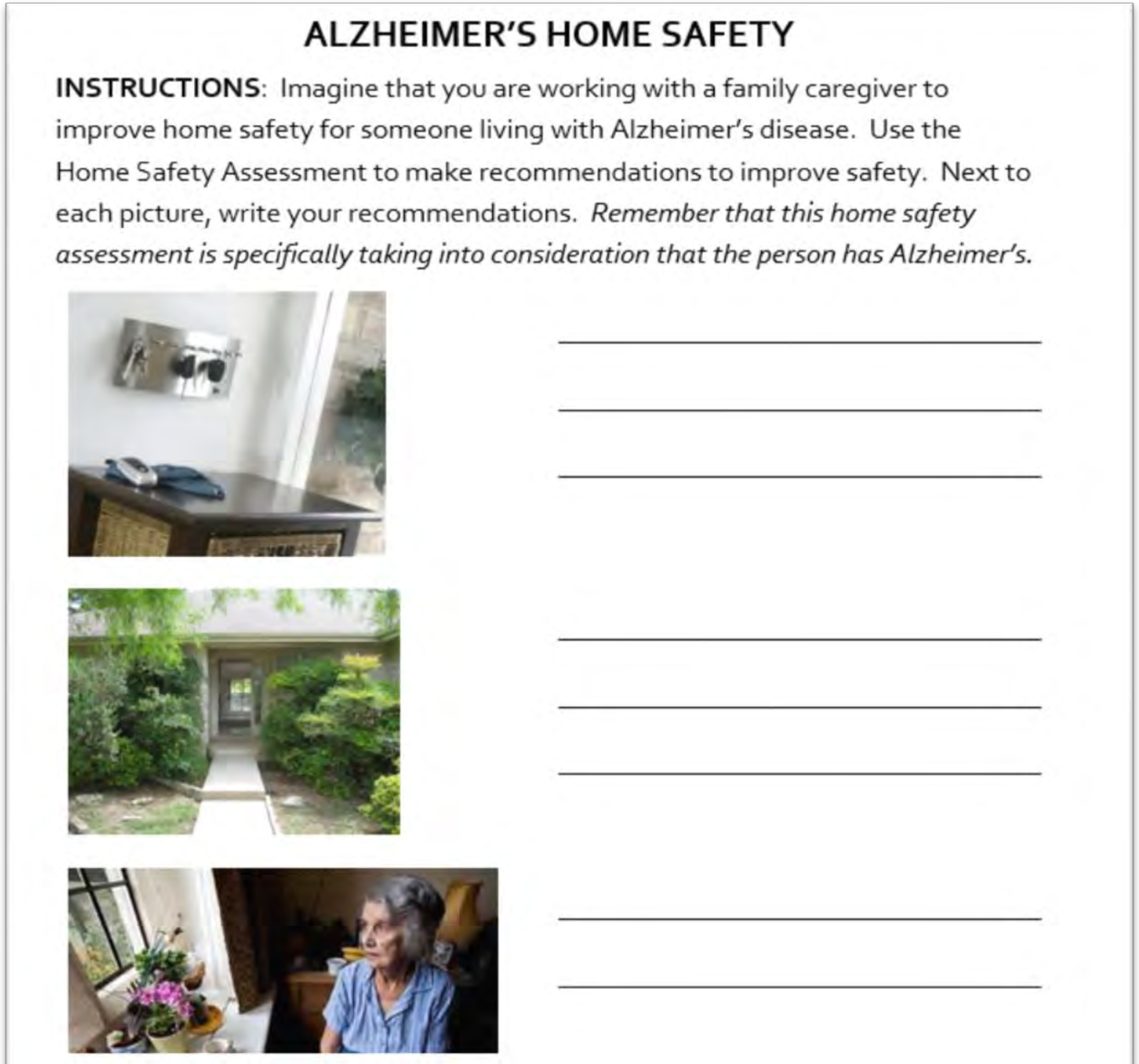
Wandering is always a potential risk



Assessing Home Environment

- Medications
- Hazards
- Weapons
- Fire

Alzheimer's Home Safety



ALZHEIMER'S HOME SAFETY

INSTRUCTIONS: Imagine that you are working with a family caregiver to improve home safety for someone living with Alzheimer's disease. Use the Home Safety Assessment to make recommendations to improve safety. Next to each picture, write your recommendations. *Remember that this home safety assessment is specifically taking into consideration that the person has Alzheimer's.*

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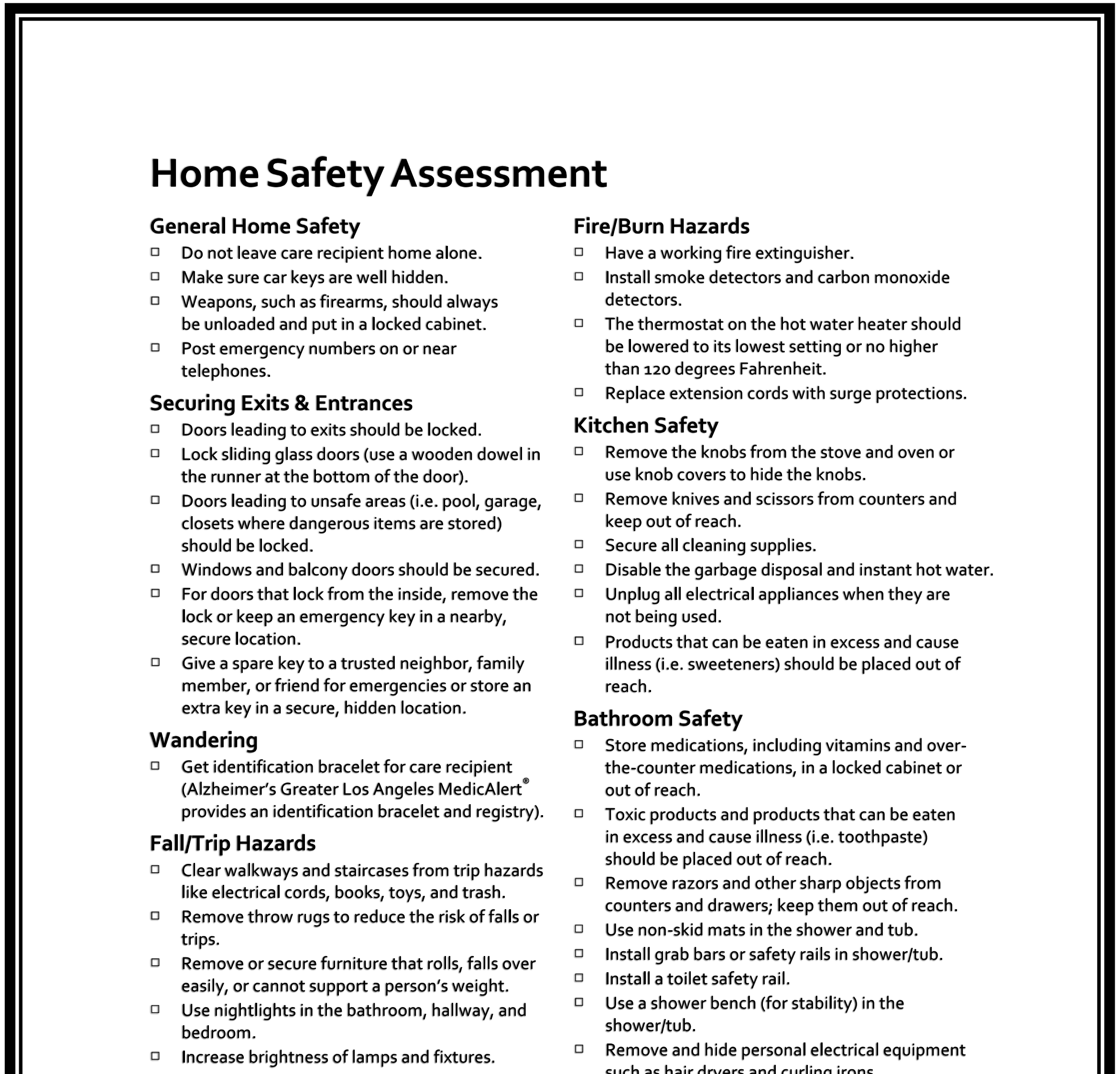


Home Safety Assessment

General Home Safety
- ☐ Do not leave care recipient home alone.
- ☐ Make sure car keys are well hidden.
- ☐ Weapons, such as firearms, should always be unloaded and put in a locked cabinet.
- ☐ Post emergency numbers on or near telephones.

Securing Exits & Entrances
- ☐ Doors leading to exits should be locked.
- ☐ Lock sliding glass doors (use a wooden dowel in the runner at the bottom of the door).
- ☐ Doors leading to unsafe areas (i.e. pool, garage, closets where dangerous items are stored) should be locked.
- ☐ Windows and balcony doors should be secured.
- ☐ For doors that lock from the inside, remove the lock or keep an emergency key in a nearby, secure location.
- ☐ Give a spare key to a trusted neighbor, family member, or friend for emergencies or store an extra key in a secure, hidden location.

Wandering
- ☐ Get identification bracelet for care recipient (Alzheimer's Greater Los Angeles MedicAlert® provides an identification bracelet and registry).

Fall/Trip Hazards
- ☐ Clear walkways and staircases from trip hazards like electrical cords, books, toys, and trash.
- ☐ Remove throw rugs to reduce the risk of falls or trips.
- ☐ Remove or secure furniture that rolls, falls over easily, or cannot support a person's weight.
- ☐ Use nightlights in the bathroom, hallway, and bedroom.
- ☐ Increase brightness of lamps and fixtures.

Fire/Burn Hazards
- ☐ Have a working fire extinguisher.
- ☐ Install smoke detectors and carbon monoxide detectors.
- ☐ The thermostat on the hot water heater should be lowered to its lowest setting or no higher than 120 degrees Fahrenheit.
- ☐ Replace extension cords with surge protections.

Kitchen Safety
- ☐ Remove the knobs from the stove and oven or use knob covers to hide the knobs.
- ☐ Remove knives and scissors from counters and keep out of reach.
- ☐ Secure all cleaning supplies.
- ☐ Disable the garbage disposal and instant hot water.
- ☐ Unplug all electrical appliances when they are not being used.
- ☐ Products that can be eaten in excess and cause illness (i.e. sweeteners) should be placed out of reach.

Bathroom Safety
- ☐ Store medications, including vitamins and over-the-counter medications, in a locked cabinet or out of reach.
- ☐ Toxic products and products that can be eaten in excess and cause illness (i.e. toothpaste) should be placed out of reach.
- ☐ Remove razors and other sharp objects from counters and drawers; keep them out of reach.
- ☐ Use non-skid mats in the shower and tub.
- ☐ Install grab bars or safety rails in shower/tub.
- ☐ Install a toilet safety rail.
- ☐ Use a shower bench (for stability) in the shower/tub.
- ☐ Remove and hide personal electrical equipment such as hair dryers and curling irons.

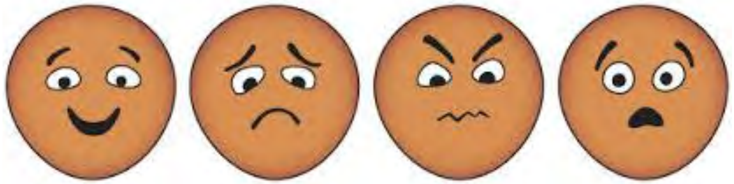
Behavioral Symptoms

Remember…

Changes in the brain
cause changes in how
people communicate

Remember…

Neither the person nor the behavior is the problem – the problem is the need or feeling that the person is trying to communicate with the behavior



Remember…

Behavior IS communication

"If we spent as much time trying to understand behavior as we spend trying to manage or control it, we might discover that what lies behind it is a genuine attempt to communicate."

Goldsmith, M. *Slow Down and Listen to Their Voices*. Journal of Dementia Care 4 (4) 24-25 (1996)

Behavioral Symptoms

What behavioral symptoms have you encountered?

Behavioral expressions affect almost all individuals at some point of disease

Lykestsos, CG. (2011) *Alzheimers Dement* 7; 532-539

Behavioral Symptoms Are NOT

- Not intentional
- Not trying to be difficult
- Not due to poor listening

REMIND FAMILIES…
behaviors are **not on purpose**
Behaviors are **part of the disease process**

Potential for Downward Spiral

Person with dementia has challenging behavior

↓ Increased caregiver stress/poor coping skills

↓ Decreased ability of caregiver to use behavioral strategies

↓ More challenging behaviors

Potential for Downward Spiral

- Decreased quality of life
- Increased functional decline
- Increased caregiver distress
- Increased healthcare utilization/ hospitalizations and cost
- Earlier nursing home placement

Gitlin, LN., et al. (2012). *JAMA*, 308(19), 2020-2029.

Remember…When Someone Has Alzheimer's…

The caregiver will need to figure out what is wrong or what is needed, based on the way the person is acting and thinking

IDEA!

IDentify Behaviors

- Identify problems

Explore

- Understand the causes/triggers
- Understand the meaning

Adjust

- Problem solve

IDentify Behaviors/Problems

- What is the specific difficult/challenging behavior?
- Is it observable?
- Is it measurable?
- Can others see it?
- Is it something new and unusual?

Explore: Understand the Causes/Triggers

What is causing this behavior?

Health issues

Psycho-social needs

Environmental issues

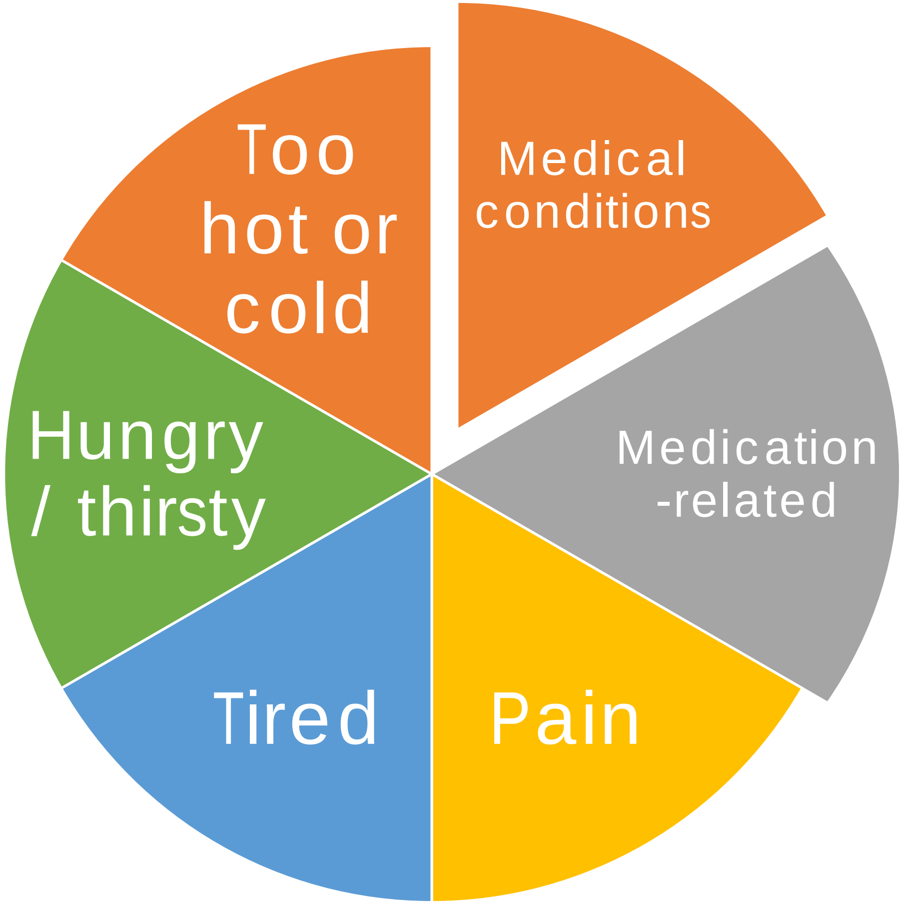
Task-related

Communication difficulty

How Do You Feel When...?

Remind families that when someone has Alzheimer's disease, he/she may not be able to SAY that something is wrong, that he/she is not feeling well, or that he/she is in pain.

Explore: Understand the Health/Physical Triggers



Explore: Understand the Health/Physical Triggers

1/3 of community dwelling older adults with dementia had undetected illness associated with behaviors

Hodgson et al. (2011). *Alzheimer's Disease and Associated Disorders*, 25, 109-115; Husebo et al. (2011) *BMJ*.

Explore: Understand the Health/Physical Triggers

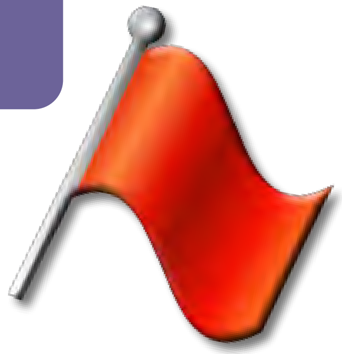
Caregivers need to be able to identify changes in baseline

Any sudden and unusual change in cognitive state or behavior that is a rapid decline from baseline may be a sign that something is wrong

Identification of Red Flag Behaviors

Contact doctor if sudden and unusual changes are present

- Sudden incontinence
- Sudden disorientation to time and place
- Sudden sluggishness or agitation
- Sudden decreased attention
- New aggressiveness



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?

Explore: Understand the Health/Physical Triggers

When people with Alzheimer's have an undetected illness, they are:

- More likely to refuse care
- More likely to have significantly lower cognitive and functional status scores
- More likely to be hospitalized
- More likely to be prescribed psychotropic medications for their behaviors

Hodgson et al. (2011). *Alzheimer's Disease and Associated Disorders*, 25, 109-115.

Explore: Understand the Psycho-Social Triggers

- Socialization/interactions
- Emotional needs
  - Comfort
  - Security
  - Belonging
  - Purpose
  - Control
  - Fear
  - Boredom

Explore: Understand the Environmental Triggers

- Change in environment, routine, and/or staffing
- Clutter/crowding
- Noise
- Temperature
- Distractions
- Lighting
- Unfamiliar

UCLA Health: Hallucinations

https://www.uclahealth.org/dementia/hallucinations
or
https://www.youtube.com/watch?v=cpV57QGdU7I

Running time: 4 minutes 3 seconds

The project described was supported by Grant Number 1C1CMS330982 from the Department of Health and Human Services, Centers for Medicare & Medicaid Services. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. Department of Health and Human Services or any of its agencies. This project was funded, in part, by the Archstone Foundation.

Is there anything in this picture that could be an environmental trigger?

Examining the Environment

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?

Explore: Understand the Task Triggers

- Too complicated
- Too many steps
- Unfamiliar
- Lack of structure
- Mismatch to cognitive level
- Boring/nothing to do
- Demeaning

Explore: Understand the Communication Triggers

- Is it hard for the person to understand?
- Is it hard for the person to speak?
- Is the person speaking a native language?

Explore: Understand the Meaning

- What does this behavior mean to the person exhibiting it?
- What is he/she trying to say?
- What does the behavior mean to the caregiver?
- Is this behavior distressing to the caregiver?

Consider:
Who is this a "problem" for?

> “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”
>
> - Maya Angelou

Case Example: “I Want My Mother!”

- What does it mean?
- What does “mother” mean?
- How does the person feel if you say: “But your mother died 10 years ago!”
- What would be a better response to teach the caregiver?

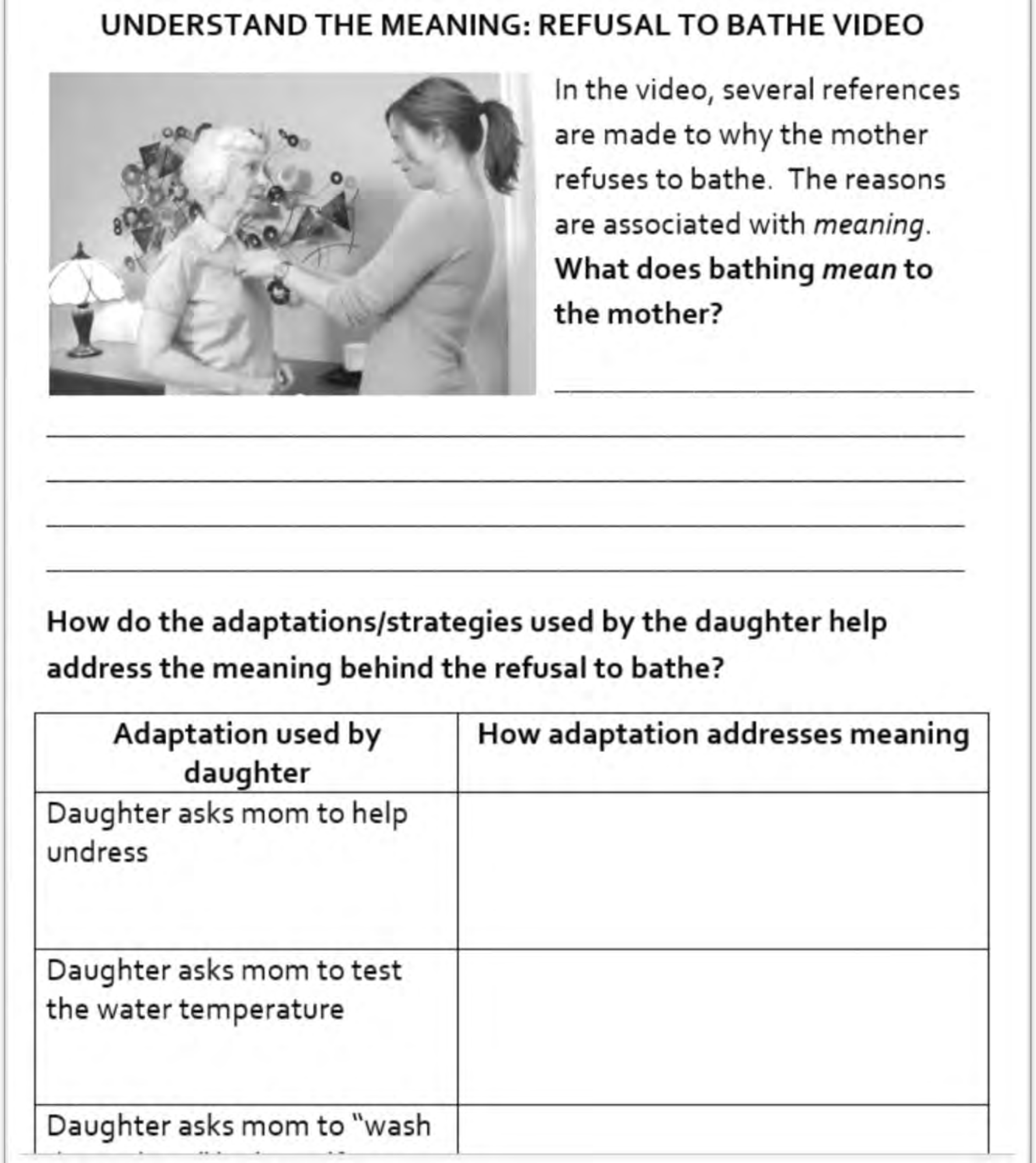
UCLA Video: Bathing

https://www.uclahealth.org/dementia/refusal-to-bathe or https://www.youtube.com/watch?t=55&v=sl3Dc1kERto

Running time: 4 minutes 28 seconds

The project described was supported by Grant Number 1C1CMS330982 from the Department of Health and Human Services, Centers for Medicare & Medicaid Services. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the official views of the U.S. Department of Health and Human Services or any of its agencies. This project was funded, in part, by the Archstone Foundation.

Understanding the Meaning: Refusal to Bathe Video



UNDERSTAND THE MEANING: REFUSAL TO BATHE VIDEO

In the video, several references are made to why the mother refuses to bathe. The reasons are associated with *meaning*. **What does bathing *mean* to the mother?**

____

____

____

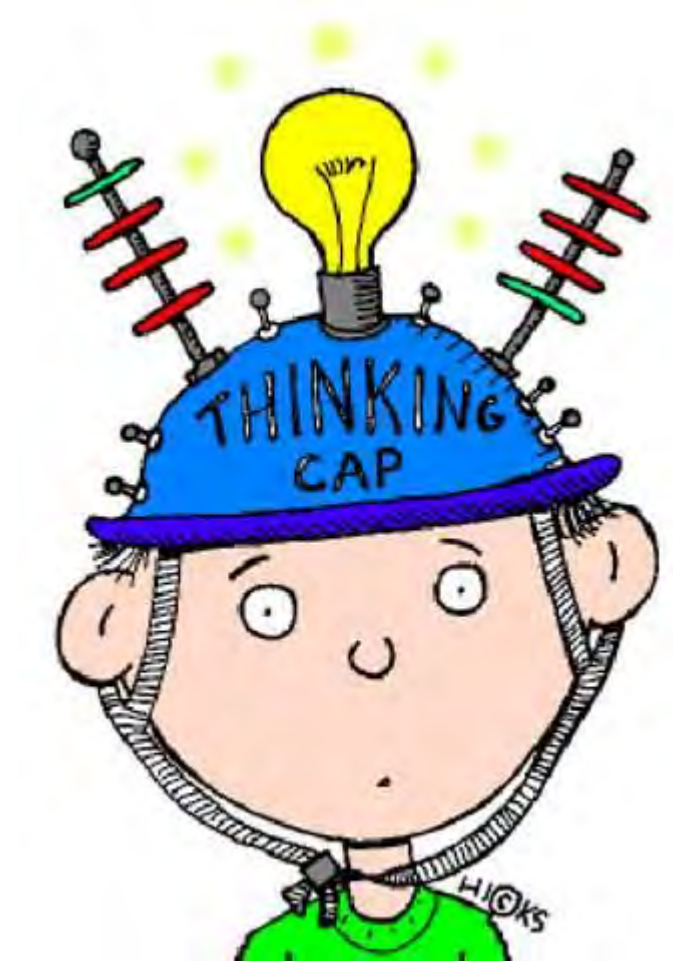
____

____

How do the adaptations/strategies used by the daughter help address the meaning behind the refusal to bathe?

Adaptation used by daughter	**How adaptation addresses meaning**
Daughter asks mom to help undress	
Daughter asks mom to test the water temperature	
Daughter asks mom to "wash	

Always pay attention to the person's feelings



Strategies Not Solutions

Adjust

- Understand what can be changed
- Set the tone
- Stay calm
- Do not demand
- Try different things; no one size fits all

Adjust: Distraction and Redirection

- 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

Adjust: Addressing Causes/Triggers

- Keep tasks and activities simple
- Break down tasks with step-by-step instructions
- Find meaningful, simple activities
- Keep the home as calm and quiet as possible
- Comfort the person

Adjust: Communication and Connection Strategies

Components that determine impact of communication:

- 55% Body language (postures, gestures, eye contact)
- 38% Tone of voice
- 7% Content or actual words

http://tandemcarers.org.au/e-learning/modules/module2/resource/Module2-Res01.pdf

Adjust: Communication and Connection Strategies

Find news ways to communicate and connect

- Words
- Movement
- How we approach someone
- Facial expressions
- Tone of voice
- Touch
- Music

❓ Culturally Appropriate Communication

Adjust: Compassionate Communication Strategies

DON'T

- Don't argue
- Don't reason
- Don't confront
- Don't remind them they forgot and question memory
- Don't take it personally
- Don't insist; try again later

Adjust: Compassionate Communication Strategies

DO

- Give short, one sentence explanations
- Allow plenty of time for comprehension and response…and then triple the time
- Repeat instructions or sentences exactly the same way

Adjust: Compassionate Communication Strategies

DO

- Agree with them
- Accept the blame
- Leave the room, if necessary
- Respond to feelings rather than words
- Give yourself permission to alter the truth

Adjust: Compassionate Communication Strategies

DO

- Be patient and reassuring
- Go with the flow
- Use a gentle tone of voice
- Use gentle touch and remember importance of non-verbal communication
- Respect the person

DON’T REASON

Member: “What doctor’s appointment? There’s nothing wrong with me.”

Don’t: (*reason*) “You’ve been seeing the doctor every three months for the last two years. It’s written on the calendar and I told you about it yesterday.”

Do: (*short explanation*) “It’s just a regular checkup.”

(*accept blame*) “I’m sorry if I forgot to tell you.”

DON’T ARGUE

Member: “I didn’t write this check; someone is forging my signature .”

Don’t: (*argue*) “What? Don’t be silly! No one is forging your signature.”

Do: (*respond to feeling*) “That’s a scary thought.”

(*reassure*) “I’ll make sure no one does that.”

(*distract*) “Would you help me fold the towels?”

DON’T CONFRONT

Member: “Nobody’s going to make decisions for *me*. You can go now…and don’t come back!”

Don’t: (*confront*) “I’m not going anywhere; mom, you can’t remember enough to make your own decisions.”

Do: (*accept blame or respond to feeling*) “I’m sorry this is so tough.” (*reassure*) “I love you and we’ll get through this together.”

DON'T TAKE IT PERSONALLY

Member: "Who are you? Where's my husband?"

Don't: (*take it personally*) "What do you mean—who's your husband? I am!"

Do: (*go with the flow and reassure*) "He'll be here for dinner."

(*reassure*) "How about some chocolate chip cookies?"

DON’T REMIND THEM THEY FORGOT AND QUESTION MEMORY

Member: “Joe hasn’t called for a long time.
I hope his okay.”

Don’t: (*remind and question memory*)
“Mom, Joe called yesterday and you talked to him for 10 minutes. Don’t you remember?”

Do: (*reassure*) “You really like talking to Joe.”

(*distract*) “Let’s call Joe when we get back from our walk.”

IDEA!

*ID*entify Behaviors

Identify problems

*E*xplore

Understand the causes/triggers

Understand the meaning

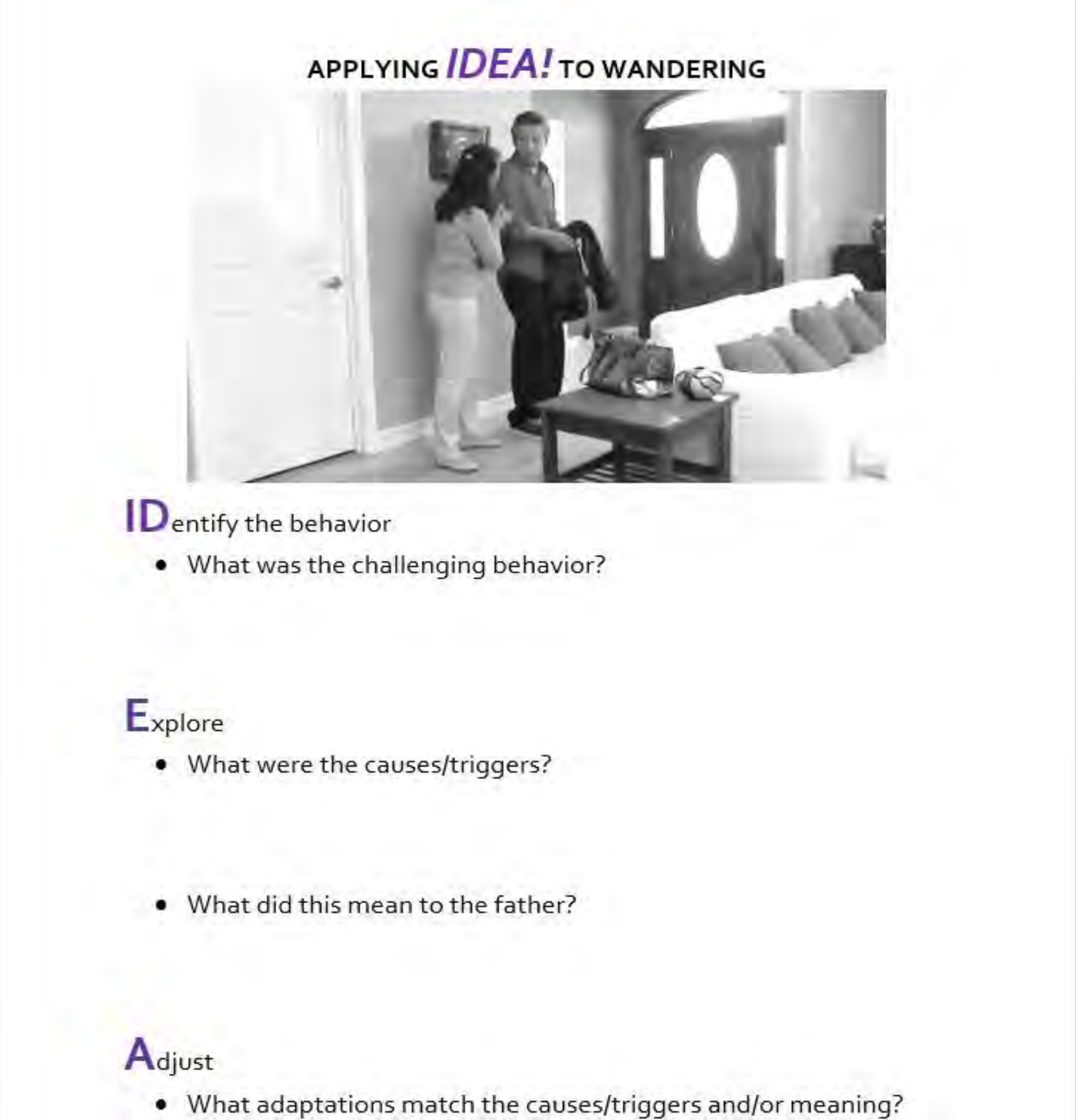
*A*djust

Problem solve

UCLA Health: Wandering

https://www.uclahealth.org/dementia/wandering
or
https://www.youtube.com/watch?v=Sw0yEB508mI
Running time: 4 minutes 5 seconds

Applying *IDEA!*



APPLYING *IDEA!* TO WANDERING

IDentify the behavior

- What was the challenging behavior?

Explore

- What were the causes/triggers?

- What did this mean to the father?

Adjust

- What adaptations match the causes/triggers and/or meaning?

IDEA!

*ID*entify Behaviors

- Wandering

*E*xplore

- Causes/triggers: keys, coat
- Meaning: wants to go home/kids need him

*A*djust

- Approach calmly; provide reassurance and comfort; find a meaningful activity
- Remove keys and coat

Remember…

- Validate concerns and frustrations of families
- If families are not speaking to you about challenging behaviors, may need to ask different questions
- Learn from experiences of families

Remember…

- Share *IDEA!* with families
- Help families work through challenging behaviors, using *IDEA!*
- Apply cultural lens to *IDEA!* to increase effectiveness
- Send families Caregiver Tip Sheets

Caregiver Tip Sheets

Bathing

People with Alzheimer's disease or dementia may be afraid of bathing or uneasy with having someone help them with bathing. Sometimes they worry about falling or can have trouble knowing which is the hot versus the cold water faucets.

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- afraid of falling
- feeling uneasy getting undressed in front of you
- scared or confused
- feeling helpless

Alzheimer's
GREATER LOS ANGELES
844.HELP.ALZ
alzgla.org

Supported by DHHS, ACL (#90AL0002-01-00)

WHAT CAN YOU DO?

PREPARE THE BATHROOM IN ADVANCE

- make sure the room is calm and warm
- run the water so it is not too hot or too cold
- don't use bright lights if possible

MAKE THE BATHROOM SAFE

- use a non-slip mat in the tub or shower as a bath
- consider a tub seat
- fill the tub with only 4 inches of water
- remove things that may be dangerous such as ra clippers, hair dryer, etc.
- watch carefully – don't leave him or her alone

ALLOW TIME & BE POSITIVE

- allow your person to enjoy it… if he or she finds ba relaxing
- stay calm
- be direct… "Your bath is ready now"
- instead of "Do you want to take a bath?" give one
- "Let's wash your left arm… good!, now your other a patient… don't rush

BE REALISTIC

- don't argue or get frustrated… a daily bath may b
- consider a sponge bath instead of a tub bath
- show what you need from them… pretend to wash that he or she can copy

---

日本語資料

アルツハイマー・ロスアンゼルスは、アルツハイマー病およびその他の関連する記憶障害の影響を受ける個人、家族、およびコミュニティに対する無料サービスを提供しています。ご質問、助けが必要、またはどこから始めていいかわからない方は、844.HELP ALZ（844.435.7259）いただき、専門家とお話ください。無料の情報、教育、支援をご提供するとともに、コミュニティの情報源による支援を提供いたします。現在、ホットラインは英語のみとなりますが、通訳サービスをご利用いただくか、ご家族やお友達に通訳をお願いいただくこともできます。当社の日本語資料を提供しております。アジア人および太平洋諸島サービスマネージャーに直接お話する場合は、323.930.6259へお電話ください。

自宅を安全な場所に

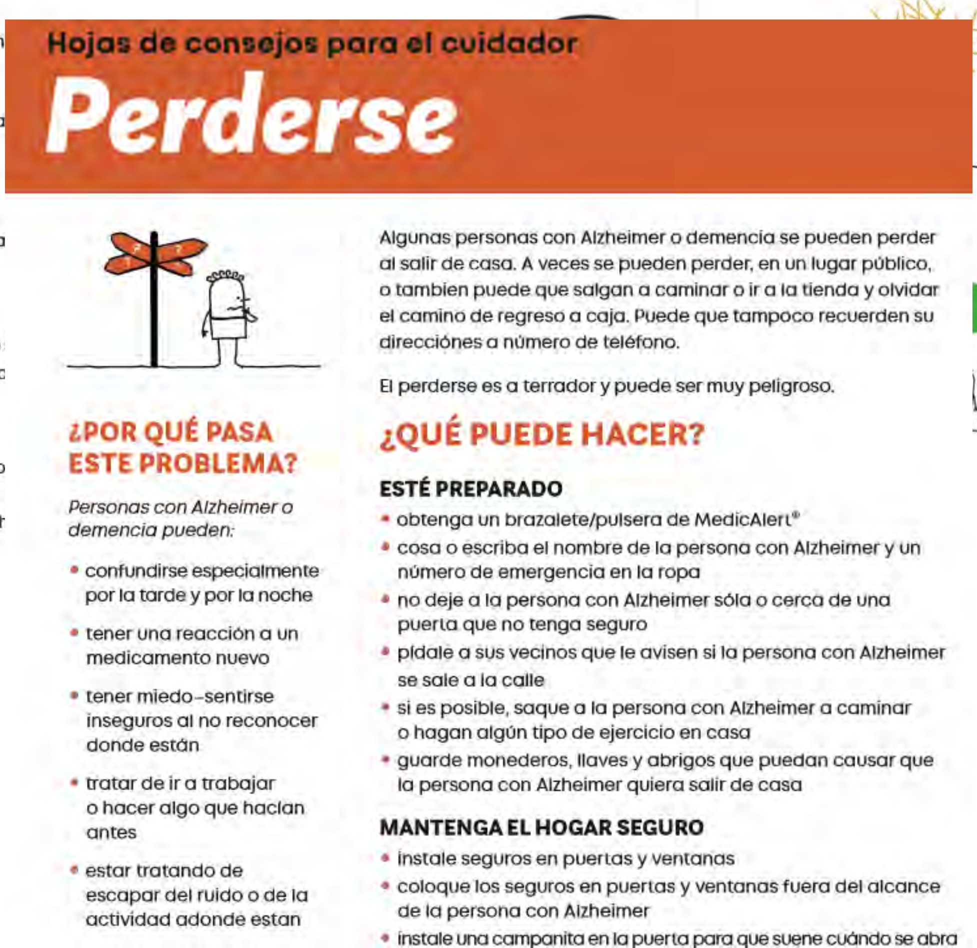
怒り、いら立ち、けんか

迷子になる

入浴

繰り返し

運転



Hojas de consejos para el cuidador

Perderse

Algunas personas con Alzheimer o demencia se pueden perder al salir de casa. A veces se pueden perder, en un lugar público, o tambien puede que salgan a caminar o ir a la tienda y olvidar el camino de regreso a caja. Puede que tampoco recuerden su direcciónes a número de teléfono.

El perderse es a terrador y puede ser muy peligroso.

¿POR QUÉ PASA ESTE PROBLEMA?

Personas con Alzheimer o demencia pueden:

- confundirse especialmente por la tarde y por la noche
- tener una reacción a un medicamento nuevo
- tener miedo–sentirse inseguros al no reconocer donde están
- tratar de ir a trabajar o hacer algo que hacían antes
- estar tratando de escapar del ruido o de la actividad adonde estan

¿QUÉ PUEDE HACER?

ESTÉ PREPARADO

- obtenga un brazalete/pulsera de MedicAlert®
- cosa o escriba el nombre de la persona con Alzheimer y un número de emergencia en la ropa
- no deje a la persona con Alzheimer sóla o cerca de una puerta que no tenga seguro
- pídale a sus vecinos que le avisen si la persona con Alzheimer se sale a la calle
- si es posible, saque a la persona con Alzheimer a caminar o hagan algún tipo de ejercicio en casa
- guarde monederos, llaves y abrigos que puedan causar que la persona con Alzheimer quiera salir de casa

MANTENGA EL HOGAR SEGURO

- instale seguros en puertas y ventanas
- coloque los seguros en puertas y ventanas fuera del alcance de la persona con Alzheimer
- instale una campanita en la puerta para que suene cuándo se abra

---

Caregiver Tip Sheets free to download:

www.alzheimersla.org/professionals

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

Case Scenario: Using *IDEA*!

Juanita tells you that her father often gets anxious in the afternoon. Her dad paces through the house, following Juanita around, and says over and over again that he is looking for his daughter.

He says that it is time for her to be home from school.

Juanita gets annoyed with her dad. The repeated questioning bothers Juanita and the following her around makes it difficult for her to prepare dinner.

Medications for Behavioral Symptoms

Alzheimer's
LOS ANGELES

Remember…

- Behavior is a way of communicating
- Medications may limit a person’s ability to express what he/she needs
- Providers may over-rely on medications

Remember…

There are no FDA-approved pharmacotherapies for behaviors

Medications for Behavioral Symptoms

- Rule out medical problems first
- Use non-pharmacological approaches first
- Use medications very carefully
- Medications most effective when combined with non-drug approaches

Medications for Behavioral Symptoms

When to consider medications?

- Non-drug approaches fail after being consistently applied
- Severe symptoms
- Potential harm to self or others

Medications for Behavioral Symptoms

Antipsychotics

- Moderate effects at best
- Benefits need to be balanced against adverse events, including mortality
- Black box warning

Old And Overmedicated: The Real Drug Problem In Nursing Homes

DECEMBER 08, 2014 4:57 AM ET

NPR, Ina Jaffe, Robert Benincasa

Antipsychotic drugs aren't necessary in the vast majority of dementia cases, gerontologists say. The pills can be stupefying and greatly raise the risk of falls — and hip fracture.

It turned out Beatrice DeLeon was given Risperdal and Seroquel, which are approved to treat bipolar disorder and schizophrenia. But professor Bradley Williams, who teaches pharmacy and gerontology at the University of Southern California, says antipsychotics should only be used as a last resort, and just for a month or so, before gradually being eliminated.

Antipsychotic Use in Community-Dwelling Older Adults with Dementia

- Not just a problem in nursing homes
- Less information known about antipsychotics used outside of nursing homes, but overuse occurring

GAO-15-211. Antipsychotic Drug Use. January 2015

Medications for Behavioral Symptoms

- Avoid antipsychotics as first line of treatment
- Use *IDEA!*

Gitlin, LN., et al. (2012). *JAMA*, 308(19), 2020-2029.

PART III

Caring for the Family

What are We Tackling Today?

- Role of Family Caregivers
- Diverse Perspectives on "Caregiving"
- Family Caregiver Identification
- Family Caregiver Assessment
- Supporting Caregivers
- Making Referrals
    - Alzheimer's Los Angeles

Role of Family Caregivers

16 million UNPAID caregivers

Alzheimer's Association *Alzheimer's Disease Facts and Figures 2018*

What Do Caregivers Do?

In groups of 5-6, write down all of the things that caregivers do.

Which group will come up with the most???

What Do Caregivers Do?

- Manage co-existing conditions/ treatment
- Medication management
- Recognize acute medical conditions/ issues
- Wound care
- Manage behavioral symptoms
- Appointments
- Transportation

What Do Caregivers Do?

- Hygiene
- Meals
- Housekeeping
- Home safety
- Finances
- Decision-making
- Supervision
- Socialization

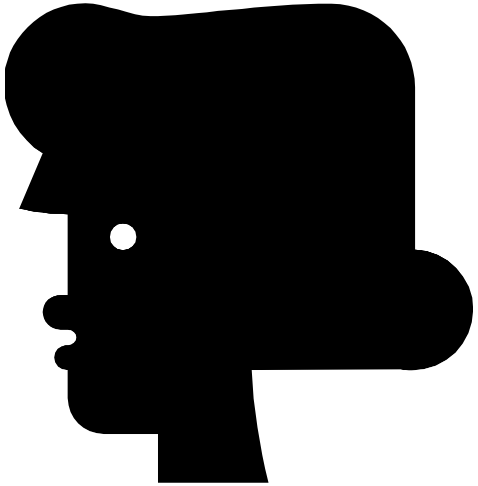
18.4 billion hours of UNPAID care

Alzheimer's Association *Alzheimer's Disease Facts and Figures 2018*

Caregivers are our key to keeping members at home

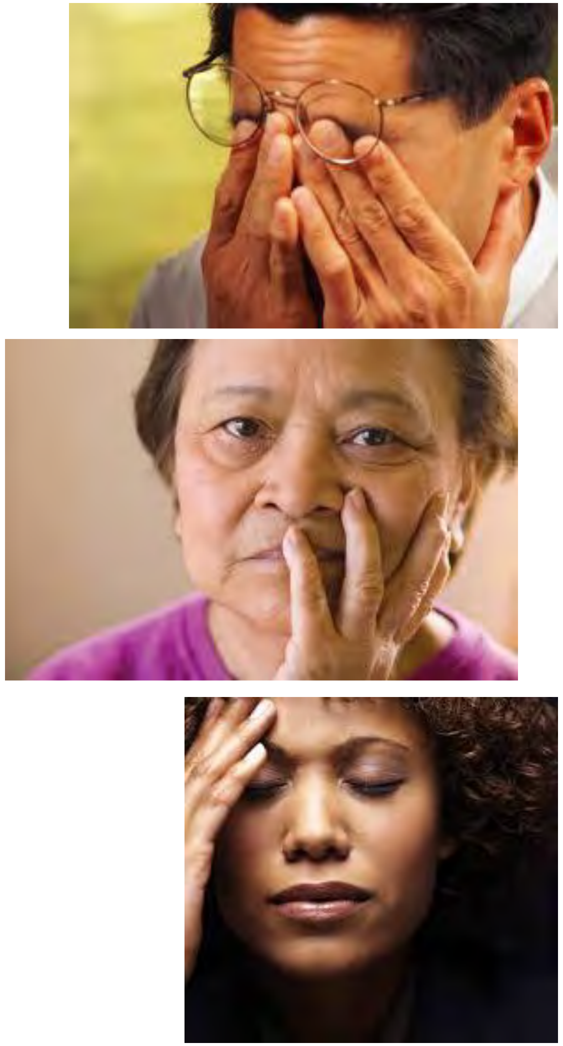
AND YET…

Caregivers are largely unidentified
by health plans and
healthcare providers



AND YET...

Caregivers of Alzheimer's members have high rates of stress, burnout, and depression



Importance of Caregivers

- Caregivers are our eyes, ears, and hands
- Integration of caregivers into care planning and care coordination processes
- Successes/failures rest disproportionately on caregivers

Unique Caregiver Considerations

- Caregiving is more demanding as disease progresses
- Caregivers need to learn whole new language (behavior & communication)
- Person with dementia cannot change (only caregiver can adapt)
- Role changes may occur

Diverse Perspectives on **“Caregiving”**

Alzheimer’s
LOS ANGELES

Caregiving in Diverse Communities

- Among people 70+, 44% of Latinos, 34% of blacks, and 25% of whites received home-based family caregiving
- Ethnic minority caregivers provide more care than white caregivers

American Psychological Association. *Cultural Diversity and Caregiving*. http://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx

Caregiving in Diverse Communities

- African American caregivers report less stress and depression than white caregivers, and greater rewards
- Hispanic and Asian American caregivers more depressed than white caregivers
- Asian American caregivers use fewer professional support services than white caregivers

American Psychological Association. *Cultural Diversity and Caregiving*.
http://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx

Caregiving in Diverse Communities

- Whites most likely to receive help from spouses
- Hispanics most likely to receive help from adult children
- African Americans most likely to receive help from non-family members

American Psychological Association. *Cultural Diversity and Caregiving*. http://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx

Caregiving and the LGBT Community

- 1/3 older people who are LGBT live alone (compared to 1/5 people who are non-LGBT)
- 40% of older people who are LGBT say their support network has become smaller over time
- African American LGBT adults are 3x as likely as white or Hispanic LGBT adults to say people from church/faith community are part of support system

American Psychological Association. *Cultural Diversity and Caregiving*.
http://www.apa.org/pi/about/publications/caregivers/faq/cultural-diversity.aspx

Caregiving

- Caregiving = family responsibility
- Filial roles/responsibilities
- Normal expectation
- Inherited responsibility
- Honor
- Duty

Case Study

Mei:

It is an honor for me to care for my mother. Being a caregiver upholds my family's dignity. A daughter is meant to care for her mother as she ages and gets sick.

Caregiving

- Consider family dynamics
- Role of extended family
- Caregiver vs. decision-making

Case Study

Brianna's family is her primary support system. She also has a neighbor who she calls her daughter.

Brianna's church community provides a lot of support.

LGBT Considerations and Caregiving

- Who is "immediate family?"
- Role of friends and partners who are not legally recognized to make decisions
- Lack of family caregivers
- Importance of using the person's preferred language (pronouns and how relationships are defined)

Remember…

- What pronoun does the person use, irrespective of what is in the chart?
  He? She? They?
- When the person is defining his/her/their relationship, do they use the term "friend," "partner," "spouse," "roommate"?

Professionals should use the preferred language of their members

Case Study

David and James have been living as partners for 30 years. They are not legally married. David's family has never fully accepted James.

As David's dementia progresses, James assumes a greater caregiving role.

***Will David's family recognize James** as the decision maker?*

Caregiving

- Unwilling to ask for help
- Not wanting to “burden” others
- Self-sacrifice & health impact
- Financial strain felt more deeply in some communities

Potentially Resulting In…

- Caregivers not planning ahead for their own needs & well-being
- Increased caregiver stress, depression, fatigue, burnout
- Crises

Remember…

- Cultural values and beliefs are related to providing care
- Honor and duty to take care of a loved one
- “A heavy job done with love”
- Modeled behavior in some families
- For some, it is a burden

Family Caregiver Identification

Alzheimer's
LOS ANGELES

Caregiver Identification

“Caregiver”

- Words can be lost in translation
- Words can be offensive
- Words may not capture meaning

Caregiver Identification

Family Dynamics

- Hands on caregiving vs. decision-making
- Consensus-based
- Fictive-kin

Caregiver Identification

- Identify person who might help you most when you need it
- May be many people
- Many hats being worn

Caregiver Identification

Who is the caregiver in this family?

Caregiver Identification

Who lives with the member with dementia?

Caregiver Identification

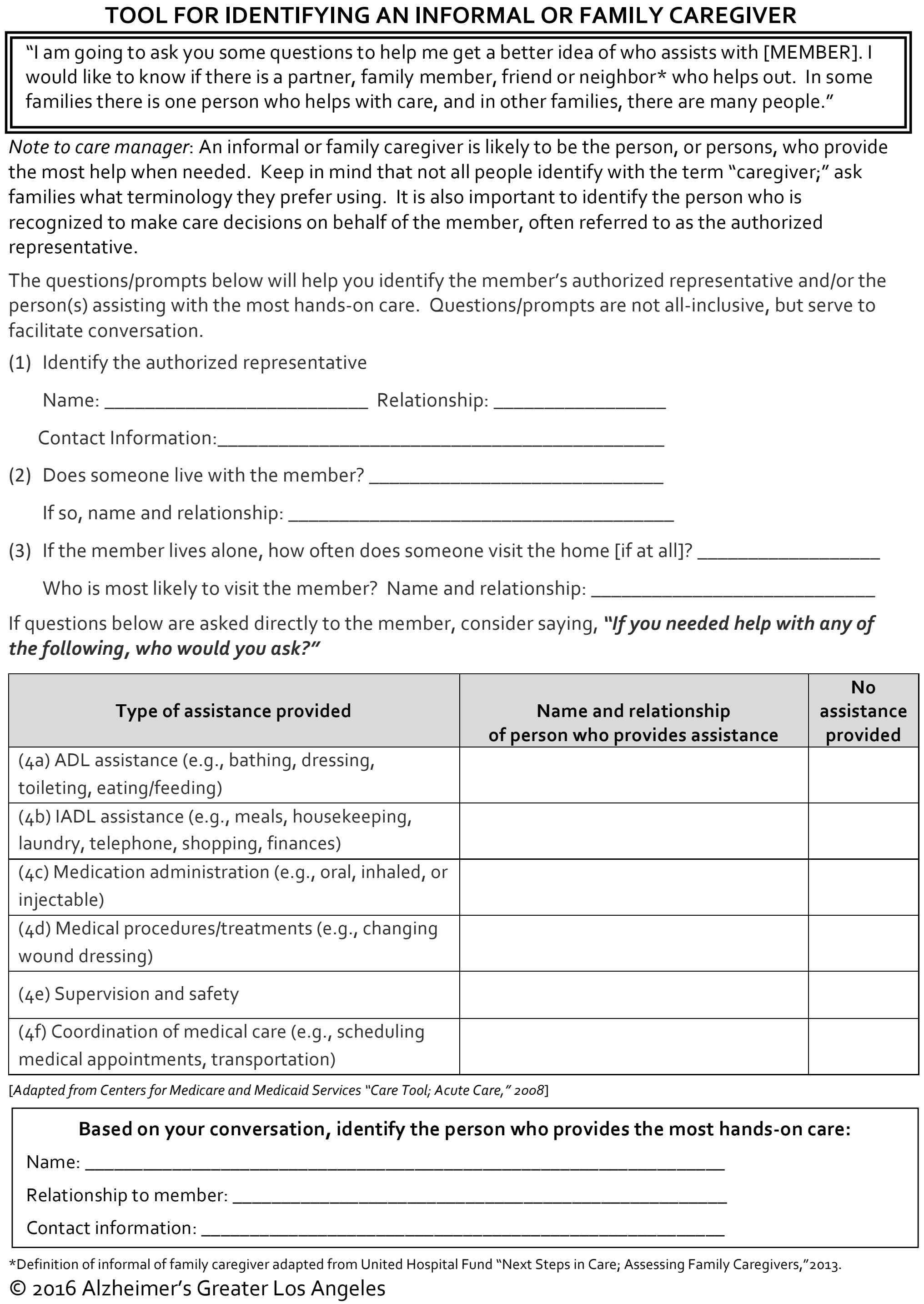
Who is most likely to help when the most help is needed?

Caregiver Identification

Who makes decisions in this family?

Tools for Identifying an Informal or Family Caregiver

Document family caregiver in care management/ medical record



TOOL FOR IDENTIFYING AN INFORMAL OR FAMILY CAREGIVER

> "I am going to ask you some questions to help me get a better idea of who assists with [MEMBER]. I would like to know if there is a partner, family member, friend or neighbor* who helps out. In some families there is one person who helps with care, and in other families, there are many people."

Note to care manager: An informal or family caregiver is likely to be the person, or persons, who provide the most help when needed. Keep in mind that not all people identify with the term "caregiver;" ask families what terminology they prefer using. It is also important to identify the person who is recognized to make care decisions on behalf of the member, often referred to as the authorized representative.

The questions/prompts below will help you identify the member's authorized representative and/or the person(s) assisting with the most hands-on care. Questions/prompts are not all-inclusive, but serve to facilitate conversation.

(1) Identify the authorized representative

Name: ___________________________ Relationship: _________________

Contact Information:____

(2) Does someone live with the member? ______________________________

If so, name and relationship: _______________________________________

(3) If the member lives alone, how often does someone visit the home [if at all]? ________________

Who is most likely to visit the member? Name and relationship: ____________________________

If questions below are asked directly to the member, consider saying, ***"If you needed help with any of the following, who would you ask?"***

Type of assistance provided	Name and relationship of person who provides assistance	No assistance provided
(4a) ADL assistance (e.g., bathing, dressing, toileting, eating/feeding)		
(4b) IADL assistance (e.g., meals, housekeeping, laundry, telephone, shopping, finances)		
(4c) Medication administration (e.g., oral, inhaled, or injectable)		
(4d) Medical procedures/treatments (e.g., changing wound dressing)		
(4e) Supervision and safety		
(4f) Coordination of medical care (e.g., scheduling medical appointments, transportation)		

[Adapted from Centers for Medicare and Medicaid Services "Care Tool; Acute Care," 2008]

Based on your conversation, identify the person who provides the most hands-on care:

Name: ____

Relationship to member: ____

Contact information: ____

---

*Definition of informal of family caregiver adapted from United Hospital Fund "Next Steps in Care; Assessing Family Caregivers,"2013.

Caregiver Identification

- Use guiding questions/prompts
- Facilitate a discussion around the questions
- Remember that some people will not admit to needing help. Try saying, "If you needed help with any of the following, who would you ask?"

Role Play: Caregiver Identification

Tony has diabetes, high cholesterol, and early/mid stage Alzheimer's. In general, you feel that you are able to get fairly reliable information from Tony. Though Tony previously managed his own medical care, several recent hospitalizations and missed medical appointments concern you.

Role Play: Caregiver Identification

Based on Tony's medical history and your conversations with him, you know that Tony needs assistance with several IADLs and may be struggling with ADLs. Tony does not like to admit needing help, but he has mentioned to you a "lady friend" that he spends time with. You do not know about Tony's family.

Role Play: Caregiver Identification

Facilitate a conversation with Tony to identify who is assisting with his care. Use the Tool for Identifying an Informal or Family Caregiver to facilitate this conversation. Remember to be careful about the language you use in this conversation, as you want to be respectful and continue building rapport.

Family Caregiver Assessment

Alzheimer's
LOS ANGELES

“Nobody ever asks ‘How’s Waldo?’ ”

Importance of Caregiver Assessment

Why assess?

Stress, fatigue, burnout, depression

Inability to maintain care at home

Hospitalization/ nursing home placement

Importance of Caregiver Assessment

Areas of concern may include:

- Social isolation
- Capacity to provide care
- Anxiety
- Physical/emotional strain
- Need for informal support
- Depression

Judge et al (2011). *The Gerontologist*, 51(2), 261-272.

What is the Toll on Caregivers?

- Depression
- Fatigue
- Burnout
- Emotional stress

Toll on Alzheimer’s Caregivers

Physical and emotional **“burden” of ADRD** caregiving costs $9.3 billion in additional health care for caregivers

~60% of ADRD caregivers rate emotional stress as high or very high

More than 1/3 report symptoms of depression

Alzheimer's Association, *Alzheimer's Disease Facts and Figures 2014*

Case Study

Janice is the primary caregiver for her husband. Janice rarely leaves the house because her husband needs around-the-clock supervision. His behaviors have become challenging and embarrassing so it is easier to stay home than to go out. Janice rarely has friends over anymore. She is tired and exhausted. She feels trapped.

HBO: The Alzheimer’s Project

https://www.hbo.com/documentaries/the-alzheimers-project-caregivers

Running time: 2 minutes 38 seconds

*Note: The video clip was manually extracted

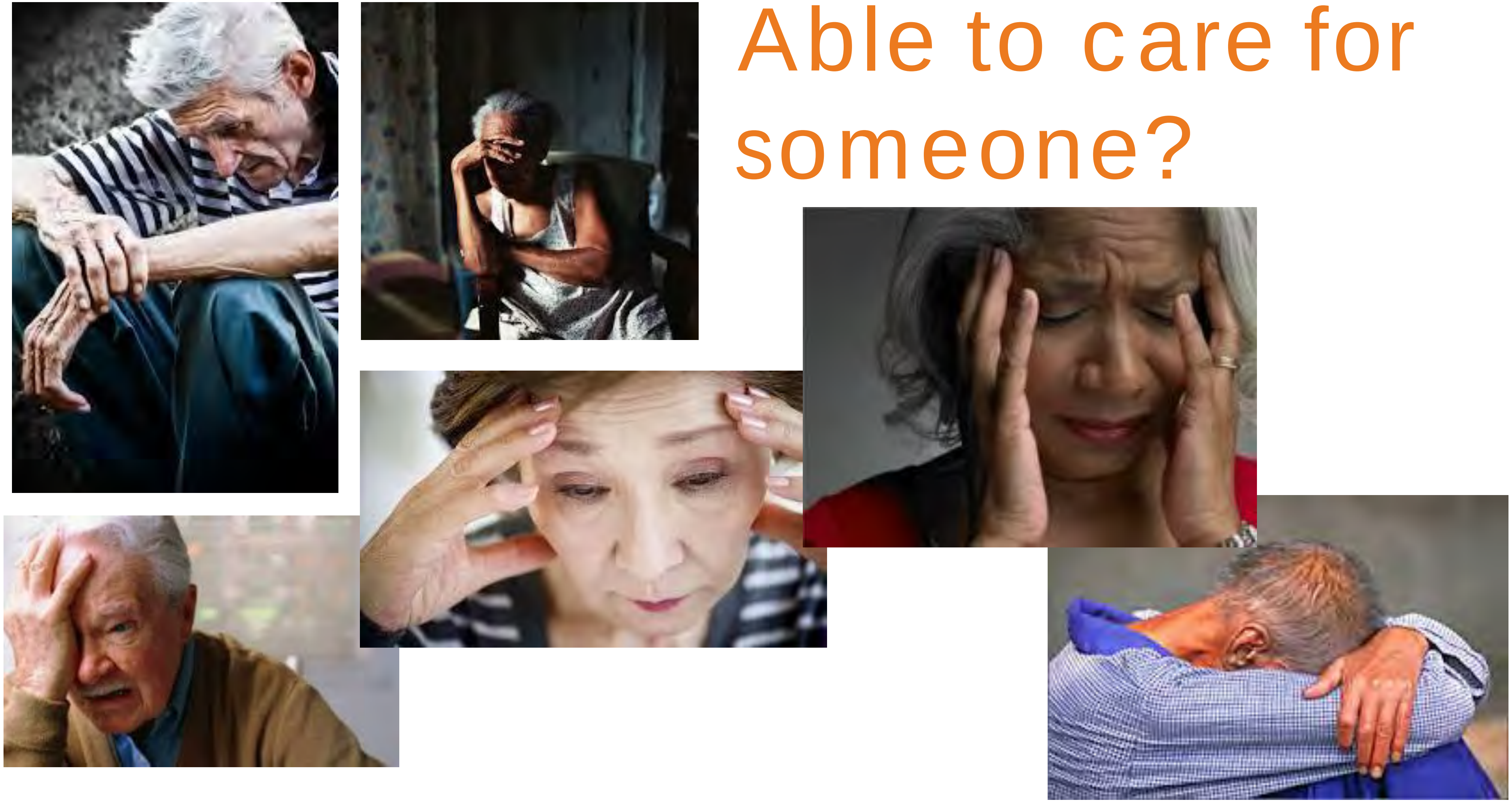
Things to Look For

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

Caregiver Isolation, Anxiety, Depression

Able to care for someone?



Caregiver Functional/Health Limitations

Impact on:

- Lifting?
- Bathing?
- Walking?
- Other?

Caregiver Assessment

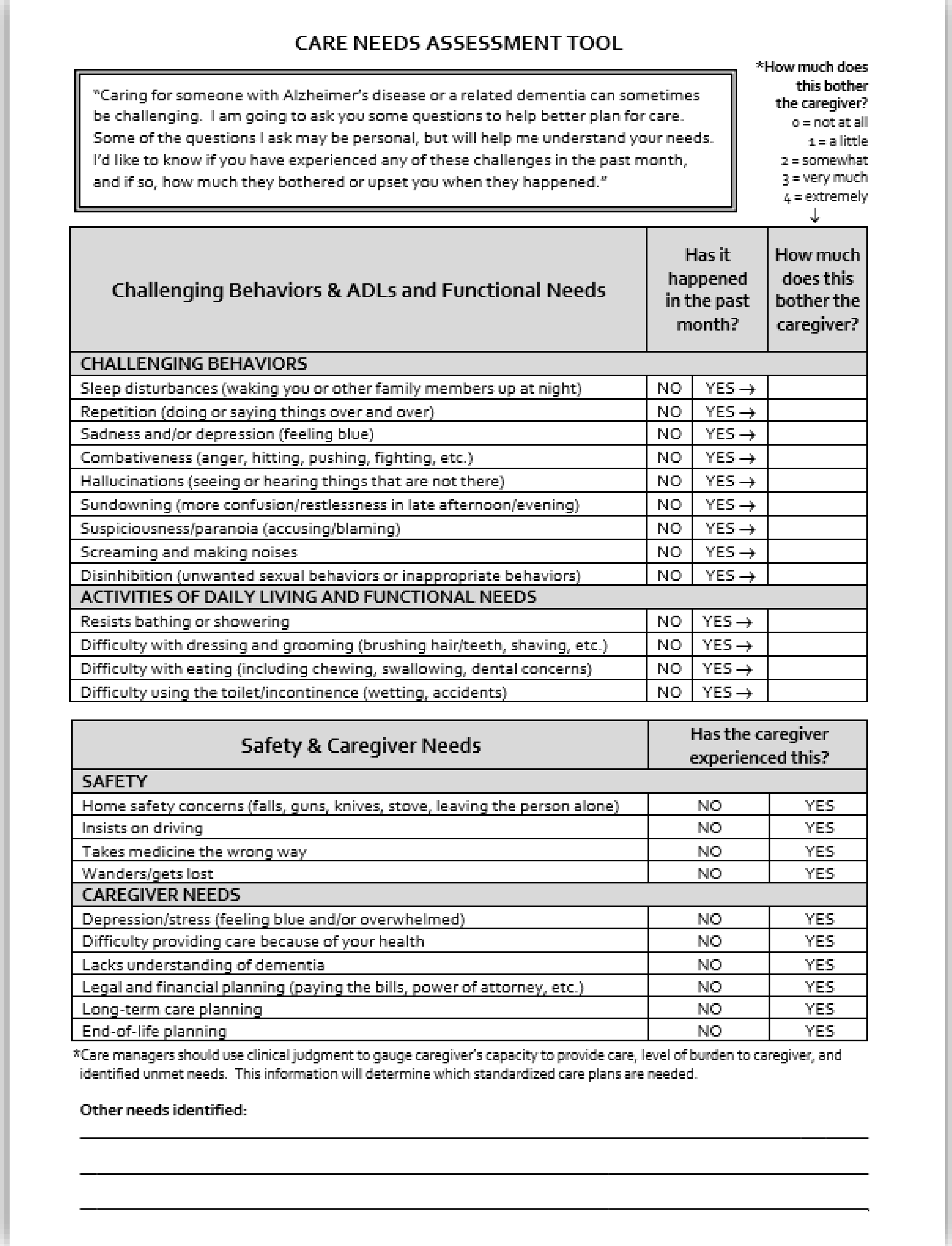
Why is assessment so important?

- Not all caregivers will ask for help
- Many caregivers will only ask for help once they are exhausted, burned out, and already stressed
- Helps professionals identify areas of need so supports can be put in place
- Helps professionals link caregivers to necessary services

Identifying Needs/Areas of Concern

- Puts a name to areas of concern
- Narrows down family needs
- Allows DCS to work with caregiver to determine next steps

Care Needs Assessment Tool



CARE NEEDS ASSESSMENT TOOL

> "Caring for someone with Alzheimer's disease or a related dementia can sometimes be challenging. I am going to ask you some questions to help better plan for care. Some of the questions I ask may be personal, but will help me understand your needs. I'd like to know if you have experienced any of these challenges in the past month, and if so, how much they bothered or upset you when they happened."

*How much does this bother the caregiver?
0 = not at all
1 = a little
2 = somewhat
3 = very much
4 = extremely
↓

Challenging Behaviors & ADLs and Functional Needs	Has it happened in the past month?		How much does this bother the caregiver?
CHALLENGING BEHAVIORS			
Sleep disturbances (waking you or other family members up at night)	NO	YES →	
Repetition (doing or saying things over and over)	NO	YES →	
Sadness and/or depression (feeling blue)	NO	YES →	
Combativeness (anger, hitting, pushing, fighting, etc.)	NO	YES →	
Hallucinations (seeing or hearing things that are not there)	NO	YES →	
Sundowning (more confusion/restlessness in late afternoon/evening)	NO	YES →	
Suspiciousness/paranoia (accusing/blaming)	NO	YES →	
Screaming and making noises	NO	YES →	
Disinhibition (unwanted sexual behaviors or inappropriate behaviors)	NO	YES →	
ACTIVITIES OF DAILY LIVING AND FUNCTIONAL NEEDS			
Resists bathing or showering	NO	YES →	
Difficulty with dressing and grooming (brushing hair/teeth, shaving, etc.)	NO	YES →	
Difficulty with eating (including chewing, swallowing, dental concerns)	NO	YES →	
Difficulty using the toilet/incontinence (wetting, accidents)	NO	YES →	

Safety & Caregiver Needs	Has the caregiver experienced this?	
SAFETY		
Home safety concerns (falls, guns, knives, stove, leaving the person alone)	NO	YES
Insists on driving	NO	YES
Takes medicine the wrong way	NO	YES
Wanders/gets lost	NO	YES
CAREGIVER NEEDS		
Depression/stress (feeling blue and/or overwhelmed)	NO	YES
Difficulty providing care because of your health	NO	YES
Lacks understanding of dementia	NO	YES
Legal and financial planning (paying the bills, power of attorney, etc.)	NO	YES
Long-term care planning	NO	YES
End-of-life planning	NO	YES

*Care managers should use clinical judgment to gauge caregiver's capacity to provide care, level of burden to caregiver, and identified unmet needs. This information will determine which standardized care plans are needed.

Other needs identified:

Benjamin Rose Institute Caregiver Strain Instrument

Benjamin Rose Institute Caregiver Strain Instrument

Benjamin Rose Institute Caregiver Strain Instrument Bass, Noelker & Reschlin, 1996; Bass et al., 1994b

"The following questions are about you, the caregiver, as they relate to providing care to the care recipient [CR]. The following items refer to how a caregiver feels and behaves as a result of providing care. There are no right or wrong answers."

	Mark one box ☒ in each row			
The answer options for the next set of questions are "Strongly agree," "Agree," "Disagree," or "Strongly disagree."	Strongly agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
Caregiver Mastery During the past 4 weeks, because of helping [CR] would you say that you were:				
1. unsure whether he or she was getting proper care.	☐3	☐2	☐1	☐0
2. uncertain about how to best care for him/her.	☐3	☐2	☐1	☐0
3. that you should be doing more for him/her.	☐3	☐2	☐1	☐0
4. that you could do a better job of caring for him/her.	☐3	☐2	☐1	☐0
Score _________________ (Sum of items 1–4)				
Relationship Strain During the past 4 weeks, because of helping [CR] would you say:				
5. that he/she tried to manipulate you.	☐3	☐2	☐1	☐0
6. that your relationship with him/her was strained.	☐3	☐2	☐1	☐0
7. that he/she made requests over and above what he/she needed.	☐3	☐2	☐1	☐0
8. that you were resentful toward him/her.	☐3	☐2	☐1	☐0
9. that you were angry toward him/her.	☐3	☐2	☐1	☐0
Score _________________ (Sum of items 5–9)				
Health Strain During the past 4 weeks, because of helping [CR] would you say that:				
10. your physical health was worse than before.	☐3	☐2	☐1	☐0
11. you felt downhearted, blue, or sad more often.	☐3	☐2	☐1	☐0
12. you were more nervous or bothered by nerves than before.	☐3	☐2	☐1	☐0
13. you had less pep or energy.	☐3	☐2	☐1	☐0
14. you were bothered more by aches and pains	☐3	☐2	☐1	☐0
Score _________________ (Sum of items 10–14)				

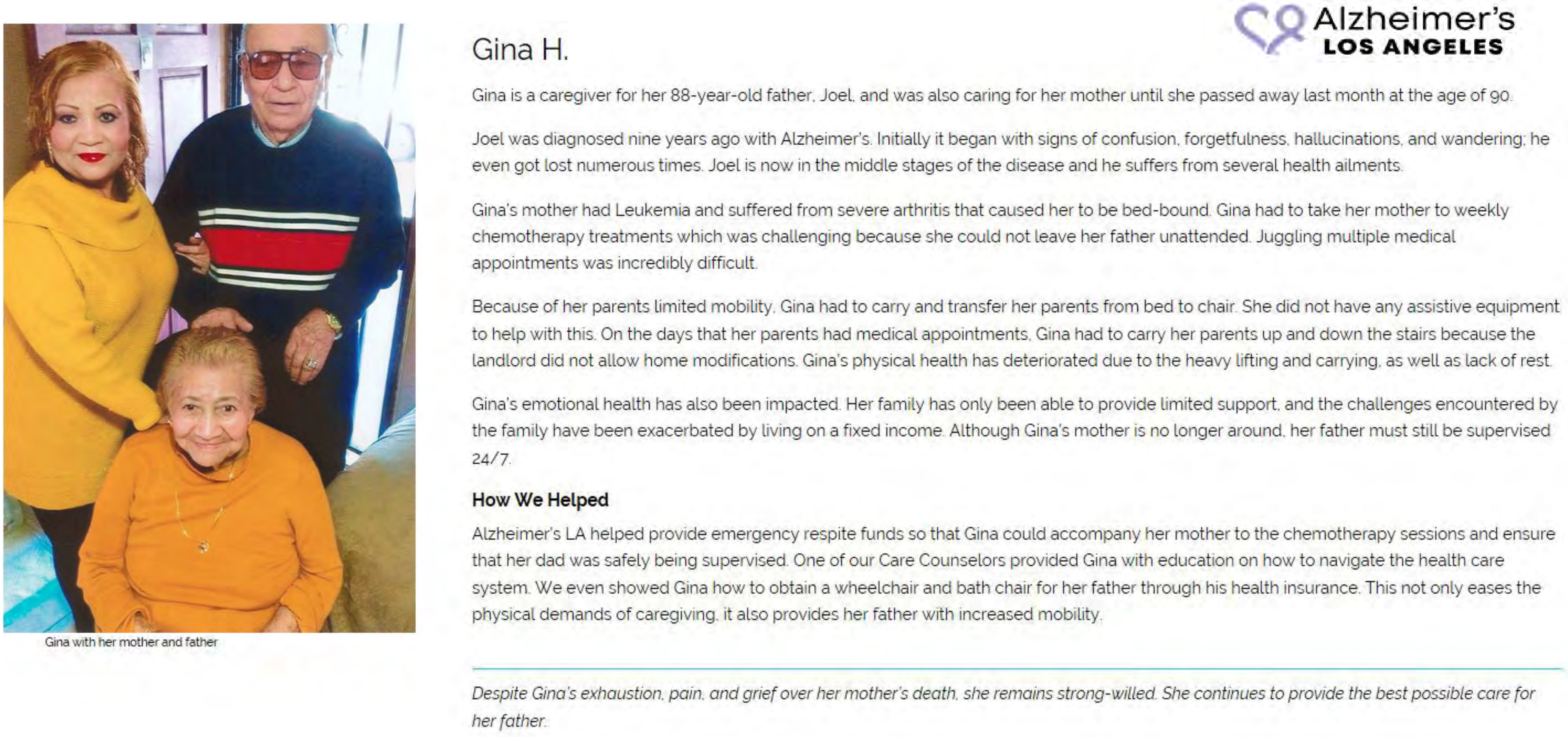
Using a Caregiver Needs Assessment: Marina and Marco

1) Read the scenario
2) Use the Care Needs Assessment Tool and the Benjamin Rose Institute Caregiver Strain Instrument to better assess needs
3) Prioritize needs
4) Determine next steps

Supporting Caregivers

Alzheimer's
LOS ANGELES

Importance of Support



Alzheimer's LOS ANGELES

Gina H.

Gina with her mother and father

Gina is a caregiver for her 88-year-old father, Joel, and was also caring for her mother until she passed away last month at the age of 90.

Joel was diagnosed nine years ago with Alzheimer's. Initially it began with signs of confusion, forgetfulness, hallucinations, and wandering; he even got lost numerous times. Joel is now in the middle stages of the disease and he suffers from several health ailments.

Gina's mother had Leukemia and suffered from severe arthritis that caused her to be bed-bound. Gina had to take her mother to weekly chemotherapy treatments which was challenging because she could not leave her father unattended. Juggling multiple medical appointments was incredibly difficult.

Because of her parents limited mobility, Gina had to carry and transfer her parents from bed to chair. She did not have any assistive equipment to help with this. On the days that her parents had medical appointments, Gina had to carry her parents up and down the stairs because the landlord did not allow home modifications. Gina's physical health has deteriorated due to the heavy lifting and carrying, as well as lack of rest.

Gina's emotional health has also been impacted. Her family has only been able to provide limited support, and the challenges encountered by the family have been exacerbated by living on a fixed income. Although Gina's mother is no longer around, her father must still be supervised 24/7.

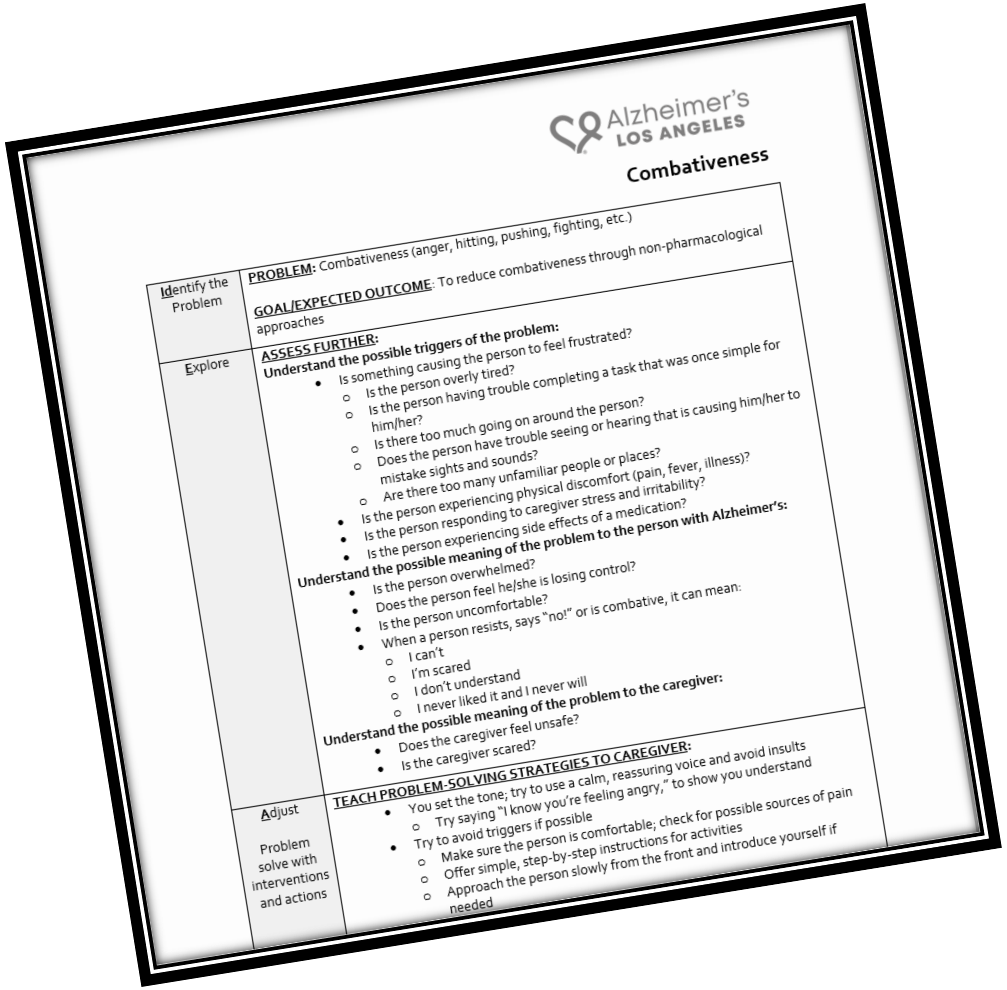
How We Helped

Alzheimer's LA helped provide emergency respite funds so that Gina could accompany her mother to the chemotherapy sessions and ensure that her dad was safely being supervised. One of our Care Counselors provided Gina with education on how to navigate the health care system. We even showed Gina how to obtain a wheelchair and bath chair for her father through his health insurance. This not only eases the physical demands of caregiving, it also provides her father with increased mobility.

Despite Gina's exhaustion, pain, and grief over her mother's death, she remains strong-willed. She continues to provide the best possible care for her father.

Why Use Best Practice Care Plans?

- Reduces variability in care management practices
- Improves care management
- Provides framework to address needs



Alzheimer's LOS ANGELES

Combativeness

Identify the Problem	**PROBLEM:** Combativeness (anger, hitting, pushing, fighting, etc.) **GOAL/EXPECTED OUTCOME**: To reduce combativeness through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is something causing the person to feel frustrated? ○ Is the person overly tired? ○ Is the person having trouble completing a task that was once simple for him/her? ○ Is there too much going on around the person? ○ Does the person have trouble seeing or hearing that is causing him/her to mistake sights and sounds? ○ Are there too many unfamiliar people or places? • Is the person experiencing physical discomfort (pain, fever, illness)? • Is the person responding to caregiver stress and irritability? • Is the person experiencing side effects of a medication? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person overwhelmed? • Does the person feel he/she is losing control? • Is the person uncomfortable? • When a person resists, says "no!" or is combative, it can mean: ○ I can't ○ I'm scared ○ I don't understand ○ I never liked it and I never will **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel unsafe? • Is the caregiver scared?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • You set the tone; try to use a calm, reassuring voice and avoid insults ○ Try saying "I know you're feeling angry," to show you understand • Try to avoid triggers if possible ○ Make sure the person is comfortable; check for possible sources of pain ○ Offer simple, step-by-step instructions for activities ○ Approach the person slowly from the front and introduce yourself if needed

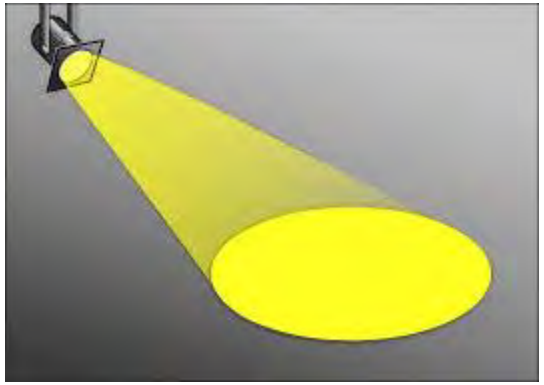
How to Use Best Practice Care Plans

- Ideas for how to proceed
- Cues for care manager
- Action items that caregiver can choose to use
- Choices = greater control
- Collaborative
- Not prescriptive

Family-Centered Best Practice Care Plans

Use family-centered lens to ensure that care accounts for:

- culture
- values
- preferences
- language
- literacy level, and
- decision-making processes



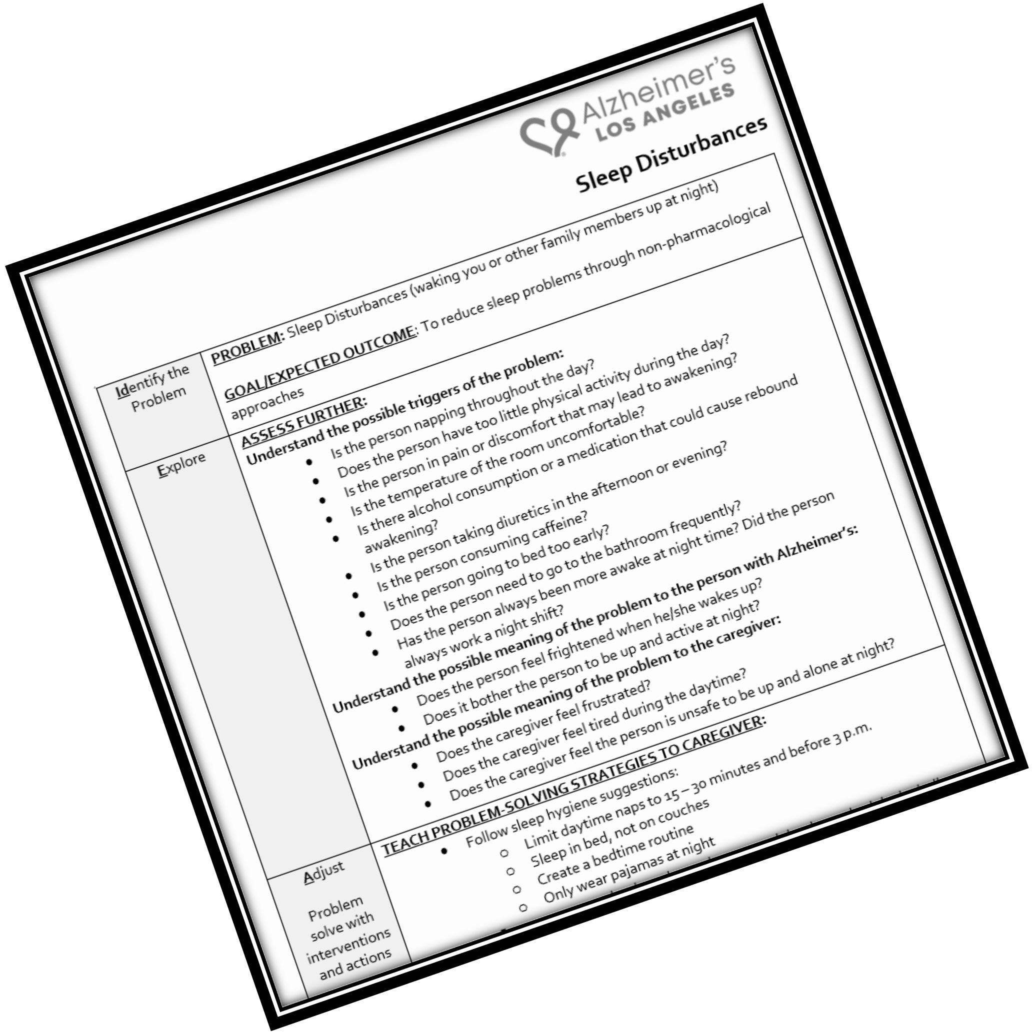
Family-Centered Best Practice Care Plans

- Activities member enjoys
- Cultural and linguistic considerations
- Family roles/responsibilities
- Social support systems

Best Practice Care Plans Problem Areas

Challenging Behaviors

- Sleep Disturbances
- Repetition
- Sadness and/or Depression
- Combativeness
- Hallucinations
- Sundowning
- Suspiciousness and Paranoia
- Screaming and Making Noises
- Disinhibition



Alzheimer's LOS ANGELES

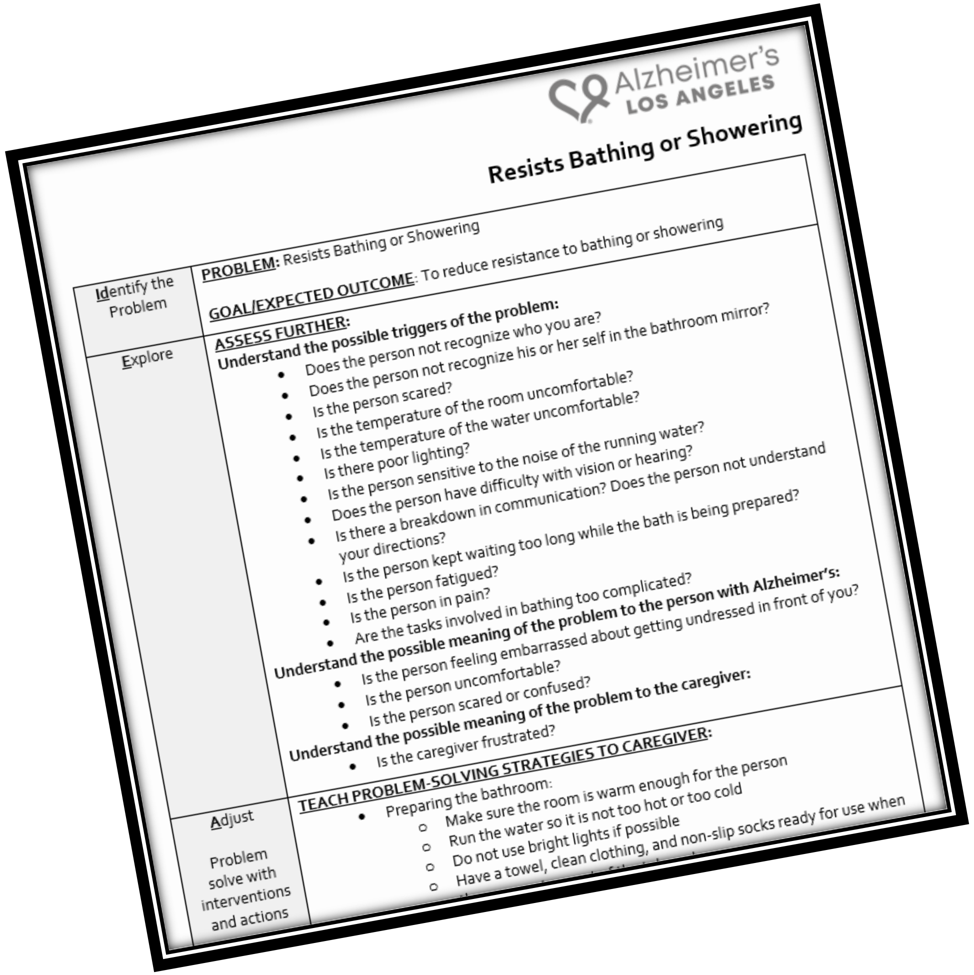
Sleep Disturbances

Identify the Problem	**PROBLEM:** Sleep Disturbances (waking you or other family members up at night) **GOAL/EXPECTED OUTCOME:** To reduce sleep problems through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is the person napping throughout the day? • Does the person have too little physical activity during the day? • Is the person in pain or discomfort that may lead to awakening? • Is the temperature of the room uncomfortable? • Is there alcohol consumption or a medication that could cause rebound awakening? • Is the person taking diuretics in the afternoon or evening? • Is the person consuming caffeine? • Is the person going to bed too early? • Does the person need to go to the bathroom frequently? • Has the person always been more awake at night time? Did the person always work a night shift? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Does the person feel frightened when he/she wakes up? • Does it bother the person to be up and active at night? **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel frustrated? • Does the caregiver feel tired during the daytime? • Does the caregiver feel the person is unsafe to be up and alone at night?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Follow sleep hygiene suggestions: ○ Limit daytime naps to 15 – 30 minutes and before 3 p.m. ○ Sleep in bed, not on couches ○ Create a bedtime routine ○ Only wear pajamas at night

Best Practice Care Plans Problem Areas

Activities of Daily Living and Functional Needs

- Resists Bathing or Showering
- Difficulty with Dressing and Grooming
- Difficulty with Eating
- Difficulty Using the Toilet/Incontinence



Alzheimer's LOS ANGELES

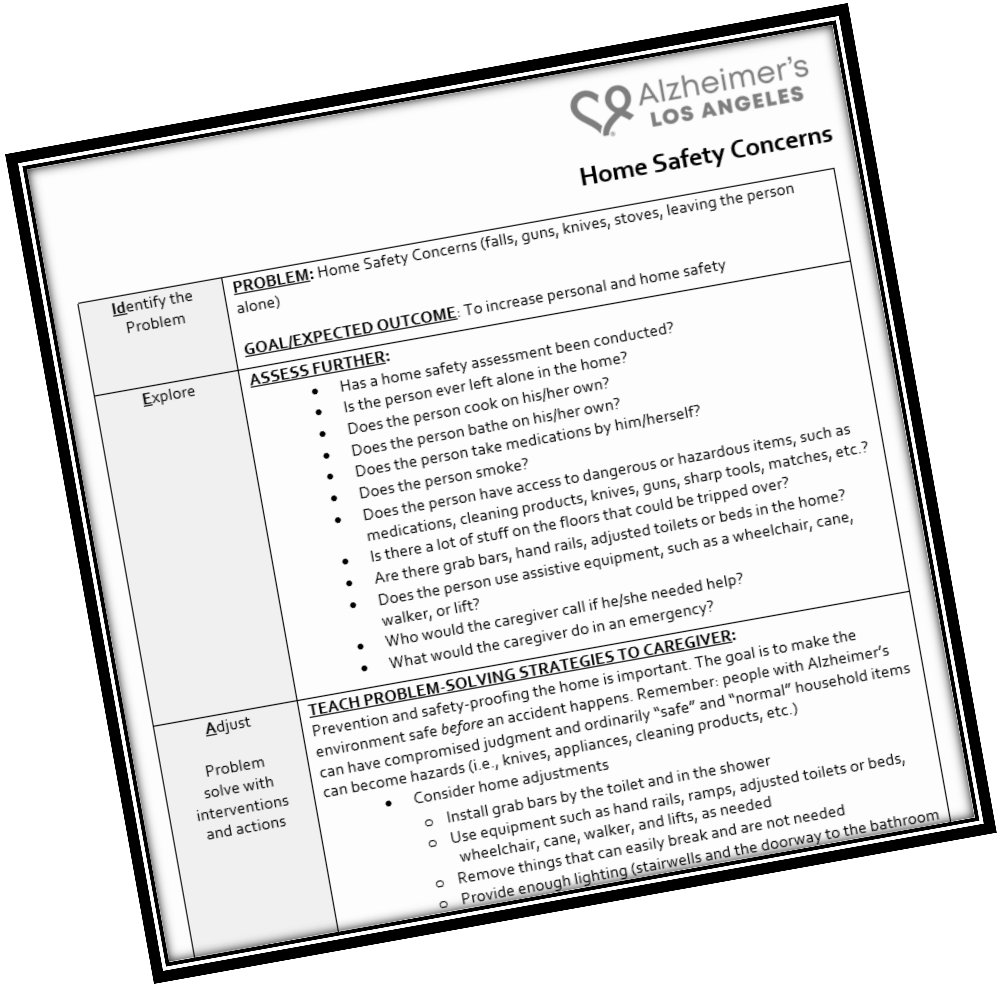
Resists Bathing or Showering

Identify the Problem	**PROBLEM:** Resists Bathing or Showering **GOAL/EXPECTED OUTCOME**: To reduce resistance to bathing or showering
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Does the person not recognize who you are? • Does the person not recognize his or her self in the bathroom mirror? • Is the person scared? • Is the temperature of the room uncomfortable? • Is the temperature of the water uncomfortable? • Is there poor lighting? • Is the person sensitive to the noise of the running water? • Does the person have difficulty with vision or hearing? • Is there a breakdown in communication? Does the person not understand your directions? • Is the person kept waiting too long while the bath is being prepared? • Is the person fatigued? • Is the person in pain? • Are the tasks involved in bathing too complicated? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person feeling embarrassed about getting undressed in front of you? • Is the person uncomfortable? • Is the person scared or confused? **Understand the possible meaning of the problem to the caregiver:** • Is the caregiver frustrated?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Preparing the bathroom: ○ Make sure the room is warm enough for the person ○ Run the water so it is not too hot or too cold ○ Do not use bright lights if possible ○ Have a towel, clean clothing, and non-slip socks ready for use when

Best Practice Care Plans Problem Areas

Safety

- Home Safety Concerns
- Insists on Driving
- Takes Medicine the Wrong Way
- Wanders/Gets Lost



Alzheimer's LOS ANGELES

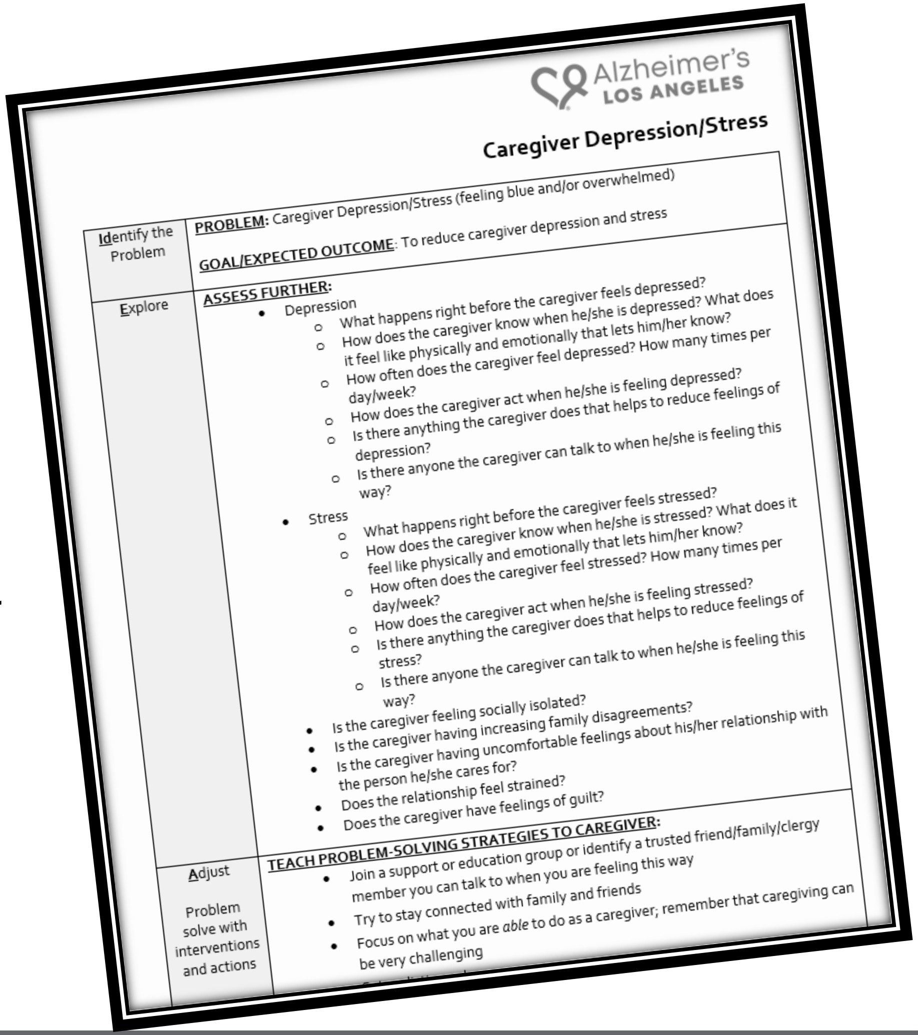
Home Safety Concerns

Identify the Problem	**PROBLEM:** Home Safety Concerns (falls, guns, knives, stoves, leaving the person alone) **GOAL/EXPECTED OUTCOME**: To increase personal and home safety
Explore	**ASSESS FURTHER:** • Has a home safety assessment been conducted? • Is the person ever left alone in the home? • Does the person cook on his/her own? • Does the person bathe on his/her own? • Does the person take medications by him/herself? • Does the person smoke? • Does the person have access to dangerous or hazardous items, such as medications, cleaning products, knives, guns, sharp tools, matches, etc.? • Is there a lot of stuff on the floors that could be tripped over? • Are there grab bars, hand rails, adjusted toilets or beds in the home? • Does the person use assistive equipment, such as a wheelchair, cane, walker, or lift? • Who would the caregiver call if he/she needed help? • What would the caregiver do in an emergency?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** Prevention and safety-proofing the home is important. The goal is to make the environment safe *before* an accident happens. Remember: people with Alzheimer's can have compromised judgment and ordinarily "safe" and "normal" household items can become hazards (i.e., knives, appliances, cleaning products, etc.) • Consider home adjustments ○ Install grab bars by the toilet and in the shower ○ Use equipment such as hand rails, ramps, adjusted toilets or beds, wheelchair, cane, walker, and lifts, as needed ○ Remove things that can easily break and are not needed ○ Provide enough lighting (stairwells and the doorway to the bathroom

Best Practice Care Plans Problem Areas

Caregiver Needs

- Caregiver Depression/Stress
- Difficulty Providing Care Because of Your Health
- Lacks Understanding of Dementia
- Legal and Financial Planning
- Long-Term Care Planning
- End-of-Life Planning



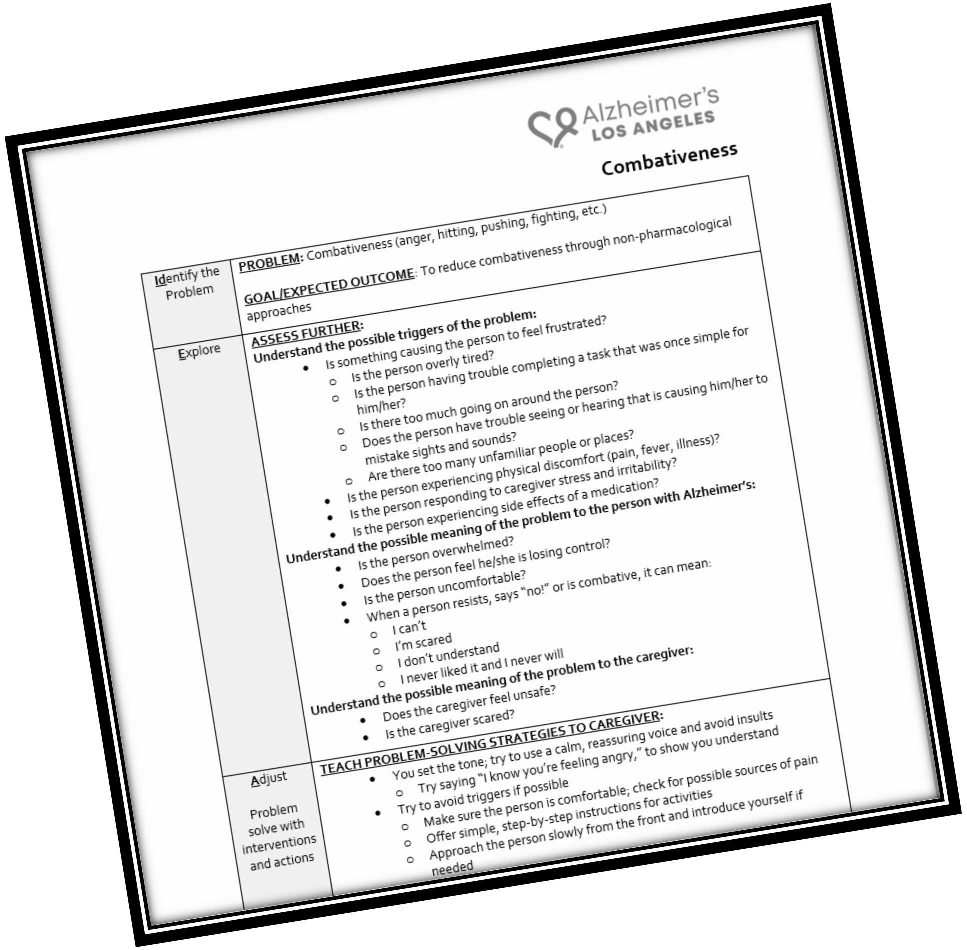
Alzheimer's LOS ANGELES

Caregiver Depression/Stress

Identify the Problem	**PROBLEM:** Caregiver Depression/Stress (feeling blue and/or overwhelmed) **GOAL/EXPECTED OUTCOME**: To reduce caregiver depression and stress
Explore	**ASSESS FURTHER:** • Depression ○ What happens right before the caregiver feels depressed? ○ How does the caregiver know when he/she is depressed? What does it feel like physically and emotionally that lets him/her know? ○ How often does the caregiver feel depressed? How many times per day/week? ○ How does the caregiver act when he/she is feeling depressed? ○ Is there anything the caregiver does that helps to reduce feelings of depression? ○ Is there anyone the caregiver can talk to when he/she is feeling this way? • Stress ○ What happens right before the caregiver feels stressed? ○ How does the caregiver know when he/she is stressed? What does it feel like physically and emotionally that lets him/her know? ○ How often does the caregiver feel stressed? How many times per day/week? ○ How does the caregiver act when he/she is feeling stressed? ○ Is there anything the caregiver does that helps to reduce feelings of stress? ○ Is there anyone the caregiver can talk to when he/she is feeling this way? • Is the caregiver feeling socially isolated? • Is the caregiver having increasing family disagreements? • Is the caregiver having uncomfortable feelings about his/her relationship with the person he/she cares for? • Does the relationship feel strained? • Does the caregiver have feelings of guilt?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • Join a support or education group or identify a trusted friend/family/clergy member you can talk to when you are feeling this way • Try to stay connected with family and friends • Focus on what you are *able* to do as a caregiver; remember that caregiving can be very challenging

Components of Best Practice Care Plans

- ***ID***entify the problem, goal, expected outcome
- Assess further
- ***E***xplore triggers and meaning
- Provide problem-solving strategies (***A***djustments/adaptations)
- Clinical support needs
- Caregiver support and community resources
- Follow-up



Alzheimer's LOS ANGELES

Combativeness

Identify the Problem	**PROBLEM:** Combativeness (anger, hitting, pushing, fighting, etc.) **GOAL/EXPECTED OUTCOME**: To reduce combativeness through non-pharmacological approaches
Explore	**ASSESS FURTHER:** **Understand the possible triggers of the problem:** • Is something causing the person to feel frustrated? ○ Is the person overly tired? ○ Is the person having trouble completing a task that was once simple for him/her? ○ Is there too much going on around the person? ○ Does the person have trouble seeing or hearing that is causing him/her to mistake sights and sounds? ○ Are there too many unfamiliar people or places? • Is the person experiencing physical discomfort (pain, fever, illness)? • Is the person responding to caregiver stress and irritability? • Is the person experiencing side effects of a medication? **Understand the possible meaning of the problem to the person with Alzheimer's:** • Is the person overwhelmed? • Does the person feel he/she is losing control? • Is the person uncomfortable? • When a person resists, says "no!" or is combative, it can mean: ○ I can't ○ I'm scared ○ I don't understand ○ I never liked it and I never will **Understand the possible meaning of the problem to the caregiver:** • Does the caregiver feel unsafe? • Is the caregiver scared?
Adjust Problem solve with interventions and actions	**TEACH PROBLEM-SOLVING STRATEGIES TO CAREGIVER:** • You set the tone; try to use a calm, reassuring voice and avoid insults ○ Try saying "I know you're feeling angry," to show you understand • Try to avoid triggers if possible ○ Make sure the person is comfortable; check for possible sources of pain ○ Offer simple, step-by-step instructions for activities ○ Approach the person slowly from the front and introduce yourself if needed

Working With Marina

Look at Marina’s Care Needs Assessment and Benjamin Rose Institute Caregiver Strain Instrument. What care plans do you want to consider using? Remember that you would need to determine mutually acceptable goals and not overwhelm Marina.

Working With Marina

Now, develop a care plan for Marina (in the format you use) that addresses at least one of her dementia/caregiving-specific needs.

Given everything we have discussed, why are referrals to home and community-based services so important in dementia care management?

Better Outcomes

- Ensure social determinants of health are met
- Reduce caregiver stress and burnout
- Improve quality of life

- Reduce hospitalizations/ readmissions
- Prevent/delay institutionalization

Making Referrals

Considerations Before Making a Referral

- Clarify service need
- Be specific
- Carefully match caregiver to agency (consider language, cost, geography, culture)
- Be proactive and anticipatory
- Go the extra mile for families; high touch

Alzheimer’s Los Angeles

Video: ABC7 Day in a Life

https://www.youtube.com/watch?v=zL8kRGk1zws
Running Time: 5 minutes 18 seconds

Alzheimer’s Los Angeles

- Serving diverse communities in Los Angeles, San Bernardino, and Riverside Counties
- Multi-lingual services
- Culturally competent services

Alzheimer's Los Angeles

- Website www.alzheimersla.org
- Helpline 844.HELP.ALZ | 844.435.7259
- Care counseling
- Family caregiver education
- Disease education
- Support groups

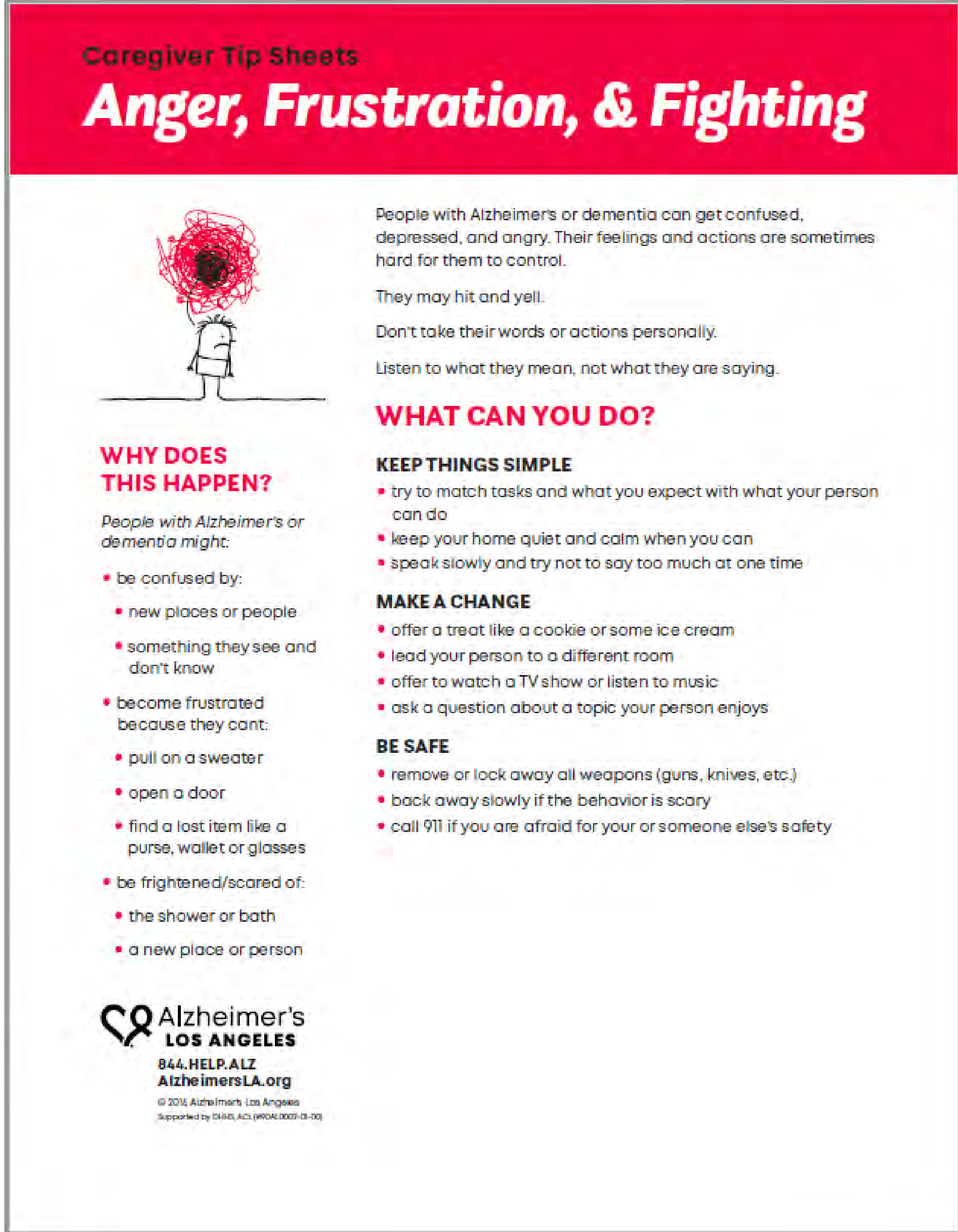
Alzheimer's Los Angeles

- Early stage services
- Activity programs
- MedicAlert
- Professional training
- Advocacy

- Multiple topics
- English, Spanish, Chinese, and Japanese
- Free to download

www.alzheimersla.org/professionals

Caregiver Tip Sheets



Caregiver Tip Sheets

Anger, Frustration, & Fighting

People with Alzheimer's or dementia can get confused, depressed, and angry. Their feelings and actions are sometimes hard for them to control.

They may hit and yell.

Don't take their words or actions personally.

Listen to what they mean, not what they are saying.

WHY DOES THIS HAPPEN?

People with Alzheimer's or dementia might:

- be confused by:
  - new places or people
  - something they see and don't know
- become frustrated because they cant:
  - pull on a sweater
  - open a door
  - find a lost item like a purse, wallet or glasses
- be frightened/scared of:
  - the shower or bath
  - a new place or person

WHAT CAN YOU DO?

KEEP THINGS SIMPLE

- try to match tasks and what you expect with what your person can do
- keep your home quiet and calm when you can
- speak slowly and try not to say too much at one time

MAKE A CHANGE

- offer a treat like a cookie or some ice cream
- lead your person to a different room
- offer to watch a TV show or listen to music
- ask a question about a topic your person enjoys

BE SAFE

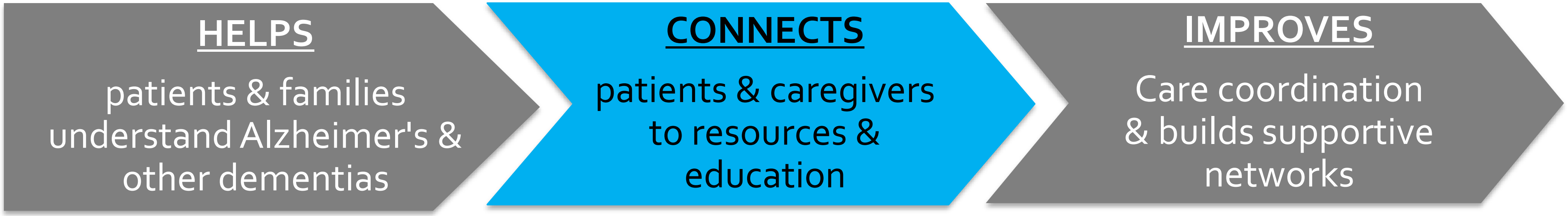
- remove or lock away all weapons (guns, knives, etc.)
- back away slowly if the behavior is scary
- call 911 if you are afraid for your or someone else's safety

Alzheimer's
LOS ANGELES
844.HELP.ALZ
AlzheimersLA.org

Supported by DHHS, ACL [illegible]

Why ALZ Direct Connect?

- ☐ Free
- ☐ Provides psycho-social-educational support
- ☐ Improves care coordination
- ☐ Connects families to resources *before* a crisis
- ☐ Provider receives feedback



HELPS

patients & families understand Alzheimer's & other dementias

CONNECTS

patients & caregivers to resources & education

IMPROVES

Care coordination & builds supportive networks

ALZ Direct Connect Referral Program

Alzheimer's LOS ANGELES

ALZ DIRECT CONNECT

REFERRAL PROGRAM

Partnering with healthcare and aging service providers to improve care and support for people with Alzheimer's or dementias & their families

ALZ DIRECT CONNECT allows healthcare and aging services providers to directly link patients/clients and families to Alzheimer's Los Angeles for:

- access to care coordination & psychosocial support
- referrals to supportive services
- help with understanding the disease & navigating its progression
- a 360 approach to care through feedback to the referring provider

HELPS families understand Alzheimer's & other dementias

CONNECTS families to resources & education

IMPROVES coordinated care & builds supportive networks

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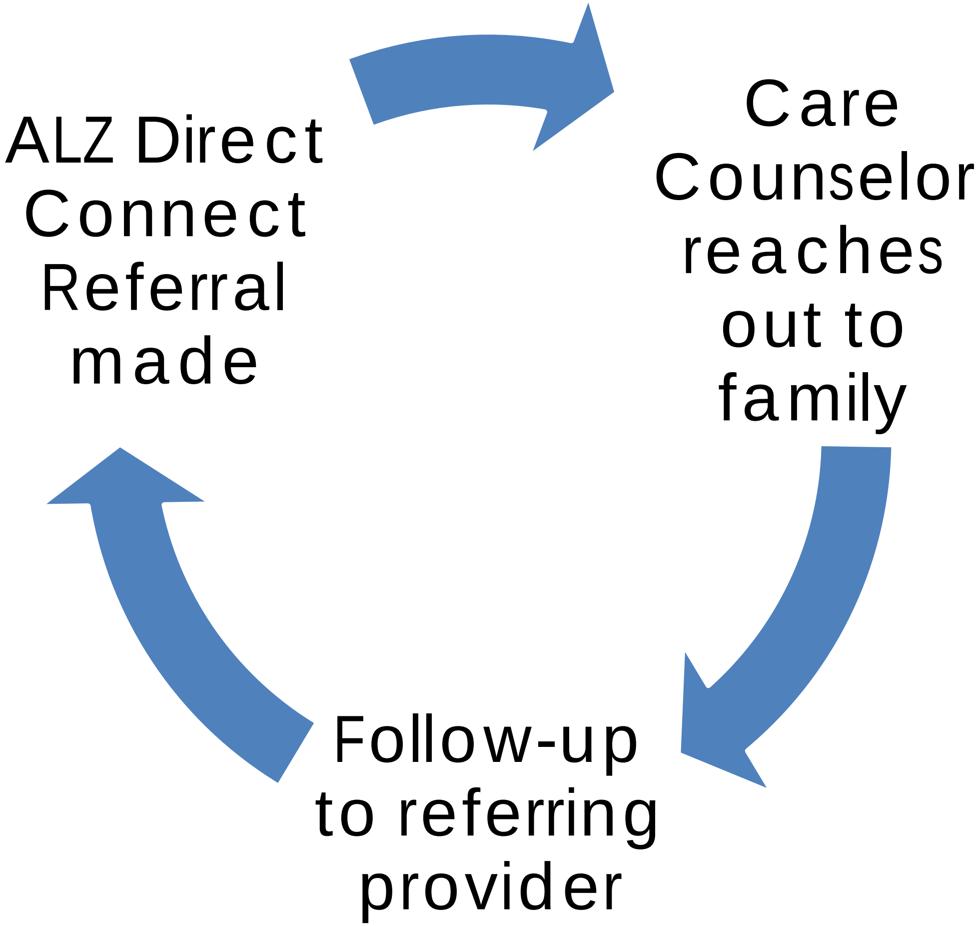
ALZ DIRECT CONNECT does not fulfill mandatory legal reporting requirements for healthcare professionals. Alzheimer's Los Angeles maintains high professional & ethical standards for care & safety and therefore reports any and all allegations or suspicions of elder abuse and/or child abuse.

See reverse side for ALZ Direct Connect Referral Form



ALZ Direct Connect Referral made

Care Counselor reaches out to family

Follow-up to referring provider

Download referral form at:

www.alzheimersla.org/alzdirectconnect

"What maybe a physician should do is... prescribe something that would give you the opportunity to **learn about [Alzheimer's]** and have the **interaction**...that would probably be the biggest help."

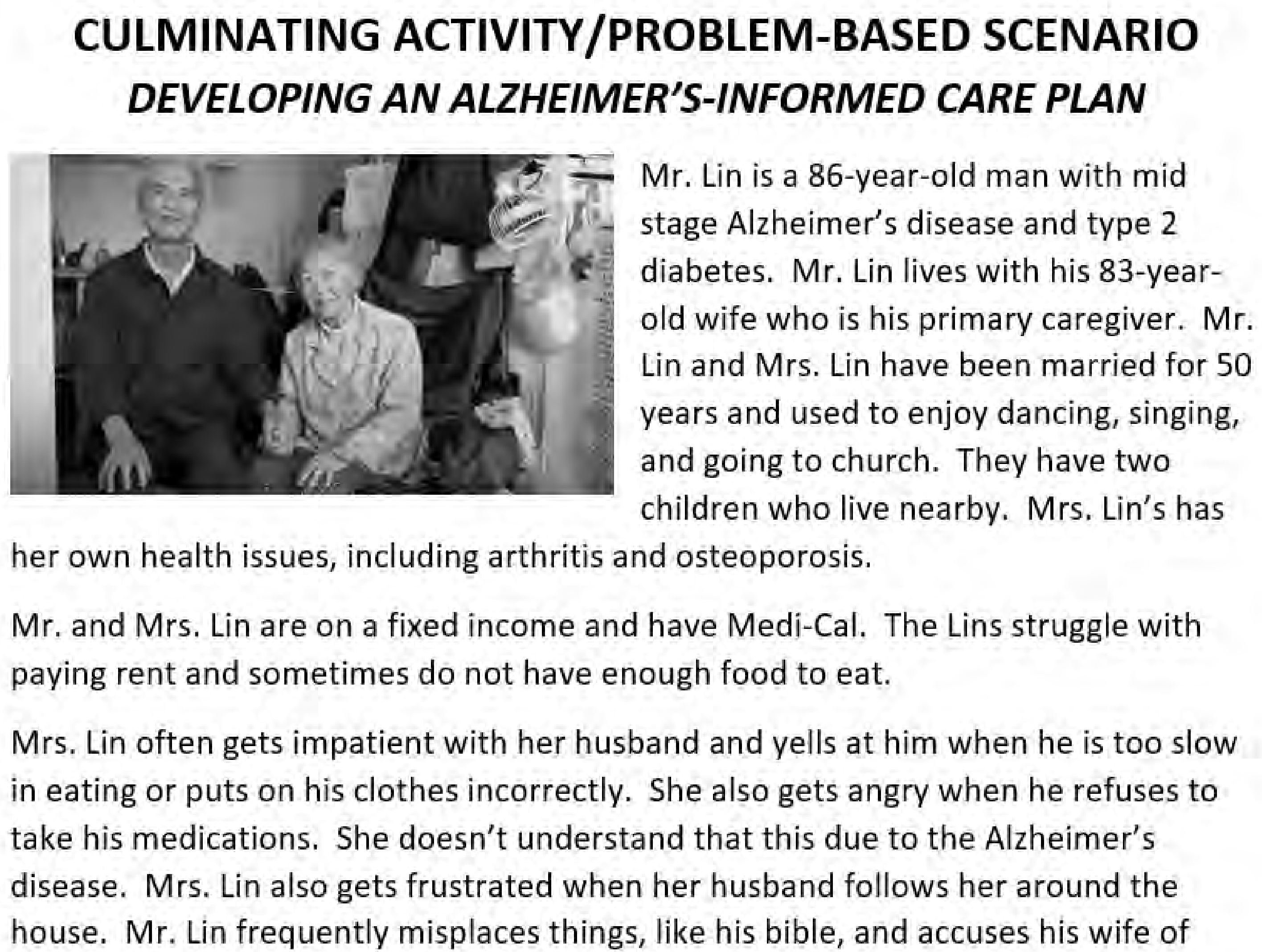
- Focus Group Participant

Video: A Lonely Journey

https://www.youtube.com/watch?v=4tFjcMeYDFg

Running Time 1 minute 52 seconds

Culminating Activity/Problem-Based Scenario: **Developing an Alzheimer's**-Informed Care Plan



CULMINATING ACTIVITY/PROBLEM-BASED SCENARIO

DEVELOPING AN ALZHEIMER'S-INFORMED CARE PLAN

Mr. Lin is a 86-year-old man with mid stage Alzheimer's disease and type 2 diabetes. Mr. Lin lives with his 83-year-old wife who is his primary caregiver. Mr. Lin and Mrs. Lin have been married for 50 years and used to enjoy dancing, singing, and going to church. They have two children who live nearby. Mrs. Lin's has her own health issues, including arthritis and osteoporosis.

Mr. and Mrs. Lin are on a fixed income and have Medi-Cal. The Lins struggle with paying rent and sometimes do not have enough food to eat.

Mrs. Lin often gets impatient with her husband and yells at him when he is too slow in eating or puts on his clothes incorrectly. She also gets angry when he refuses to take his medications. She doesn't understand that this due to the Alzheimer's disease. Mrs. Lin also gets frustrated when her husband follows her around the house. Mr. Lin frequently misplaces things, like his bible, and accuses his wife of

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