



Dementia Care Specialist Training

Building Dementia-Capable Systems of Care

Learning Objectives



Learning Objectives

At the conclusion of this training, you will:

- Increase ability to **conduct a cognitive screen**
- Apply **IDEA!** strategy to behavioral symptoms
- Increase ability to **identify an informal or family caregiver**
- Increase ability to **assess needs of an informal or family caregiver**
- Increase self-efficacy in developing and implementing **standardized care plans** for members with Alzheimer's and their caregivers

Dementia Cal MediConnect Project



Coordinated Care Initiative




Cal MediConnect
Dual
Demonstration




Three-way
contract



Dementia Cal
MediConnect
Project



Dementia
Capable
System of
Care



Dementia Capable System of Care

- Improved dementia screening, diagnosis, and documentation
- Use of Guideline for Alzheimer's Disease Management & standardized care plans
- Identification, assessment, and engagement of families
- Families linked to home and community-based organizations for support and services



Take-Aways from Dementia Care Manager (Tier 1) Training



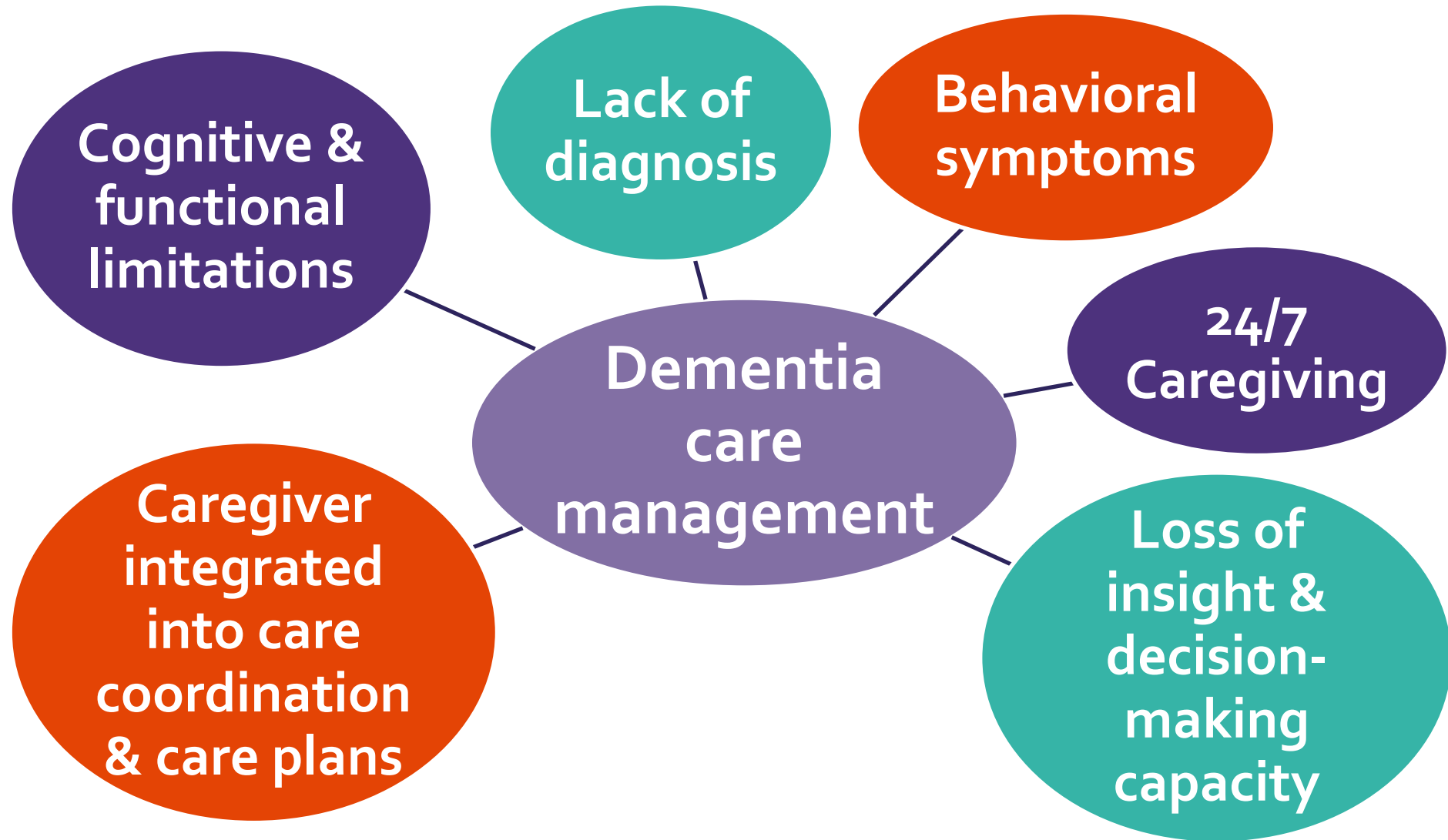
What did you learn in the Dementia Care Manager (Tier 1) Training that “stuck out” or was useful to you?



The Role of Dementia Care Specialists



What Makes Dementia Care Management Unique?



What is a Dementia Care Specialist?

- Specially trained professionals in dementia care
- Understands unique needs of people with dementia and families
- Knowledgeable about dementia screening
- Knowledgeable about Guideline for Alzheimer's Disease Management

Alzheimer's Greater Los Angeles and Administration on Aging.

Adapted from *Establishing Partnerships Between managed Care and Aging Services Organizations* Manual.

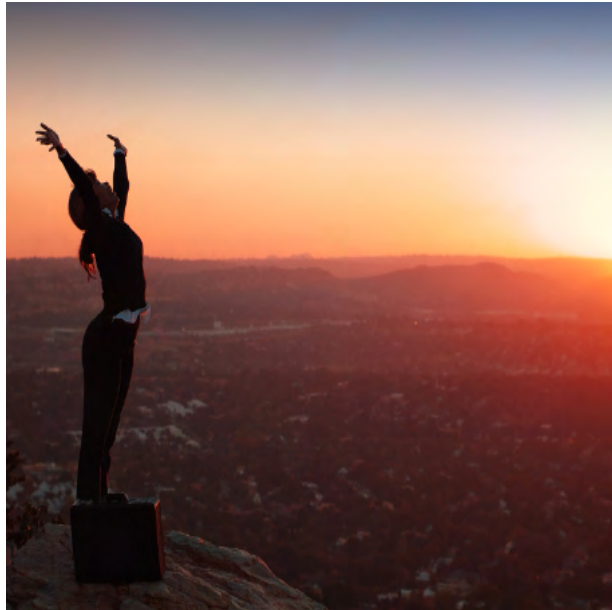
What is a Dementia Care Specialist?

- Coordinates care through use of caregiver identification, caregiver assessment, and standardized care plans
- Connects families to dementia-specific resources and support services
- Advocates within plan/agency to encourage better care

Alzheimer's Greater Los Angeles and Administration on Aging.

Adapted from *Establishing Partnerships Between managed Care and Aging Services Organizations* Manual.

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)



How We See Alzheimer's



Lens on Alzheimer's



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





Negative
words and
images lead
to...

- Stigma
- Labels
- Fear
- Dehumanization
- Diminishing person
- Poor care





Consider
reframing...

**YOU CANT LIVE
A POSITIVE LIFE
WITH A NEGATIVE
MIND.**

Reframing Alzheimer's

LIFE INVOLVES CHANGE

- Perspectives change
- Relationships change
- People change
- Experiences change



Reframing Alzheimer's

As change occurs, we need to
find **NEW & MEANINGFUL**
ways to connect



Hearing from Those Affected



Hearing from Those Affected



Hearing from Those Affected



- What did you learn?
- How might hearing from someone affected by Alzheimer's change your practice?
- What is your perspective now?

Using a Family-Centered Approach

- Honor, respect, and dignity for member and family
- Maintain voice of member; recognize as FULL person
- Promote well-being of family



Using a Family-Centered Approach

- Plan care with values and preferences of member and family in mind (cultural, religious, familial, etc.)
- Promote meaning and purpose
- Emphasize social connectedness



Using a Family-Centered Approach

- Tell me a bit about what the member was like before he/she started to show trouble with memory.
- How has this affected you (as a family/caregiver)?
- What are a few things that have always been important to the member?
- Who are some people who are very important to the member?

Who Are We?



Alzheimer's Disease and Related Dementias



Alzheimer's Disease in the USA 2015



Alzheimer's Association.
2015 Alzheimer's Disease
Facts and Figures.

Alzheimer's & Dementia,
2015;11(3)332+

*Slide courtesy of Cordula
Dick-Muehlke, PhD*

15.5
million unpaid
caregivers

1/9
people age 65
and older has
Alzheimer's

a new case
every

67
seconds

5.3
million people
have Alzheimer's

6th
leading
cause of death

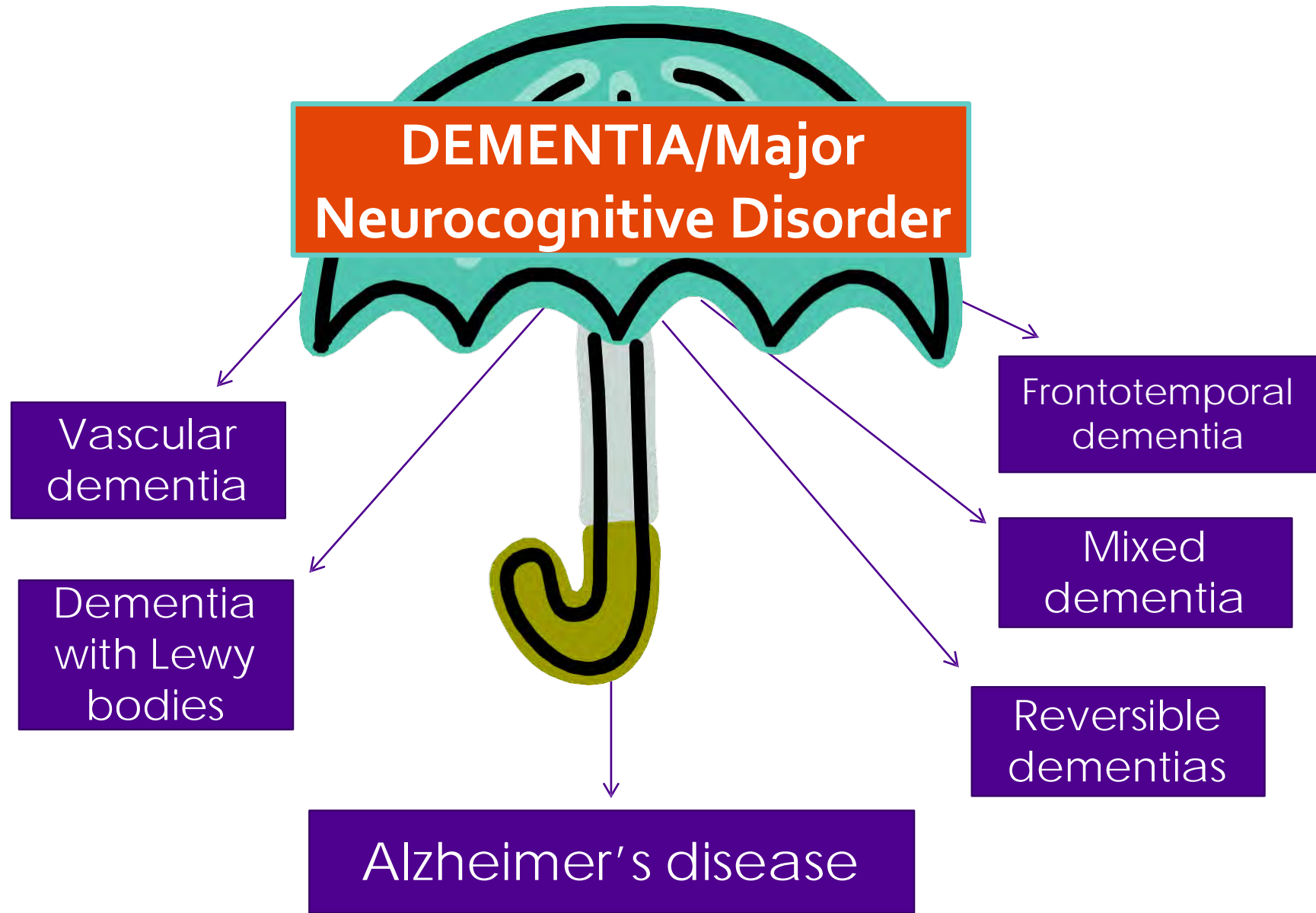
1/3
people age 85
and older has
Alzheimer's

HSAG Podcast: Dementia: The Basics



<https://www.youtube.com/watch?v=Aljqjrg7gfU>

Health Services Advisory Group, Inc., 2014



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 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



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.

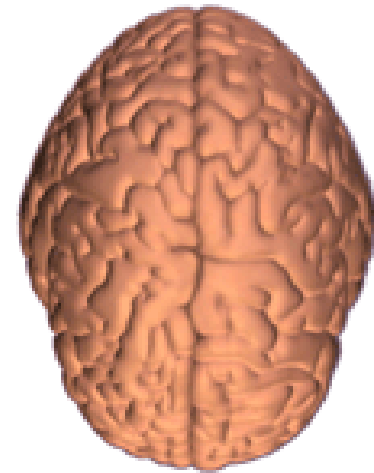
What is Frontotemporal Dementia?

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



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



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)



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



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



Remember...



Not everyone with dementia
has Alzheimer's disease

BUT

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



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



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.

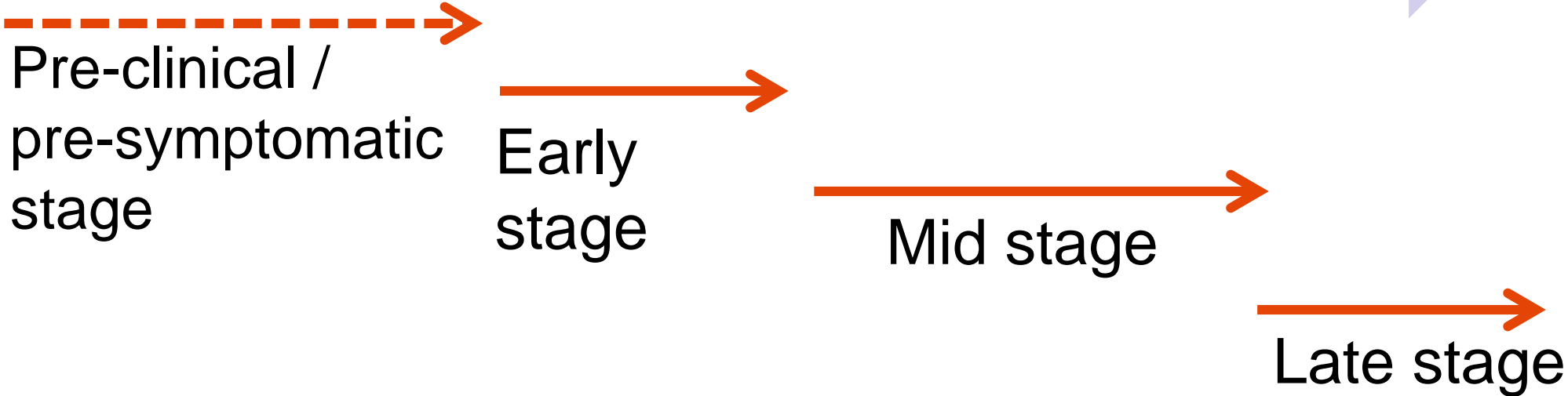
**Be concise,
accurate, &
culturally
sensitive**

MYTH vs. 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.			

Alzheimer's Disease Progression



Domains Affected by Alzheimer's

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



#ADAM

Through the Eyes of Family Caregivers



How much information should you share so the family better understands the disease and can start planning ahead, but does not feel overwhelmed?



How can information be presented in a manner that is culturally sensitive?



How do you want the family to use the information you share?

Getting to a Diagnosis



Why Get a Diagnosis?

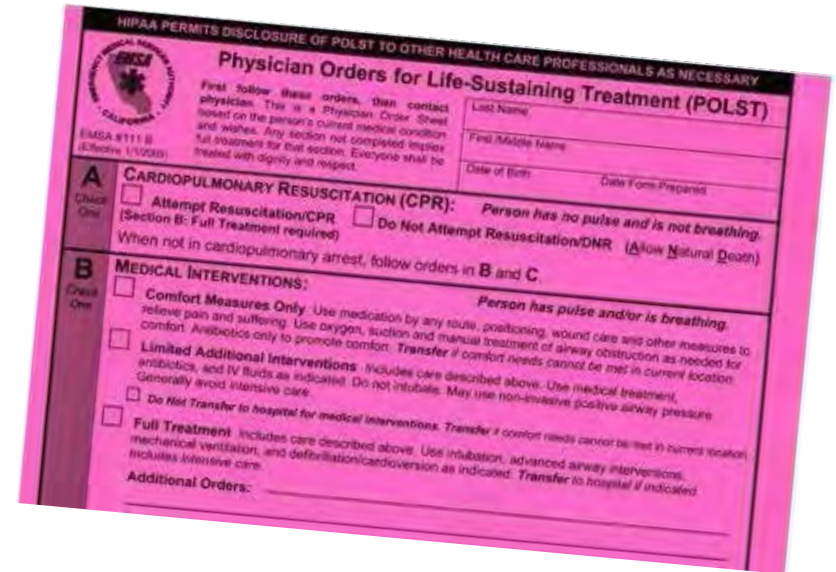


There is no cure for
Alzheimer's disease so
why get a diagnosis?



Importance of Diagnosis

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



The image shows a pink Physician Orders for Life-Sustaining Treatment (POLST) form. At the top, it states "HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY". The form is titled "Physician Orders for Life-Sustaining Treatment (POLST)" and includes a California State Seal logo. It contains fields for "Last Name", "First Middle Name", and "Date of Birth". A section for "Date Form Prepared" is also present. The form is divided into three main sections: Section A: "CARDIOPULMONARY RESUSCITATION (CPR):" with options for "Attempt Resuscitation/CPR" and "Do Not Attempt Resuscitation/DNR (Allow Natural Death)". Section B: "MEDICAL INTERVENTIONS:" with options for "Comfort Measures Only", "Limited Additional Interventions", and "Full Treatment". Each section includes detailed instructions and a "Transfer" condition. An "Additional Orders:" field is at the bottom.

Importance of Diagnosis

- Optimize disease management
- Care planning
- Drug and non-drug treatments
- Medication review
- Safety
- Management of co-existing conditions
- 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



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 ethn racial differences in Alzheimer disease.

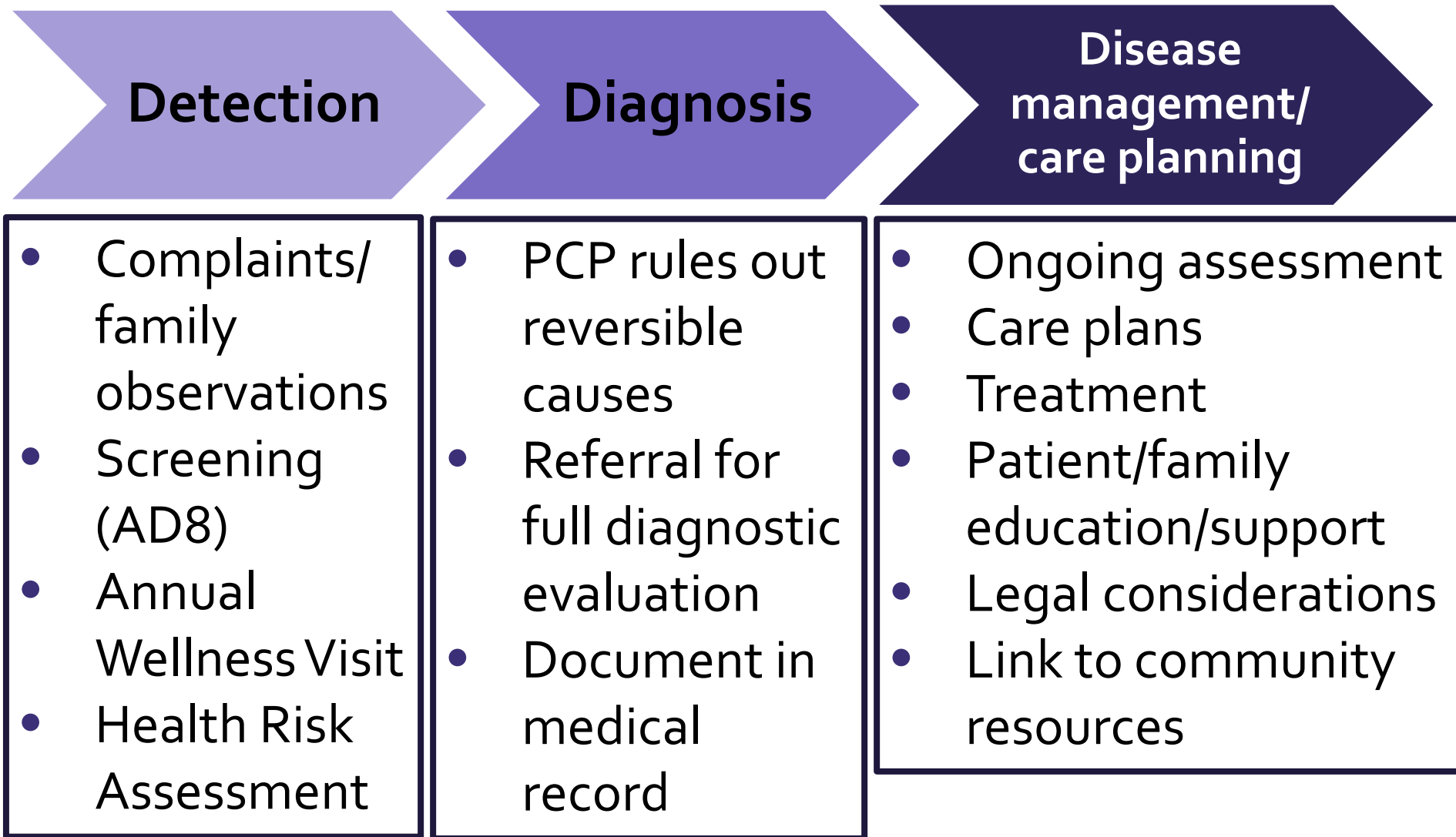


Explaining Importance of Diagnosis

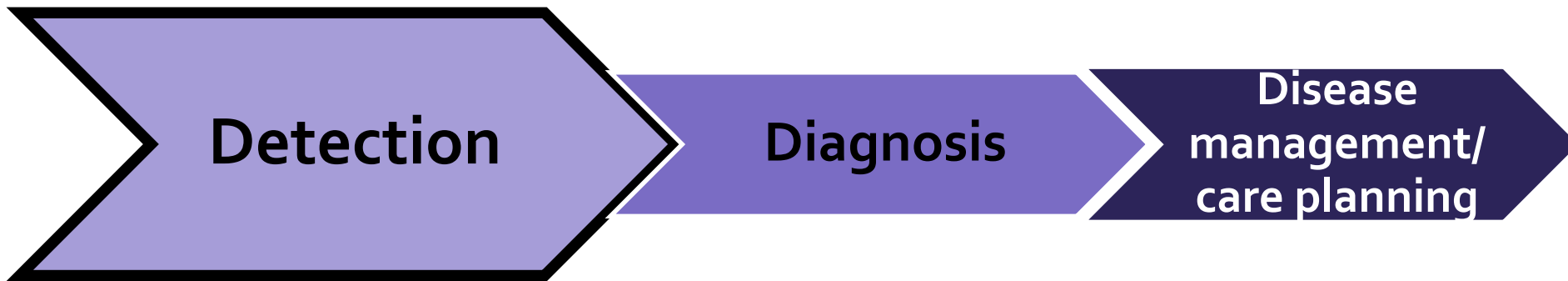


In groups, brainstorm effective strategies for educating culturally / ethnically diverse families on the importance of a diagnosis.





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.

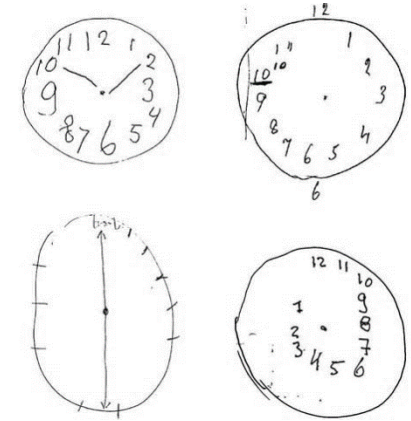
Taking Complaints Seriously

- 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



Cognitive Assessment Challenges/Considerations

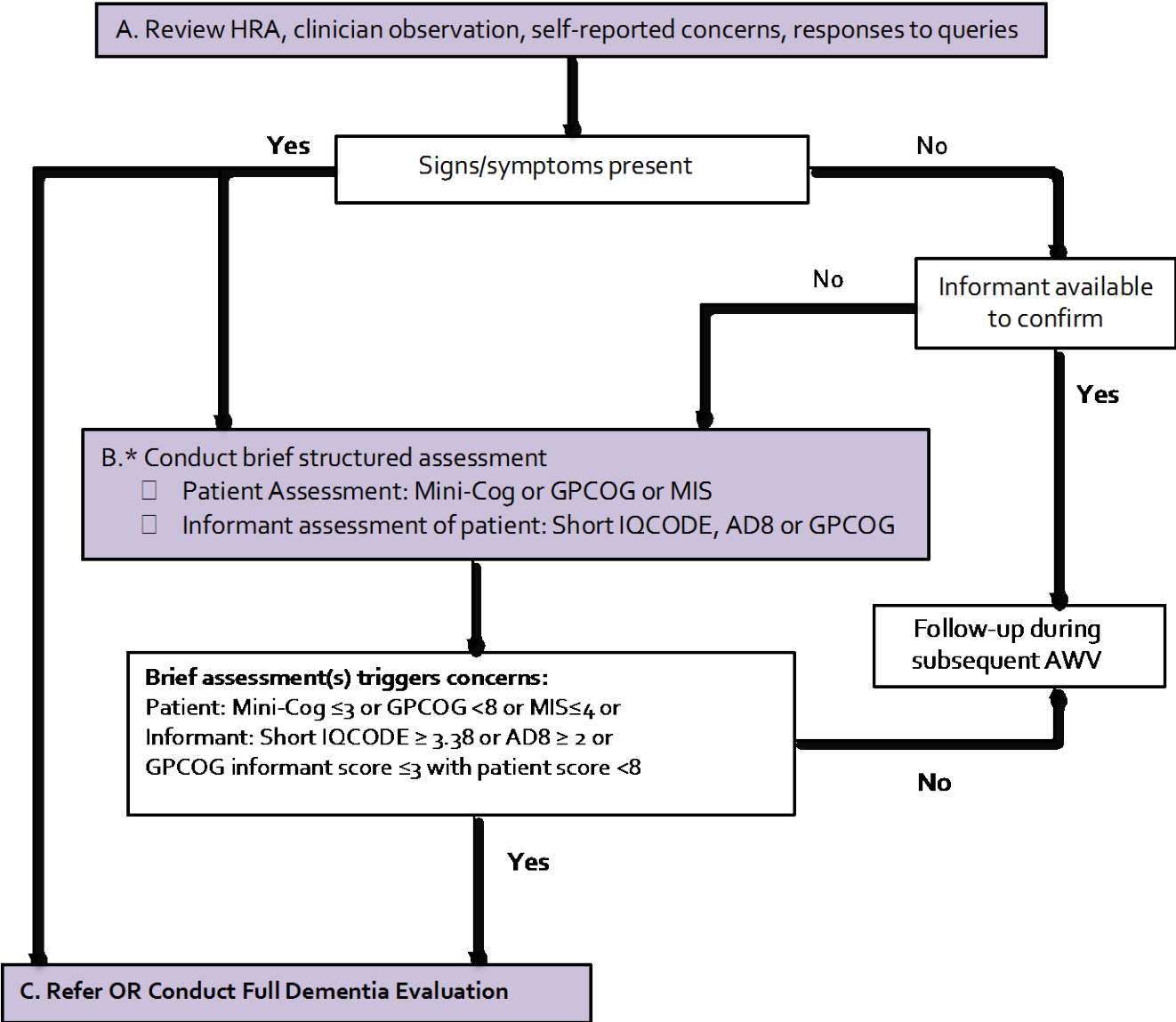
Member

- Denial/shame
- Unable to accurately describe symptoms
- Poor historian
- May resist exam and diagnostic work-up

Caregiver

- Denial/shame
- Masking/
overcompensation
- Need to rely heavily on caregiver reports
- Possible bias due to burnout/exhaustion

Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition



Assessing Cognition and Recommending Follow-Up



https://www.youtube.com/watch?v=5DS_FVXsdHY

Alzheimer's Association, 2013

Cognitive Screening Tool: AD8

- Validated 8-item screening tool
- Telephonic
- Can be used with individuals who have low literacy
- Multiple languages
- Best used with “informant”
- Does not diagnose; may indicate need for further assessment

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
Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.

Cognitive Screening Tool: AD8

- Read each statement aloud
- Ask informant to answer YES if there has been a change in the last several years
- Add up the sum of the number of items marked YES
- 0-1: Normal cognition
2 or greater: Cognitive impairment is likely to be present

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)			
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Copyright 2005. The AD8 is a copyrighted instrument of the Alzheimer's Disease Research Center, Washington University, St. Louis, Missouri. All Rights Reserved.

Using a Cognitive Screening Tool



María Teresa is a high risk member. She is 78 years old and has diabetes and high blood pressure. You work with María Teresa telephonically. She has alluded to cognitive decline, problems with disease self-management, and remembering things. When speaking to María Teresa you have noticed forgetfulness.

What screening tool might you consider using? Why?



- 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.

Diagnosis

- Medical History
- Cognitive testing
- Physical Examination
- Neurological Examination
- Laboratory Tests
- Brain Scans/Images
- Psychiatric Evaluation
- Interviews With Family



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
- Importance of family
- Unnecessary tests ordered
- Non-optimal decisions about discharge
- Poor care transitions



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
- 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.



- 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.

Guideline for Alzheimer's Disease Management

ASSESSMENT	<p>Monitor Changes Conduct and document an assessment and monitor changes in:</p> <ul style="list-style-type: none"> • Daily functioning, including feeding, bathing, dressing, mobility, toileting, continence, and ability to manage finances & medications • Cognitive status using a reliable and valid instrument • Comorbid medical conditions which may present with sudden worsening in cognition, function, or as change in behavior • Behavioral symptoms, psychotic symptoms, and depression • Medications, both prescription and non-prescription (at every visit) • Living arrangement, safety, care needs, and abuse and/or neglect • Need for palliative and/or end-of-life care planning 	<p>Reassess Frequently Reassessment should occur at least every 6 months, and sudden changes in behavior or increase in the rate of decline should trigger an urgent visit to the PCP.</p>	<p>Assess Capacity Assess the patient's decision-making capacity and determine whether a surrogate has been identified.</p> <p>Identify Culture & Values Identify the patient's and family's culture, values, primary language, literacy level, and decision-making process.</p>	
TREATMENT	<p>Develop Treatment Plan Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family:</p> <ul style="list-style-type: none"> • Use of cholinesterase inhibitors, NMDA antagonist, and other medications, if clinically indicated, to treat cognitive decline • Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation 	<p>Treat Behavioral Symptoms Treat behavioral symptoms and mood disorders using:</p> <ul style="list-style-type: none"> • Non-pharmacologic approaches, such as environmental modification, task simplification, appropriate activities, etc. • Referral to social service agencies or support organizations, including the Alzheimer's Association's MedicAlert® + Safe Return® program for patients who may wander 	<p>Non-Pharmacological Treatment First IF non-pharmacological approaches prove unsuccessful, THEN use medications, targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.</p> <p>Treat Co-Morbid Conditions Provide appropriate treatment for comorbid medical conditions.</p> <p>Provide End-of-Life Care Provide appropriate end-of-life care, including palliative care as needed.</p>	
PATIENT & FAMILY EDUCATION & SUPPORT	<p>Integrate Medical Care & Support Integrate medical care with education and support by connecting patient and caregiver to support organizations for linguistically and culturally appropriate educational materials and referrals to community resources, support groups, legal counseling, respite care, consultation on care needs and options, and financial resources. Organizations include:</p> <ul style="list-style-type: none"> • Alzheimer's Association (800) 272-3900 www.alz.org • Family Caregiver Alliance (800) 445-8106 www.caregiver.org • or your own social service department 	<p>Discuss Diagnosis & Treatment Discuss the diagnosis, progression, treatment choices, and goals of Alzheimer's Disease care with the patient and family in a manner consistent with their values, preferences, culture, educational level, and the patient's abilities.</p> <p>Involve Early-Stage Patients Pay particular attention to the special needs of early-stage patients, involving them in care planning, heeding their opinions and wishes, and referring them to community resources, including the Alzheimer's Association.</p>	<p>Discuss Stages Discuss the patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making.</p> <p>Discuss End-of-Life Decisions Discuss the intensity of care and other end-of-life care decisions with the Alzheimer's Disease patient and involved family members while respecting their cultural preferences.</p>	
LEGAL CONSIDERATIONS	<p>Planning Include a discussion of the importance of basic legal and financial planning as part of the treatment plan as soon as possible after the diagnosis of Alzheimer's Disease.</p>	<p>Capacity Evaluations Use a structured approach to the assessment of patient capacity, being aware of the relevant criteria for particular kinds of decisions.</p>	<p>Elder Abuse Monitor for evidence of and report all suspicions of abuse (physical, sexual, financial, neglect, isolation, abandonment, abduction), as required by law.</p>	<p>Driving Report the diagnosis of Alzheimer's Disease in accordance with law.</p>

Guideline for Alzheimer's Disease Management is care plan roadmap

Remember...



Interdisciplinary
Care Teams (ICTs)
ensure that disease
is managed and
services are
coordinated

- Include member and family/informal caregiver(s)
- Family-centered approach
- Other components in a successful team?

What Concerns You About this ICT?



What Looks Right About this ICT?



Guideline for Alzheimer's Disease Management



For each category of the Guideline (Assessment, Treatment, Patient & Family Education & Support, Legal Considerations), **determine who on an interdisciplinary care team would likely take a lead role for each sub-section.**

Explain key roles of team members.

Medications



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



Helping Caregivers Manage Medications

- 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



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; talk to the doctor
- Speak to 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*.

Medications for Cognition



Medications for Cognitive Symptoms

- May delay or prevent symptoms for becoming worse for a limited time and may help control some behavioral symptoms
- May allow members to maintain certain daily functions a little longer



National Institute on Aging. Alzheimer's Disease Education and Referral Center. *Alzheimer's Disease Medications Fact Sheet*. NIH Publication No. 08-3431. November 2008. Updated January 2014.

Medications for Cognitive Symptoms

- Cholinesterase inhibitors
- Donepezil (Aricept[®])
- Rivastigmine (Exelon[®])
- Galantamine (Razadyne[®])
 - NMDA antagonist Memantine (Namenda[®])
 - Indicated for moderate to severe Alzheimer's
 - Side effects uncommon, but can be significant



National Institute on Aging. Alzheimer's Disease Education and Referral Center. *Alzheimer's Disease Medications Fact Sheet*.
NIH Publication No. 08-3431. November 2008. Updated January 2014.

Side Effects

May include:

- Nausea
- Vomiting
- Diarrhea
- Weight loss
- Loss of appetite
- Muscle weakness
- Dizziness
- Headache
- Constipation
- Confusion



National Institute on Aging. Alzheimer's Disease Education and Referral Center. *Alzheimer's Disease Medications Fact Sheet*. NIH Publication No. 08-3431. November 2008. Updated January 2014.

Medications for Behavioral Expressions



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 Expressions

- 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 Expressions

When to consider medications?

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



Medications for Behavioral Expressions

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 Expressions

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



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

Antipsychotics and Dementia: Managing Medications



<https://www.youtube.com/watch?v=LIIKE4NHXAQ>

Alzheimer's Australia, 2014

Note: some terminology and care practices in Australia differ than those in the United States.

Behavioral Expressions/ Symptoms



Remember...



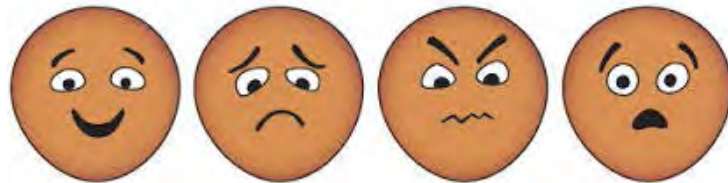
Changes in the brain
cause changes in how people
communicate



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 Expressions



What behavioral expressions/symptoms have you encountered?

Behavioral expressions affect almost all individuals at some point of disease¹



¹ Lykestsos, CG. (2011) *Alzheimers Dement* 7; 532-539

Behavioral Expressions Are NOT

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



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.

HSAG Podcast: Understanding Needs-Driven Behaviors



<https://www.youtube.com/watch?v=GSpRCUVroGg>

Health Services Advisory Group, Inc., 2014

IDEA!

Identify Behaviors

Identify problems

Educate Yourself

Understand the causes/triggers

Understand the meaning

Adapt

Problem solve



Identify Behaviors/Problems

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



Educate Yourself: Understand the Causes/Triggers

What is **causing** this behavior?

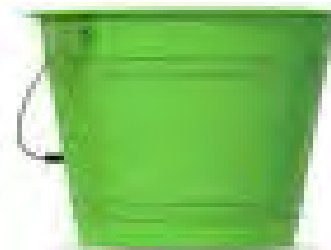
Health
issues

Environmental
issues

Communication
difficulty

Psycho-social
needs

Task-
related



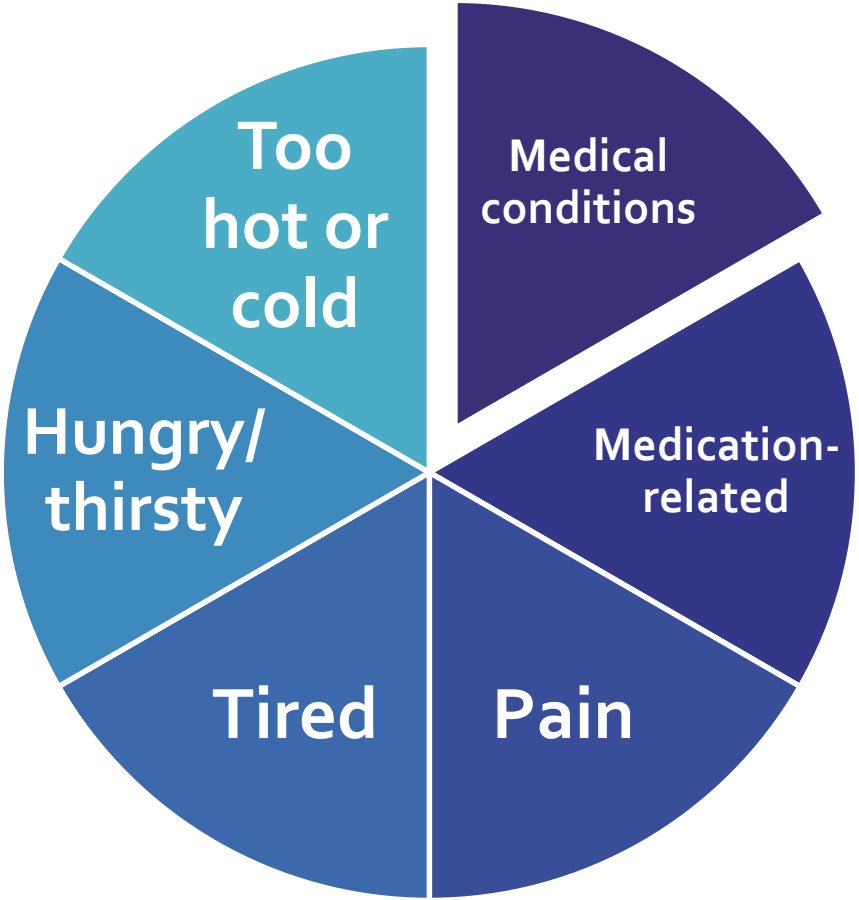
How Do You Feel When...?





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.

Educate Yourself: Understand the Health/Physical Triggers



Educate Yourself: 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*.

Educate Yourself: 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

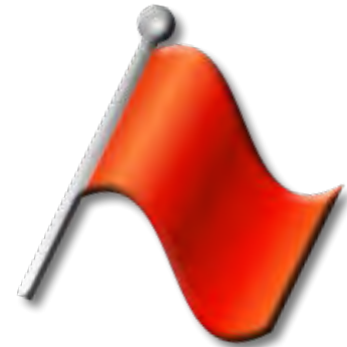
Sudden incontinence

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?



Educate Yourself: 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.

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



Educate Yourself: Understand the Psycho-Social Triggers

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



Educate Yourself: Understand the Environmental Triggers

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



UCLA Health: Hallucinations



<https://www.youtube.com/watch?v=cpV57QGdU7I>

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Examining the Environment



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

Educate Yourself: Understand the Task Triggers

- Too complicated
- Too many steps
- Unfamiliar
- Lack of structure
- Mismatch to cognitive level
- Boring
- Demeaning



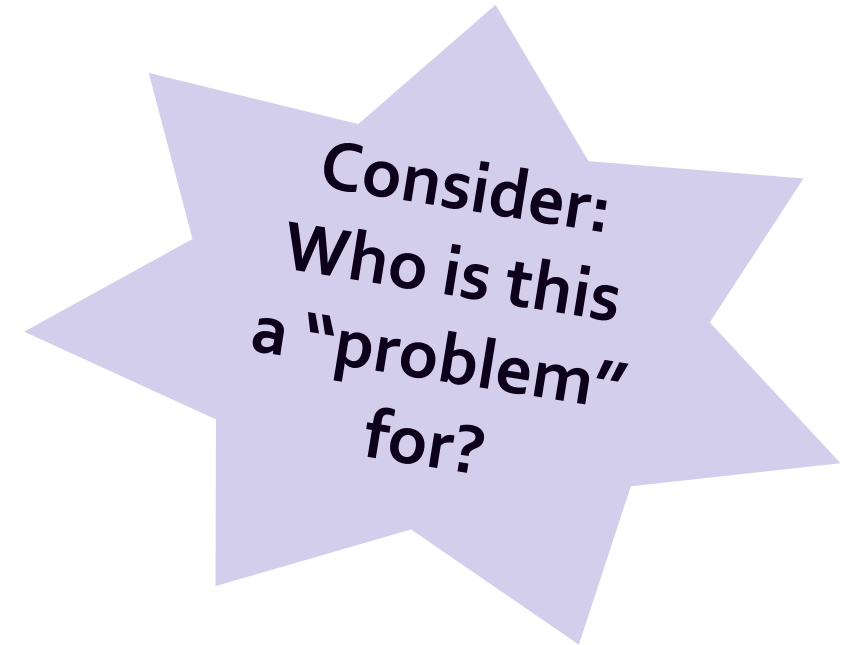
Educate Yourself: Understand the Communication Triggers

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



Educate Yourself: 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?



“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.youtube.com/watch?t=55&v=sl3Dc1kERto>

or <http://dementia.uclahealth.org/body.cfm?id=74>

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Understanding the Meaning: Refusal to Bathe Video



What does bathing mean to mother?

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 down there” by herself	

Strategies Not Solutions



Always pay attention to the person's feelings

Aadapt

Understand what can be changed

Set the tone

Stay calm

Do not demand

Try different things; no one size fits all



Aadapt: 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



Aadapt: 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

Adapt: 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>

Aadapt: Communication and Connection Strategies

Find news ways to communicate and connect

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



Remember...



Shift from the
COGNITIVE lens
to the **EMOTIONAL**
lens

CONNECT with the
person to better
understand him/her



COGNITIVE

- Factual
- Rational
- Concrete
- Doing

EMOTIONAL

- Wellness
- Connectedness
- Love
- Warmth
- Being

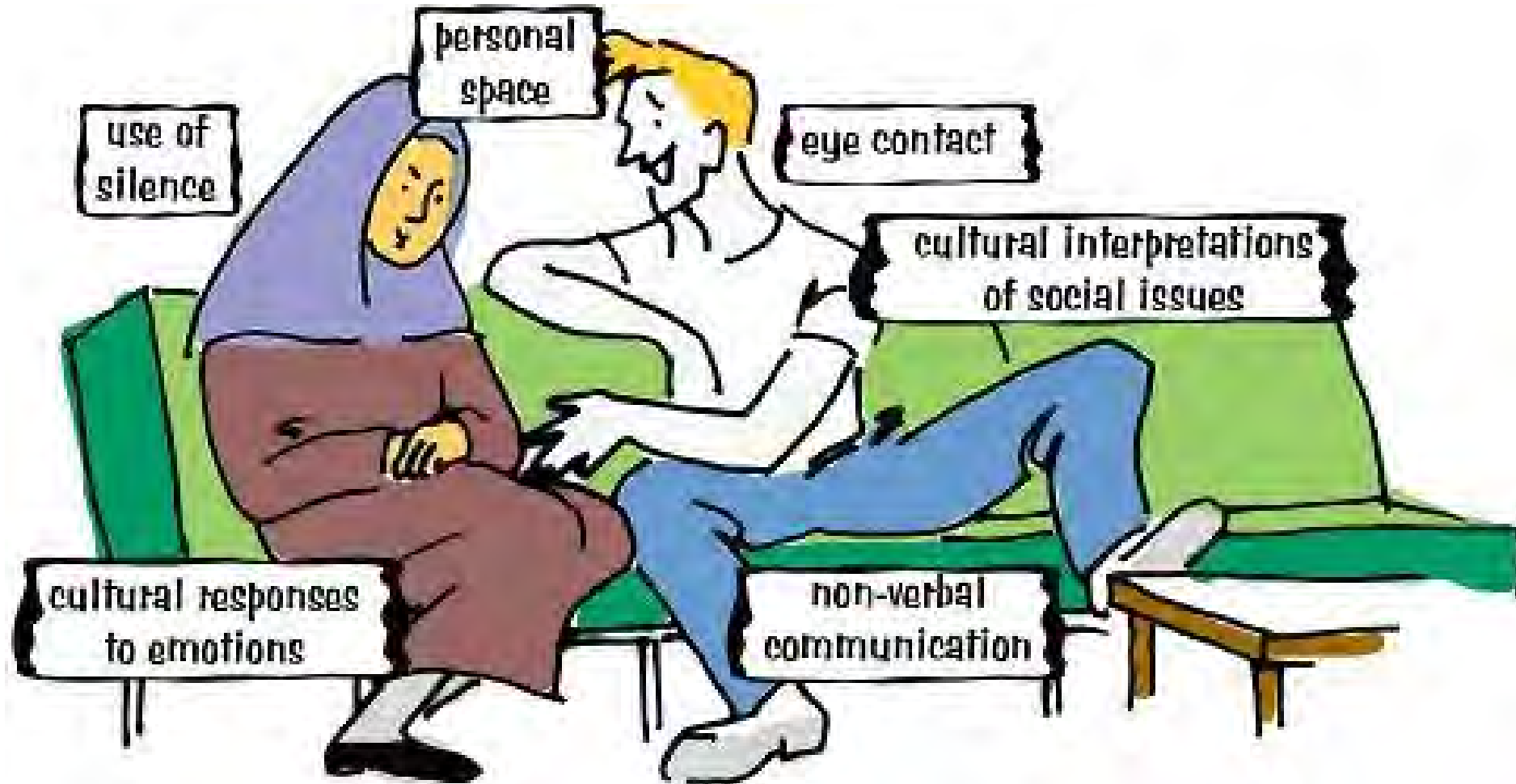
COGNITIVE

- “What do you want to do today?”
- “I made your favorite meal, why aren’t you eating it?”

EMOTIONAL

- “It’s a beautiful day today; let’s go for a walk.”
- Smell aroma from kitchen; slow down; hold hand; “this reminds me of what your mom used to make.”

Culturally Appropriate Communication



Adapt: 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



Aadapt: 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

Adapt: 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



Adapt: 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 he's 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!

Identify Behaviors

- Identify problems

Educate Yourself

- Understand the causes/triggers
- Understand the meaning

Adapt

- Problem solve



UCLA Health: Wandering



<https://www.youtube.com/watch?v=SwoyEB5o8ml>

or <http://dementia.uclahealth.org/body.cfm?id=69>

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IDEA!



Identify Behaviors

- Wandering

Educate Yourself

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

Adapt

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

Applying *IDEA!*



In groups, have one person share a case that has involved a challenging behavior and then as a group, break it down, using *IDEA!*



Applying *IDEA!*



Identify Behaviors

- _____

Educate Yourself

- Causes/triggers: _____
- Meaning: _____

Adapt

- _____
- _____
- _____

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 quick fact sheets

Family Caregiver Identification, Assessment, and Support



15.5
million
UNPAID
caregivers

Alzheimer's Association *Alzheimer's Disease Facts and Figures 2015*

 Alzheimer's | GREATER LOS ANGELES

What Do Caregivers Do?

WHAT DO THEY NOT DO?



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



Remember...



- Cultural values and beliefs related to providing care
- Honor and duty to take care of a loved one
- “A heavy job done with love”
- Modeled behavior in family



17.9
billion hours of
UNPAID
care

\$217.7
billion of
UNPAID
care hours

Alzheimer's Association *Alzheimer's Disease Facts and Figures 2015*

\$220.2 billion is nearly **8 times** the total revenue of McDonald's in 2013



8X



Alzheimer's Association *Alzheimer's Disease Facts and Figures 2015*

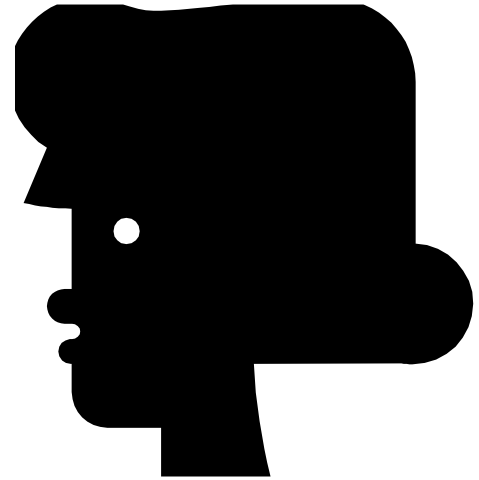
SO...



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

HSAG Podcast: Caring for the Caregiver



<https://www.youtube.com/watch?v=ErOQflfXEH4>

Family Caregiver Identification



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?**

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.



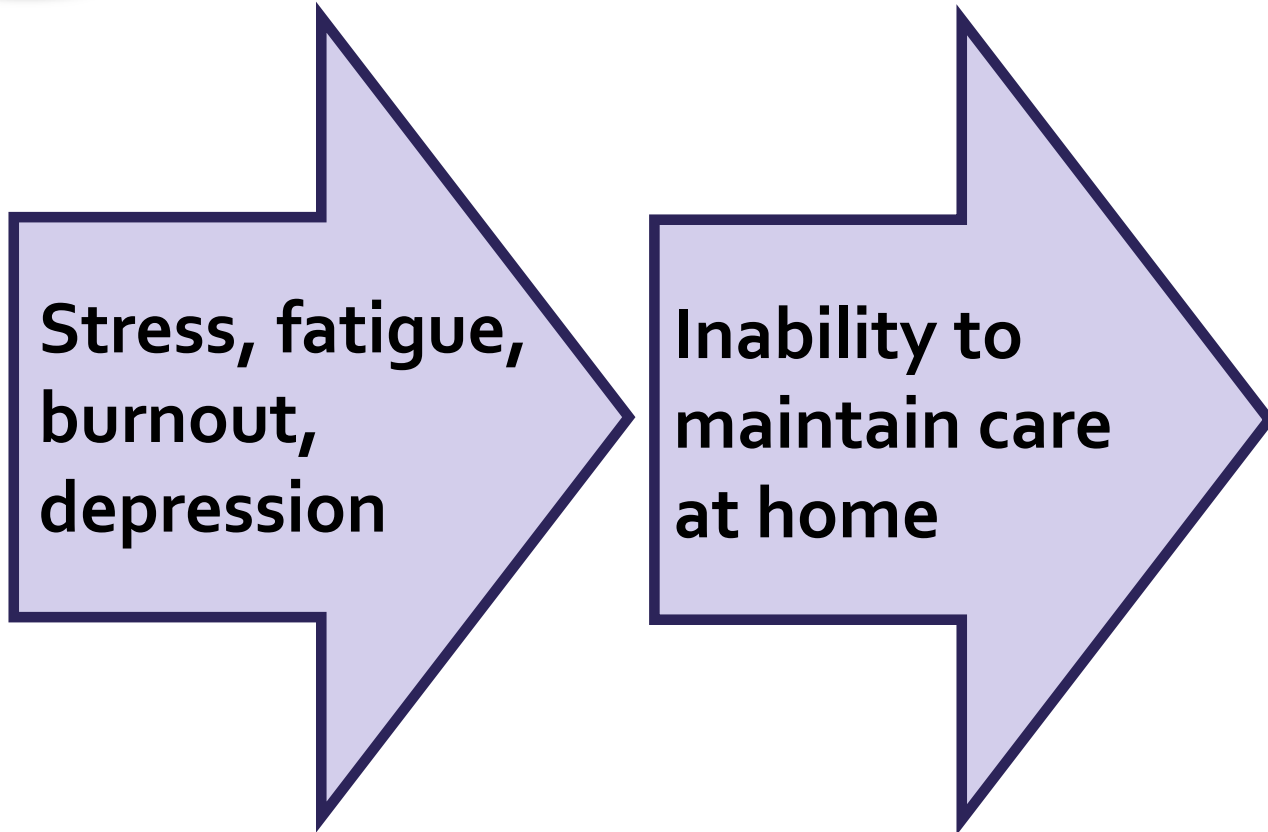
Family Caregiver Assessment



Importance of Caregiver Assessment



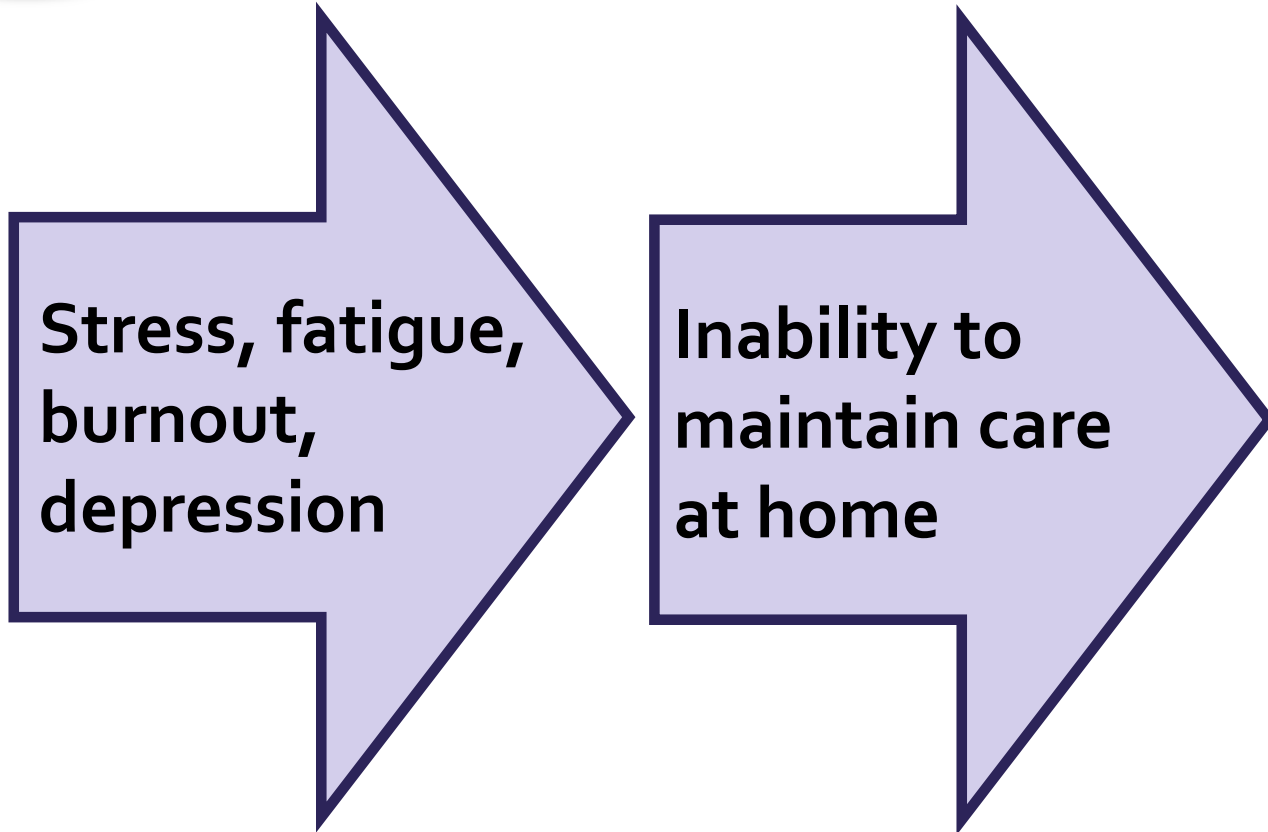
Why assess?



Importance of Caregiver Assessment



Where could intervention/mitigation occur?



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.

Caregiver Isolation, Anxiety, Depression



Able to care for someone?



Caregiver Functional/Health Limitations



Impact on:

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

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

"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 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 <input type="checkbox"/> in each row			
	Strongly agree <input type="checkbox"/>	Agree <input type="checkbox"/>	Disagree <input type="checkbox"/>	Strongly disagree <input type="checkbox"/>
<i>The answer options for the next set of questions are "Strongly agree," "Agree," "Disagree," or "Strongly disagree."</i>				
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.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2. uncertain about how to best care for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
3. that you should be doing more for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4. that you could do a better job of caring for him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 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.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
6. that your relationship with him/her was strained.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
7. that he/she made requests over and above what he/she needed.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
8. that you were resentful toward him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
9. that you were angry toward him/her.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 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.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
11. you felt downhearted, blue, or sad more often.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
12. you were more nervous or bothered by nerves than before.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
13. you had less pep or energy.	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 0
14. you were bothered more by aches and pains	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1	<input type="checkbox"/> 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 Caregiver Stress/Strain Instrument to better assess needs
- 3) Prioritize needs
- 4) Determine next steps

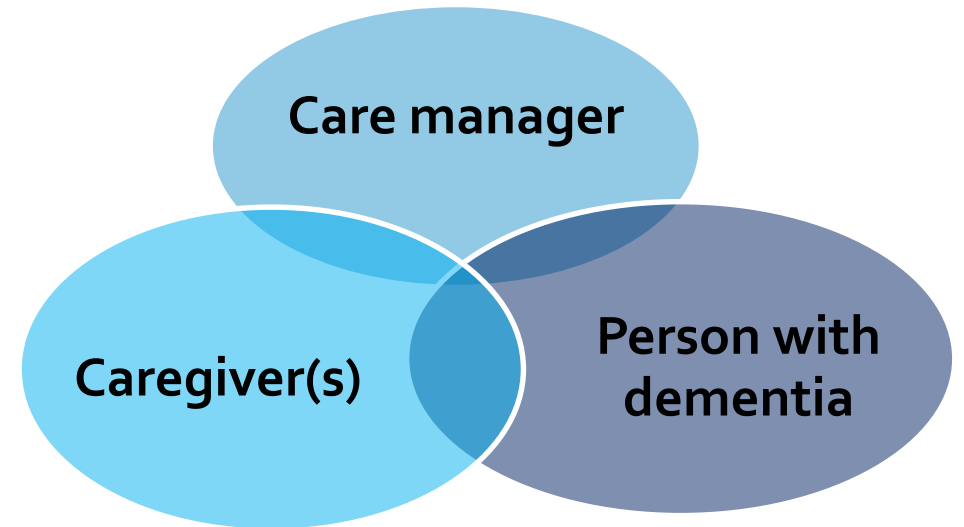


Family Caregiver Engagement



Working in Dyads/Triads

- **Partnership** between health care team, member, & caregiver(s)
- **Engaging** caregiver(s)
- **Education and support** to family caregiver(s)
- Remember to **maintain voice** of person with dementia



Caregiver Engagement



Think back to Marina and Marco's situation. How would you successfully engage Marina in care planning? What should you consider as a Dementia Care Specialist to ensure that Marina is an active participant on your team? Why might engaging Marina's daughter be helpful?



Standardized Care Plans



Why Use Standardized Care Plans?

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

Alzheimer's | GREATER LOS ANGELES

Combativeness

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

How to Use Standardized Care Plans

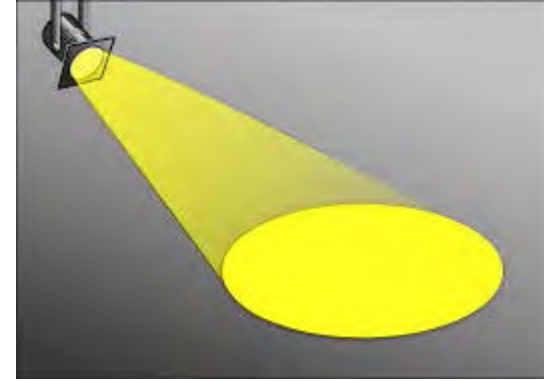
- Ideas for how to proceed
- Cues for care manager
- Action items that caregiver can choose to use
- Choices = greater control
- Collaborative
- Not prescriptive



Family-Centered Standardized Care Plans

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

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



Family-Centered Standardized Care Plans

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



Standardized Care Plans Problem Areas

Activities of Daily Living and Functional Needs:

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

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Identify the Problem

Educate Yourself

ASSESS FURTHER:

Understand the possible triggers of the problem:

- Is something causing the person to feel frustrated?
- Is the person overly tired?
- Understand 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)?
 - Are there too many unfamiliar people or places?
 - Are there too many unfamiliar people or places?
 - Are there too many unfamiliar people or places?
- Is the person experiencing side effects of a medication?
- Are there too many unfamiliar people or places?

Understand the possible meaning of the problem to the person with Alzheimer's:

- Is the person overwhelmed?
- Is the person feeling he/she is losing control?
- Does the person feel 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
 - I never liked it and I never will
 - 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?

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

Adapt

Problem solve with interventions and actions

Standardized Care Plans Problem Areas

Safety:

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

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Identify the Problem

Educate Yourself

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)?
- Are there too many unfamiliar physical stressors and irritability?
- Is the person experiencing side effects of medication?

Understand the possible meaning of the problem to the person with Alzheimer's:

- Is the person overstimulated?
- Is the person losing control?
- Is the person overwhelmed?
- Does the person feel he/she is being controlled?
- 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 don't want to do that
 - I never used it and I never will
 - 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?

TEACH PROBLEM SOLVING STRATEGIES TO CAREGIVER:

- You set the tone; try to use a calm, reassuring voice and avoid results:
 - 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 make eye contact if

Adapt

Problem solve with interventions and actions

Standardized Care Plans Problem Areas

Caregiver Needs:

- 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

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GOAL/EMPIRED OUTCOME: To reduce combativeness through non-pharmacological approaches.

Identify the Problem

Educate Yourself

ASSESS FURTHER:

Understand the possible triggers of the problem:

- Is something causing the person to feel frustrated?
- Is the person hearing 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?
- Are there too many unfamiliar physical discomfort (pain, fever, illness)?
- Are there too many unfamiliar physical discomfort (pain, fever, illness)?
- Are there too many unfamiliar physical discomfort (pain, fever, illness)?
- Are there too many unfamiliar physical discomfort (pain, fever, illness)?

Understand the possible meaning of the problem to the person with Alzheimer's:

- Is the person responding to caregiver stress and irritability?
- Is the person experiencing side effects of a medication?
- Is the person overwhelmed?
- Does the person feel he/she is losing control?
- Is the person unconfrontable?
- 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
 - I'm possible meaning of the problem to the caregiver:
- Is the caregiver feel unsafe?

Understand the possible meaning of the problem to the caregiver:

- Does the caregiver feel unsafe?

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

Adapt

Problem solve with interventions and actions

Working With Marina



Look at Marina's Care Needs Assessment and Caregiver Stress/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.



Linking to Resources/ Support



Making Referrals

- Refer for specific need and explain
- Do not overwhelm
- Consider cultural, linguistic, and economic needs



Alzheimer's Greater Los Angeles



Alzheimer's Greater Los Angeles

- Serving diverse communities
- Multi-lingual services
- Culturally competent services
- Free of charge to families


Alzheimer's Greater Los Angeles

- Website www.alzgla.org
- 24/7 Helpline 844.HELP.ALZ | 844.435.7259
- Care Counseling
- Caregiver educational classes
- Public awareness
- Early stage services
- Support groups

Alzheimer's Greater Los Angeles

- Activity programs
- MedicAlert® Found California
- Respite stipends
- Professional training
- Advocacy

ALZ Direct Connect Referral Program



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 Greater Los Angeles for:

- access to **care coordination** and **psychosocial support**
- referrals to **supportive services** (often at no cost)
- 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

coordinates care & builds supportive networks

ADDITIONAL QUESTIONS?
Contact (323) 930-6277

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

24/7 Helpline – 844.HELP.ALZ | 844.435.7259 | alagla.org

ALZ DIRECT CONNECT REFERRAL FORM

Fax or email this form to Alzheimer's Greater Los Angeles

Fax # 323.686.5106 Email alzdirectconnect@alza.org Date _____

<input type="checkbox"/> Check if primary contact PATIENT/CLIENT NAME _____ Address _____ City _____ Zip _____ Phone# _____ Email _____ Primary Language: <input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other (specify) _____	<input type="checkbox"/> Check if primary contact FAMILY CAREGIVER NAME (if available) _____ Address _____ City _____ Zip _____ Phone# _____ Email _____ Relationship to Patient/Client: <input type="checkbox"/> Spouse/Partner <input type="checkbox"/> Child <input type="checkbox"/> Professional Caregiver <input type="checkbox"/> Other (specify) _____ Primary Language: <input type="checkbox"/> English <input type="checkbox"/> Spanish <input type="checkbox"/> Other (specify) _____
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Is the patient/client on Medi-Cal AND Medicare?
 Yes No

I give permission to the referring provider to forward my contact and patient information to Alzheimer's Greater Los Angeles. I understand that a representative will contact me and/or my caregiver about support, programs, and other services and will follow up with the referring provider. Referrals will be entered into our secure database, unless indicated otherwise by checking this box .

Signature _____ Date _____
(Patient/Client or Personal Representative/Family Caregiver)

The person being referred provided verbal consent instead of signature Yes

REASON FOR REFERRAL (check all that apply)

<input type="checkbox"/> Social Work Consultation & Support	<input type="checkbox"/> Research & Clinical Trials Information
<input type="checkbox"/> Support for Newly Diagnosed	<input type="checkbox"/> Legal & Financial Considerations
<input type="checkbox"/> Support Groups	<input type="checkbox"/> Healthcare Directives
<input type="checkbox"/> Activity Programs	<input type="checkbox"/> Respite Services
<input type="checkbox"/> Safety Issues	<input type="checkbox"/> Caregiver Education
<input type="checkbox"/> Home Safety	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Driving	
<input type="checkbox"/> Wandering (MediAlert)	

Additional Information _____

REQUIRED INFORMATION

Referring Provider Name _____ Title _____

Provider Organization _____
 Healthcare organization
 Non-medical community organization

Phone # _____ Fax # _____ Email _____

How would you prefer to receive follow-up? Fax Email Follow-up unnecessary



See reverse for ALZ Direct Connect Referral

Why ALZ Direct Connect?

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





“Doctors need to prescribe services just like they prescribe medicine. After I got my diagnosis, I never knew there was any help for me, until I looked on my own.”

- Alzheimer's patient

844.HELP.ALZ | 844.435.7259

Culminating Activity



Putting It All Together: Applying Tools to Vignettes



- Divide into small groups; each group needs to have one participant with a vignette to present (vignette should include a challenging behavior)
- Present vignette to group
- Apply knowledge from training, *IDEA!*, and tools in the Dementia Care Specialist Toolkit to this vignette
- Make sure an informal or family caregiver has been identified, documented, and assessed

Putting It All Together: Applying Tools to Vignettes



- 1) What tools would you use in this vignette?
- 2) What standardized care plans would you use?
- 3) What would go into your care plan?
Remember:
 - *IDEA!*
 - Connecting families to appropriate resources
- 4) How would you ensure that care is family-centered?

Connect with us

844.HELP.ALZ | alzgla.org

24/7

