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
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?

- Cognitive & functional limitations
- Lack of diagnosis
- Behavioral symptoms
- Caregiver integrated into care coordination & care plans
- 24/7 Caregiving
- Loss of insight & decision-making capacity
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
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
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...
LIFE INVOLVES CHANGE

• Perspectives change
• Relationships change
• People change
• Experiences change
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

- 5.3 million people have Alzheimer’s
- 1/9 people age 65 and older have Alzheimer’s
- 1/3 people age 85 and older have Alzheimer’s
- 1/9 people age 65 and older have Alzheimer’s
- 15.5 million unpaid caregivers
- A new case every 67 seconds
- 6th leading cause of death

Alzheimer’s Association. 2015 Alzheimer’s Disease Facts and Figures. Alzheimer’s & Dementia, 2015;11(3)332+

Slide courtesy of Cordula Dick-Muehlke, PhD
HSAG Podcast: Dementia: The Basics

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

Health Services Advisory Group, Inc., 2014
DEMENTIA/Major Neurocognitive Disorder

- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
- Mixed dementia
- Reversible dementias

Alzheimer’s disease
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
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

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

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
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

Alzheimer’s Association. The Basics.
Explain to the member if his/her statement is a myth or fact. Explain why.
## 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.

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

Pre-clinical / pre-symptomatic stage → Early stage → Mid stage → Late stage
Domains Affected by Alzheimer’s

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

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

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

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

<table>
<thead>
<tr>
<th><strong>Member</strong></th>
<th><strong>Caregiver</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial/shame</td>
<td>Denial/shame</td>
</tr>
<tr>
<td>Unable to accurately describe symptoms</td>
<td>Masking/overcompensation</td>
</tr>
<tr>
<td>Poor historian</td>
<td>Need to rely heavily on caregiver reports</td>
</tr>
<tr>
<td>May resist exam and diagnostic work-up</td>
<td>Possible bias due to burnout/exhaustion</td>
</tr>
</tbody>
</table>
Alzheimer's Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition

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

Yes

Signs/symptoms present

No

Informant available to confirm

No

B. Conduct brief structured assessment
   - Patient Assessment: Mini-Cog or GPCOG or MIS
   - Informant assessment of patient: Short IQCODE, A8 or GPCOG

Yes

Brief assessment(s) triggers concerns:
   - Patient: Mini-Cog ≤3 or GPCOG ≤8 or MIS ≤4 or Informant: Short IQCODE ≥ 3.38 or A8 ≥ 2 or GPCOG informant score ≤3 with patient score ≤8

No

Follow-up during subsequent AWV

Yes

C. Refer OR Conduct Full Dementia Evaluation
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
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
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?
Detection

Diagnosis

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

Disease management/care planning

Diagnosis

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

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

Hospital

- Delirium
- Fall risk
- Elopement
- Dehydration risk
- Inadequate food intake

- New incontinence
- Loss of functional abilities
- Importance of family

Impact on Medical Care

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

Detection | Diagnosis

Disease management/care planning

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

Guideline for Alzheimer’s Disease Management

**Guideline for Alzheimer’s Disease Management**

**Assessment**
- Monitor changes:
  - Cognitive, behavioral, and physical changes
  - Daily functioning, including feeding, bathing, dressing, mobility, eating, and ability to manage finances and medications
  - Cognition stability or variability and rate of change
  - Memory, attention, judgment, ability to concentrate on tasks
- Original medical conditions that may present with sudden worsening or improvement; other diagnoses to consider
- Behavioral symptoms, cognitive symptoms, and depression
- Seizures, delusions, and hallucinations
- Ongoing support for safety issues, including medication management
- Need to utilize and or provide care planning

**Treatment**
- Developing a Treatment Plan: Create and implement an ongoing treatment plan with defined goals.
  - Discuss with patient and family:
    - Use of cholinesterase inhibitors, memantine, and other medications; potential side effects
    - Lifestyle modifications, diet, and nutrition
    - Regular exercise
    - Social and cognitive stimulation
  - Early diagnosis and intervention
  - Utilize caregiver support groups and assistance for ongoing support activities, such as peer groups and recreation

**Patient & Family Education & Support**
- Integrate medical care & support tailored to the needs of Alzheimer’s disease patients and their families.
  - Support groups, educational materials, and resources
  - Alzheimer’s Association
  - Alzheimer’s Caregiver Alliance
  - Other local support services

**Planning**
- Include a discussion of the importance of legal and financial planning as part of the treatment plan.

**Capacity Evaluations**
- Use a unified approach to the assessment of patient capacity, including an analysis of the patient’s history, current medical condition, and cognitive function.

**Elder Abuse**
- Monitor for evidence of elder abuse and neglect
  - Physical, emotional, and financial abuse
  - Consultation with legal and social service professionals

**Assess Capacity**
- Assess the patient’s decision-making capacity and determine whether a surrogate has been identified.

**Identify Culture & Values**
- Identify the patient’s and family’s culture, values, primary language, literacy level, and decision-making process.

**Non-Pharmacological Treatment**
- First: If non-pharmacological approaches prove unsuccessful, then use medication, tailored to specific symptoms; if clinically indicated, note that side effects may be serious and significant.
- Treat Co-Morbid Conditions: Provide appropriate treatment for co-occurring medical conditions.
- Provide Respite Care: Provide appropriate end-of-life care, including palliative care as needed.

**Discussion Stages**
- Discuss the patient’s wishes at all stages of Alzheimer’s Disease.

**Driving**
- Document the diagnosis of Alzheimer’s Disease in accordance with legal requirements.

**Alzheimer’s GREATER LOS ANGELES**
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?

Remember…
What Concerns You About this ICT?
What Looks Right About this ICT?
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

B. Williams. The Ups and Downs 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

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.*
Side Effects

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

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
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

Medications for Behavioral Expressions

• Avoid antipsychotics as first line of treatment

• Use **IDEA!**

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
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.”

Behavioral Expressions

What behavioral expressions/symptoms have you encountered?

1 Lykestos, CG. (2011) Alzheimers Dement 7; 532-539
Behavioral Expressions 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

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?
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

- Medical conditions
- Too hot or cold
- Hungry/thirsty
- Tired
- Pain
- Medication-related
1/3 of community dwelling older adults with dementia had undetected illness associated with behaviors

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

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

Contact doctor if sudden and unusual changes are present
Roger is a cheerful man who is very affectionate and has a high level of functioning. He is able to walk, go to the bathroom on his own, and eat meals that are prepared for him.
One day, Roger wakes up and is disoriented. He seems really irritated; you can see a look of anger on his face. Roger lashes out at his wife. He is also suddenly incontinent.
Understanding “Baseline”

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

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
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?
• 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?
Understanding the Meaning: Refusal to Bathe Video

What does bathing mean to mother?

<table>
<thead>
<tr>
<th>Adaptation used by daughter</th>
<th>How adaptation addresses meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter asks mom to help undress</td>
<td></td>
</tr>
<tr>
<td>Daughter asks mom to test the water temperature</td>
<td></td>
</tr>
<tr>
<td>Daughter asks mom to “wash down there” by herself</td>
<td></td>
</tr>
</tbody>
</table>
Strategies Not Solutions

Always pay attention to the person’s feelings
Adapt

Understand what can be changed

Set the tone

Stay calm

Do not demand

Try different things; no one size fits all
Adapt: 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
Adapt: 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
Components that determine impact of communication:

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

Adapt: Communication and Connection Strategies

A
dapt: 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

- Use of space
- Personal space
- Use of silence
- Eye contact
- Cultural responses to emotions
- Cultural interpretations of social issues
- Non-verbal 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
Adapt: 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
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!

**ID**entify Behaviors
- Identify problems

**E**ducate Yourself
- Understand the causes/triggers
- Understand the meaning

**A**dapt
- Problem solve
UCLA Health: Wandering

https://www.youtube.com/watch?v=SwoyEB5o8mI

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
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.

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

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

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

(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 caregivers adapted from United Hospital Fund "Most Impact on Care: Assessing Family Caregivers," 2003.
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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?

Stress, fatigue, burnout, depression

Inability to maintain care at home

Hospitalization/nursing home placement
Importance of Caregiver Assessment

Where could intervention/mitigation occur?

- 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

Able to care for someone?

Caregiver Isolation, Anxiety, Depression
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
# Alzheimer's Greater Los Angeles

## 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.*

<table>
<thead>
<tr>
<th>Challenging Behaviors &amp; ADLs and Functional Needs</th>
<th>Has it happened in the past month?</th>
<th>How much does this bother the caregiver?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep disturbances (waking you or other family members up at night)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Repetitions (doing or saying things over and over)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Sadness and/or depression (feeling blue)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Grooming difficulties (dressing, bathing, feeding, etc.)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Hallucinations (seeing or hearing things that are not there)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Sundowning (more confused/excessive in late afternoon/early evening)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Suggestiveness/passiveness (preening/blaming)</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Screaming and making noises</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td>Disinhibitions (removal of normal behaviors or inappropriate behaviors)</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>

### ACTIVITIES OF DAILY LIVING AND FUNCTIONAL NEEDS

<table>
<thead>
<tr>
<th>Activities of Daily Living and Functional Needs</th>
<th>Has the caregiver experienced this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe difficulty bathing or showering</td>
<td>NO</td>
</tr>
<tr>
<td>Difficulty with dressing and grooming (dressing, hygiene, toilet, etc.)</td>
<td>NO</td>
</tr>
<tr>
<td>Difficulty with eating (including chewing, swallowing, dental concerns)</td>
<td>NO</td>
</tr>
<tr>
<td>Difficulty using the toilet (incontinence, wetting, accidents)</td>
<td>NO</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Safety &amp; Caregiver Needs</th>
<th>Has the caregiver experienced this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home safety concerns (falls, guns, knives, stove, leaving the person alone)</td>
<td>NO</td>
</tr>
<tr>
<td>Frustrates</td>
<td>NO</td>
</tr>
<tr>
<td>Takes medicine the wrong way</td>
<td>NO</td>
</tr>
<tr>
<td>Wandering</td>
<td>NO</td>
</tr>
</tbody>
</table>

### SAFETY

<table>
<thead>
<tr>
<th>Caregiver Needs</th>
<th>Has the caregiver experienced this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression/stress (feeling blue and/or overwhelmed)</td>
<td>NO</td>
</tr>
<tr>
<td>Difficulty providing care because of your health</td>
<td>NO</td>
</tr>
<tr>
<td>Lacks understanding of dementia</td>
<td>NO</td>
</tr>
<tr>
<td>Legal and financial planning (paying the bills, power of attorney, etc.)</td>
<td>NO</td>
</tr>
<tr>
<td>Long term care planning</td>
<td>NO</td>
</tr>
<tr>
<td>End-of-life planning</td>
<td>NO</td>
</tr>
</tbody>
</table>

*Note: The person's level of care, and what helps or hinders them is important. In order to provide the best care, it is important to know their current level of function and what helps them best. The tool is designed to help you assess the person's current level of function and identify areas where support is needed.*
Benjamin Rose Institute Caregiver Strain Instrument

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.

<table>
<thead>
<tr>
<th>The answer options for the next set of questions are</th>
<th>Mark one box in each row</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly agree</td>
<td>Agree</td>
</tr>
</tbody>
</table>

### 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.
2. uncertain about how to best care for him/her
3. that you should be doing more for him/her
4. that you could do a better job of caring for him/her

**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
6. that your relationship with him/her was strained
7. that he/she made requests over and above what he/she needed
8. that you were resentful toward him/her
9. that you were angry toward him/her.

**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.
11. you felt downhearted, blue, or sad more often.
12. you were more nervous or bothered by nerves than before.
13. you had less pep or energy
14. you were bothered more by aches and pains.

**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
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
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
Challenging Behaviors:
• Combativeness
• Hallucinations
• Repetition
• Sadness or Depression
• Sleep Disturbances
• Sundowning
• Suspiciousness/Paranoia
• Screaming and Making Noises
• Disinhibition
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
Standardized Care Plans Problem Areas

Safety:
• Home Safety Concerns
• Insists on Driving
• Takes Medicine the Wrong Way
• Wanders/Gets Lost
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
Components of Standardized Care Plans

- **ID**entify the problem, goal, expected outcome
- Assess further
- **E**ducate on triggers and meaning
- Provide problem-solving strategies (A**A**daptations)
- Clinical support needs
- Caregiver support and community resources
- Follow up
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.
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
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
“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
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24/7