Dementia Care Manager Training
Effectively Working with Patients and Families to Improve Care

Jennifer Schlesinger, MPH, CHES
Director, Professional Training & Healthcare Services
Dementia Cal MediConnect Project
A new case every 67 seconds.

California Coordinated Care Initiative

Cal MediConnect Dual Demonstration

Dementia Cal MediConnect Project

Dementia Capable System of Care

Improve quality of care for people with dementia & family caregivers

Three-way contract
Why Dementia Cal MediConnect Project?

Public health crisis

- Increasing numbers
- Familial impact
- Dual eligible beneficiaries with dementia drive cost of care

Importance of project

- Success of CMC health plans depends on dementia-capable system
- Dementia care management improves care & health outcomes
- Potential for cost savings
Supporters of the Dementia Cal MediConnect Project

- Administration on Aging (funder)
- California Department of Aging
- California Department of Health Care Services
- Alzheimer’s Greater Los Angeles
- Alzheimer’s Association Northern California & Northern Nevada
- Alzheimer’s San Diego
- UCSF Institute on Health and Aging
- Health plans & medical directors
Dementia Cal MediConnect Project

Alzheimer’s organizations are partnering with health plans to provide:

• Care manager training and support
• Caregiver education and respite
• Support services through referrals
• Technical assistance
Learning Objectives
At the conclusion of this training, you will:

- Increase **understanding of Alzheimer’s disease** and related dementias (ADRD) and their symptoms
- Increase knowledge of **effective management of the cognitive and behavioral symptoms**
- Increase ability to **manage care** for people with ADRD
- Demonstrate ability to make appropriate **referrals** to home and community based services (HCBS)
- Increase **self-efficacy** in developing and implementing **care plans** for patients with ADRD and their caregivers
Cross the Line Ice-Breaker

Instructions

• Stand on one side of the room
• For each statement that is read, cross to the other side of the room if your answer is “yes”
• If your answer is “no,” stay where you are
• During the activity, look around to see where your colleagues are standing
PART I
Fundamentals of Cognitive Impairment, Dementia, and Alzheimer’s Disease
Introduction
Video: Alzheimer’s Disease Facts and Figures 2014

https://www.youtube.com/watch?v=waeuks1-3Z4

Courtesy of the Alzheimer’s Association
Alzheimer’s Disease in the USA 2015

1/9 people age 65 and older have Alzheimer’s

1/3 people age 85 and older have Alzheimer’s

5.3 million people have Alzheimer’s

15.5 million unpaid caregivers

6th leading cause of death

1 new case every 67 seconds

Slide courtesy of Cordula Dick-Muehlke, PhD

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

- Most expensive condition in the nation
- In 2015, it cost an estimated $226 billion to care for those with Alzheimer’s
- By 2015, Alzheimer’s may cost as much as $1.1 trillion

Alzheimer’s & Dementia, 2015;11(3)332+
Implications for Health Care

• Nearly **one in every five dollars** spent by Medicare is on people with ADRD

• Average per-person **Medicare** spending for those with ADRD is **three times higher** than for those without these conditions

• The average per-person **Medicaid** spending for seniors with ADRD is **19 times higher** than average per-person Medicaid spending for all other seniors
Implications for Health Care

Given the enormous burden of dementia on our healthcare system, why are care managers critical for effective dementia care planning and management?
Age-Related Memory Loss
Alzheimer’s is **not** a normal part of aging

Typical age-related changes can include:

- Missing a monthly payment
- Losing things from time to time
- Sometimes forgetting a word
- Making a bad decision once in a while
- Forgetting the day and remembering it later
Early Signs of Alzheimer’s Disease

- Repeating the same question or story over and over again
- Forgetting how to do activities that were previously routine
- Losing the ability to handle money or balance a checkbook
- Getting lost in familiar places or misplacing household objects
- Neglecting to bathe or wearing the same clothes over and over again
- Relying on someone else, such as a spouse, to make decisions or answer questions that were previously handled independently

## Activity: Normal Aging vs. Warning Signs of Alzheimer’s Disease

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

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Possible Warning Sign of Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making a bad decision once in a while</td>
<td></td>
</tr>
<tr>
<td>Missing a monthly payment</td>
<td></td>
</tr>
<tr>
<td>Forgetting which day it is and remembering it later</td>
<td></td>
</tr>
<tr>
<td>Sometimes forgetting which word to use</td>
<td></td>
</tr>
<tr>
<td>Losing things from time to time</td>
<td></td>
</tr>
<tr>
<td>Forgetting someone’s name and then recalling it</td>
<td></td>
</tr>
<tr>
<td>Not feeling like going to dinner with friends because you feel tired</td>
<td></td>
</tr>
</tbody>
</table>
Dementia
Stigma and Labeling

- Wanderer
- Crazy
- Burden
- Incompetent
- Always Sad
- Difficult
- Already Gone
- Empty Shell
- Violent/Aggressive
- Lost Self

Alzheimer's Greater Los Angeles
The Many Faces of Dementia: Moving Beyond Stereotypes

- Empty shell
- Disease of the “old”
- Dead already
- Lost self
- Crazy
- Unaware
- Burden
The Many Faces of Dementia: Moving Beyond Stereotypes

Abilities

Preferences

Strengths

Unique

Values

Strong opinions

Alzheimer's GREATER LOS ANGELES
Video: The Unspoken Impact of Dementia

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

Major Neurocognitive Disorder DSM-5

• Previously known as dementia
• Significant **cognitive decline from a previous level of performance** in one or more cognitive domains such as:
  • complex attention
  • executive function
  • learning & memory
  • language
  • perceptual–motor
  • social cognition
• Cognitive deficits **interfere with independence in everyday activities**
Alzheimer’s disease

Dementia with Lewy bodies

Vascular dementia

Frontotemporal dementia

Mixed dementia

Reversible dementias

Alzheimer’s disease
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
What is Mixed Dementia?

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

- Depression, delirium
- Emotional disorders
- Metabolic disorders (i.e. hypothyroidism)
- Eye and ear impairments
- Nutritional (i.e. B12 deficiency)
- Tumors
- Infections
- Alcohol, drugs, medical interactions
Alzheimer’s Disease
Did You Know?

Not everyone with dementia has Alzheimer’s disease

**BUT**

All people diagnosed with Alzheimer’s disease have a form of dementia
Activity: Through the Eyes, Head, and Heart of a Person with Alzheimer’s

<table>
<thead>
<tr>
<th>4 favorite memories</th>
<th>3 most important people in your life</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 things you love to do</td>
<td>1 hope for your future</td>
</tr>
</tbody>
</table>
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
Healthy Brain vs. Brain with Alzheimer’s

Image appears courtesy of Dr. Richard E. Powers,
Director of the Alabama Bureau of Geriatric Psychiatry, alzbrain.org
Healthy Brain
Alzheimer’s Brain
Video: What is Alzheimer’s Disease?

https://www.youtube.com/watch?v=gWvgjrk-gXc

Courtesy of the Alzheimer’s Association
Disease Progression
Alzheimer’s Disease Progression

Mild Cognitive Impairment

Pre-clinical/pre-symptomatic stage

From 4-20 years, 8 years average

ALZHEIMER’S DISEASE CONTINUUM

Early stage/mild

Middle stage/moderate

Late stage/severe

Death (pneumonia and/or co-morbidities)

Slide courtesy of Cordula Dick-Muehlke, PhD
Early Stage Alzheimer’s Disease

- Insight into disease
- Many losses being experienced
- Depression
- Ability to make decisions/plan ahead
Early Stage Alzheimer’s Disease

• Problems with memory and concentration
• Trouble finding the “right word” and/or remembering names
• Misplacing things
• Trouble organizing & planning (getting lost)
“You Don’t Look Like You Have Alzheimer’s”

#ENDALZ, Advocacy, Voices of Alzheimer’s, Women & Minorities
March 11, 2014

What exactly does someone with Alzheimer’s “look like?” What should I look like? Should I be unresponsive to my surroundings and bed-bound in a nursing home? Should I be incoherent and confused about where I am?

Understand that I was treated with the utmost respect and kindness by everyone in the emergency room, both before and after I told them I had Alzheimer’s disease. They even took an extra step to show me to my taxi back home so that I didn’t get lost along the way. My experience was a positive one – but it is a telling example of how deep stigma runs with this disease.

The fact that even health professionals – who should know more about this disease process than the average person – were surprised by seeing someone with Alzheimer’s who is vibrant, energetic and articulate speaks volumes.

I hope medical professionals at all levels make an effort to better understand what Alzheimer’s disease “looks like.” I hope that people in the early stages of Alzheimer’s share their diagnosis with more people. This disease may be fatal, but it doesn’t start with bed bound patients and utter confusion. It starts with people like me, who have a face, name, opinion and fulfilling life.
Middle Stage Alzheimer’s Disease

- Memory & thinking problems more obvious
- Difficulty with communication
- Nonverbal communication retained
- Behavioral symptoms
- Greater assistance needed with day-to-day activities
- More caregiver involvement
Middle Stage Alzheimer’s Disease

• Retention of social skills
  • Reports that everything is “fine”
  • Reports ability to bathe, cook, take medications, etc.
• Retention of nonverbal communication
• Appears to be healthy to outsiders and to medical professionals
Video: HBO Documentary: The Alzheimer’s Project

http://www.hbo.com/alzheimers/the-films.html
[Show a short clip related to mid-stage Alzheimer’s disease]
Late Stage Alzheimer’s Disease

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

• You will receive a card that has a description on it
• Find the stage of Alzheimer’s that best corresponds to the description
• Everyone will line up in the order that best represents the progression of the disease
• Feel free to talk to your colleagues and discuss
• In some cases, there is no “right” or “wrong” answer
Risk Factors
“Something’s just not right—our air is clean, our water is pure, we all get plenty of exercise, everything we eat is organic and free-range, and yet nobody lives past thirty.”
Major Risk Factors for Alzheimer’s Disease

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

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

Alzheimer’s Association, 2014 Alzheimer’s Disease Facts and Figures, Alzheimer’s & Dementia, Volume 10, Issue 2
Screening and Diagnosis
“Off hand, I'd say you're suffering from an arrow through your head, but just to play it safe, I'm ordering a bunch of tests.”
Alzheimer’s Association Medicare Annual Wellness Visit Algorithm for Assessment of Cognition

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

[Decision Point]

Yes

Signs/symptoms present

No

Informant available to confirm

[Decision Point]

Yes

B. Conduct brief structured assessment

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

[Decision Point]

Brief assessment(s) triggers concerns:
Patient: Mini-Cog ≤3 or GPCOG <8 or MISO ≤4, or
Informant: Short IQCODE ≥ 3.38 or AD8 ≥ 2 or
GPCOG informant score ≤3 with patient score <8

[Decision Point]

Yes

Follow up during subsequent AWV

No

[Decision Point]

No

C. Refer OR Conduct Full Dementia Evaluation

Document can be found in Care Manager Manual page 13
Assessment: AD8 Screening Tool

• Validated screening tool
• Use with patient or “informant”
• Introduce screening:
  “I am going to ask you some questions to help better plan for your care/your relative’s care.”
• Administer screening
<table>
<thead>
<tr>
<th>Remember, “Yes, a change” indicates that there has been a change in the last several years caused by cognitive (thinking and memory) problems.</th>
<th>YES, A change</th>
<th>NO, No change</th>
<th>N/A, Don’t know</th>
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<td></td>
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</table>

**TOTAL A8D SCORE**
Assessment: AD8 Screening Tool

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

• In addition to AD8, ask patient and/or caregiver, “has a doctor or other healthcare professional ever said that you have or think the person has Alzheimer’s disease or some other form of dementia?”

• Make referral to primary care provider for diagnostic workup
## Activity: Practical Application of the AD8

### AD8 Dementia Screening Interview

<table>
<thead>
<tr>
<th>Question</th>
<th>YES, A change</th>
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Patent ID#: __________  
CS ID#: __________  
Date: __________
Alzheimer’s Evaluation

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

• Treatment should be individualized
• Cholinesterase inhibitors:
  • Donepezil (Aricept®)
  • Rivastigmine (Exelon®)
  • Galantamine (Razadyne®)
• NMDA receptor antagonist (glutamate regulator) for moderate to severe symptoms:
  • Memantine (Namenda®)
PART II
Practical Dementia Care Management
The Unique Role of Care Managers in Dementia Care Management
Care Manager Role

Care manager

Patient and family caregiver

Healthcare team
What Makes Dementia Care Management Unique?
What Makes Dementia Care Management Unique?

- Care manager teaches caregiver how to manage challenging behaviors
- May or may not have a diagnosis of ADRD
- Care manager works with family to educate and support
- Robust role of caregiver and care manager
- Need to integrate caregiver into care plan
Engaging Caregivers
Working in Dyads/Triads

- **Identify caregiver(s)**
- **Partnership** between health care team, patient, & caregiver(s)
- **Education and support** to family caregiver(s)
- **Maintain voice** of person with dementia
Importance of Caregivers

• Knowledge of disease
• Management of challenging behaviors
• Ability to recognize medical issues/conditions
• Minimize caregiver stress, fatigue, burnout, depression
• Engagement of caregiver as part of team
• Key to information/feedback

Caregiver skill to manage disease

• Management of medical conditions in outpatient setting
• Decrease in unnecessary hospitalizations / readmissions
• Decrease/delay institutionalization
• Increase quality of life
Management of Alzheimer’s Disease and Related Dementias
Guideline for Alzheimer’s Disease Management

**Assessment**

**Monitor Changes**
Conduct and document an assessment and monitor changes in:
- Daily functioning, including eating, bathing, dressing, mobility, toileting, continence, and ability to manage finances and medications
- Cognitive status using a reliable and valid instrument
- Comorbid medical conditions which may present with similar symptoms to dementia

**Reassess Frequency**
Reassessment should occur at least every 6 months, and sooner if changes in behavior or functional status occur.

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

**Identify Support**
Identify the primary caregiver and assess the capability of family and other support systems, paying particular attention to caregiver’s own mental and physical health.

**Develop Treatment Plan**
Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family:
- Use of cholinesterase inhibitors, NMDA receptor antagonists, and other medications, if clinically indicated, to treat cognitive symptoms
- Referral to early-stage support groups or adult day services for appropriate structured activity, such as physical exercise and recreation

**Treat Behavioral Symptoms**
Treat behavioral symptoms and mood disorders using:
- 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 wander

**Non-Pharmacological Treatment First**
If non-pharmacologic approaches prove unsuccessful, then use medications targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.

**Treat Co-Morbid Conditions**
Provide appropriate treatment for co-morbid medical conditions.

**Provide End-of-Life Care**
Provide appropriate end-of-life care, including palliative care as needed.

**Patient & Family Education & Support**
Integrate medical care and support for caregivers 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:**
- Alzheimer’s Association
  (800) 873-3333  www.alz.org
- Family Caregiver Alliance
  (800) 445-8880  www caregiving.org

**Dissect Diagnose & Treat**
Diagnose the disease, 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.

**Involves Early-Stage Patients**
Pay particular attention to the special needs of early-stage patients, involving them in care planning, hearing their opinions and wishes, and referring them to community resources.

**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.

**Discuss End-of-Life Decisions**
Discuss the intensification of care and other end-of-life care decisions with the Alzheimer’s Disease patient and involved family members while respecting their cultural preferences.
Assessment: Assess and Reassess

- Cognitive function
- Behavior change
- Activities of daily living
- Assess capacity
- Caregiver report and **stress check**
- Consider culture and values
Treatment

• Develop treatment plan
• Treat and manage behavioral symptoms
  • Non-pharmacological approaches first
  • Referral to primary care provider for potential medication management
• Treat co-existing conditions
• Provide end-of-life care
Patient and Family Education and Support

• Integrate medical care and support services
  • Referrals
  • Social systems (family and friends)
• Discuss diagnosis, disease progression, treatment, and end of life decisions
• Planning needs
• Involve early stage patients
Legal Considerations

• Legal/financial planning
• Healthcare directives
• Physician Orders for Life Sustaining Treatment (POLST)
• Capacity evaluation
• Elder abuse reporting
• Driving
Two years ago, at the age of 69, I was diagnosed with Alzheimer’s disease. Shortly after receiving the diagnosis, I began to think a lot about the future. The more I thought about the future, the more I realized that I needed to implement plans for the inevitable progression of the disease while I had the ability to do so. This also seemed much more proactive than just sitting around worrying about having Alzheimer’s.
Mandatory Reporting: Elder Abuse & Driving
Elder Abuse

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

Who are Mandated Reporters?

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

Health practitioners are mandated reporters of elder abuse.
What Must Be Reported?

Abandonment

Isolation

Neglect

Physical abuse

Financial abuse

Abduction

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

Welfare and Institutions Code Section 15630-15632
Why Report Elder Abuse?

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

*Welfare and Institutions Code Section 15630-15632*
In California, physicians and surgeons are required to report a patient with Alzheimer’s disease and dementia to the local health officer, in writing. Reports must include the name of the patient, date of birth, and address.

See Care Manager Manual pages 55-59 for more information
Video: HBO: The Alzheimer’s Project

http://www.hbo.com/alzheimers/the-films.html

[Show a short clip related to driving]
Medication Management
“Time for your morning medication... and I understand you haven’t been eating very much.”
Alzheimer’s Considerations

• As disease progresses, cannot rely on person to take medications
• Caregiver supervision & assistance necessary for medication administration and management
• Do not leave medications unattended

Medication Fact Sheet available in Care Manager Manual page 62

Keep medications out of reach; lock up for safety
Alzheimer’s Considerations

• Sudden and unusual changes in cognition or behavior can be a sign of an adverse reaction

• Watch for medication reactions or interactions

• Refusing to take medications complicates medication management
Co-Existing Conditions
"I would go to the doctor, but I can't afford to take on any new conditions at this time."
Monitoring & Managing Co-Existing Conditions

• **Loss of cognitive ability** to understand multiple conditions and disease management
• Caregiver must **learn techniques** to manage co-existing conditions
• Consideration for **care and treatment preferences**
Anonymous  
August 12, 2014  
“...I would have done just about anything to prolong my grandma’s life; however, when you know someone has a terminal illness, you ask yourself if certain procedures are necessary anymore.  
My grandma resisted medical interventions when she was well, so I doubted she would have wanted a colonoscopy at mid-stage Alzheimer’s to see if she had colorectal cancer. Seriously, how would I, her caregiver, have even been able to get her to drink the Colyte? It’s hardly palatable when you know why you need to drink it. And the subsequent diarrhea? She could hardly wipe herself after regular bowel movements. It’s not like she had the cognitive ability to understand all of this nor did she have the functional abilities to manage it. And, if she had been diagnosed with cancer, then what?”
<table>
<thead>
<tr>
<th>Congestive heart failure</th>
<th>Challenge of Alzheimer’s disease</th>
<th>Potential adaptation strategies for caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking diuretic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compression stockings</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Safety
Safety Considerations

• Home safety
• Never leave person home alone
• Wandering
• Driving
Video: The Alzheimer's Caregiver-Janice Crenwelge on Her Husband's Wandering

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

The Alzheimer’s Caregiver, 2014
Medic Alert®

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

See Care Manager Manual page 52 for more information
Assessing Home Environment

- Medications
- Hazards
- Weapons
- Fire
Alzheimer’s Home Safety

Instructions:
Use the Home Safety Assessment on page 47 of the Care Manager Manual to complete the Alzheimer’s Home Safety worksheet.
Behavioral Symptoms
What are Behavioral Symptoms?

Expressions of the disease

EXAMPLES may include:

• Agitation
• Aggression
• Wandering
• Hallucinations

• Paranoia
• Disinhibition
• Sundowning

Alzheimer's | GREATER LOS ANGELES
Behavioral Symptoms are NOT

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

- Teach caregivers to stop and remember disease process
- Remind caregivers to STOP before they react
“It sort of makes you stop and think, doesn’t it.”
Effectively Managing Challenging Behaviors Will Require You to Be a Detective

- What is the person communicating?
- Why are they communicating this?
- Is something wrong?
- What does the person want or need?

No pipe needed - Sherlock Holmes - it’s not good for your heart or brain!
**IDEA!**

**IDentify Behaviors**
- Identify problems

**Educate Yourself**
- Understand the causes/triggers
- Understand the meaning

**Adapt**
- Problem solve

See Care Manager Manual page 22 for more information
Identify Behaviors/Problems

• What is the *specific* difficult/challenging behavior?
• Is it observable?
• Is it measurable?
• Can others see it?
What is *causing* this behavior?

- Health issues
- Psycho-social needs
- Environmental issues
- Task-related
- Communication difficulty
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.
Examples of sudden and unusual changes that caregivers should look for:

- 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.
Educate Yourself: Understand the Health/Physical Triggers

Sudden & unusual changes can be caused by:

- Delirium
- Infection
- Fever
- Dehydration
- Malnutrition
- Constipation
- Fatigue
- Pain
- Medication reactions/interactions
- Sensory deficits (vision/hearing)
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

Educate Yourself: Understand the Psycho-Social Triggers

- Socialization/interactions
- Emotional needs
  - Comfort
  - Security
  - Belonging
  - Purpose
Educate Yourself: Understand the Environmental Triggers

- Change in environment, routine, and/or staffing
- Clutter/crowding
- Noise
- Temperature
- Distractions
- Lighting
- Unfamiliar
How Would You Feel if…

• You were cold and did not have a way to tell someone you wanted a jacket?

• You were being forced to take a shower in a cold bathroom?

• You looked in the mirror, did not recognize yourself, and thought that there was a stranger in the room?
Educate Yourself: Understand the Task Triggers

- Too complicated
- Too many steps
- Unfamiliar
Educate Yourself: Understand the Communication Triggers

- Is it hard for the person to understand?
- Is it hard for the person to speak?
Educate Yourself: Understand the Meaning

• What does this behavior mean to the person exhibiting it?
• What does the behavior mean to the caregiver?
• Is this behavior distressing to the caregiver?

Consider: Who is this a “problem” for?
What Does it Mean When...???

• What does it mean when someone says, “I want to go home”?
• What does “home” mean?
• How does the person feel when the caregiver says, “But mom, you are home.”
• What would be a better response to teach the caregiver?
Strategies, Not Solutions

Always pay attention to the person’s feelings
Adapt

• Try different things
• No one size fits all
• Caregiver can change; not the person with the disease
• Caregiver sets the tone/stay calm
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
Adapt: Communication Strategies: Early Stage

• Do not ignore the person or his/her opinions
• Keep person involved
• Do not argue/correct
• Do not remind person that he/she forgot
Adapt: Communication Strategies: Middle Stage

• Allow time for responses
• Engage person one-on-one in space without distractions
• Avoid criticizing, correcting, or arguing
• Repeat what is said to clarify thoughts
Adapt: Communication Strategies: Middle Stage

• Do not overwhelm with lengthy requests or instructions
• Ask one question at a time
• Avoid open ended questions
• Use a gentle and calm tone
Adapt: Communication Strategies: Late Stage

- Do not talk about person as if he/she is not there
- Approach from front & identify yourself
- Encourage nonverbal communication
- Gentle and calm tone of voice
- Look for feelings behind words or sounds
- Use touch, sight, sounds, smells, & tastes
Fact Sheets

Anger, Frustration & Fighting

People with Alzheimer’s or dementia can get confused, depressed, and angry. Their feelings and actions are sometimes hard for them to control. They may hit and yell. Don’t take their words or actions personally. Listen to what they mean, not what they are saying.

WHAT CAN YOU DO?

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

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

Be Safe
- remove or lock away all weapons (guns, knives, etc.)
- keep away from the behavior if it is scary
- call 911 if you are afraid for you or someone else’s safety

FACT SHEETS

Fact Sheets on challenging behaviors located throughout Care Manager Manual

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

**IDentify behaviors**

Wandering

Asking for daughter
Educate Yourself:
Understand the cause/trigger of the behavior

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

**Educate Yourself:**
Understand the meaning of the behavior

Dad is anxious; responsibility as a parent
Using IDEA!

Adapt

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

• Older adults with dementia are more vulnerable to adverse reactions when pharmacological approaches are used

• Pharmacological approaches are NOT shown to be more effective than behavioral approaches

• Educate caregivers in IDEA!

Moving Away from Pharmacologic Treatments

Adverse reactions can include:

• Falls
• Hip fractures
• Delirium
• Diminished quality of life
• Increase in mortality

Non-Pharmacological Alternatives

- Caregiver education
- Exercise
- Meaningful activities
- Community-Based Adult Services (CBAS) provides opportunity for interaction, recreation, and stimulation
Non-Pharmacological Alternatives

- Nighttime routines/sleep hygiene
- Toileting schedule
- Playing soothing music
Reducing Avoidable Hospitalizations and Readmissions
Video: CNN Study: Hospitals Dangerous for Alzheimer’s Patients

https://www.youtube.com/watch?v=5AhWII27lm4

CNN, 2012
Risks Associated with Hospitalizations

Hospitalizations of elderly with dementia increase:

- Subsequent cognitive decline\textsuperscript{1,2}
- Iatrogenic complications\textsuperscript{1}
- Risk of delirium\textsuperscript{1}
- Functional decline\textsuperscript{1}
- Risk for institutionalization\textsuperscript{2}
- Risk for death\textsuperscript{2}

\textsuperscript{1} Phelan, EA, et al. (2012). \textit{JAMA}, 307(2), 165-172
\textsuperscript{2} Fong TG, et al. (2012). \textit{Ann Intern Med}, 156(12), 848-856
Reasons for Hospitalizations

Physical
(top reasons: pneumonia, congestive heart failure, UTI, syncope, fall, trauma)

Mental
(i.e. delirium, psychoses)

Behavioral
(i.e. agitation, wandering)

Environmental
(i.e. changes in routine and environment, changes in living situations/caregiver variability)

Physical (top reasons: pneumonia, congestive heart failure, UTI, syncope, fall, trauma)

Case Study: Using a Care Log to Determine Medical Needs

USING A CARE LOG TO DETERMINE MEDICAL NEEDS

Jessica is LuAnne’s youngest daughter. LuAnne was diagnosed with Alzheimer’s disease four years ago and she is in the middle stage of the disease. A paid caregiver lives with LuAnne, but Jessica visits her mother at least once or twice a week.

Before Jessica hired LuAnne’s caregiver, she spoke to a care counselor with Alzheimer’s Greater Los Angeles about tips for hiring in-home caregivers. She decided that she wanted the caregiver to keep a care log so she could track any changes in her mother’s health status, memory, mood, and/or behaviors.

Last week, Jessica was reviewing her mom’s care log.

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00am</td>
<td>Jotted up/off bed, Alzheimer’s day</td>
</tr>
<tr>
<td>9:00am</td>
<td>Got up to go to the bathroom. Alzheimer’s day</td>
</tr>
<tr>
<td>10:00am</td>
<td>Alzheimer’s day, going to bathroom every 4 hours</td>
</tr>
<tr>
<td>11:00am</td>
<td>Did not really eat breakfast</td>
</tr>
<tr>
<td>12:00pm</td>
<td>Light lunch - refused to eat. Alzheimer’s day</td>
</tr>
<tr>
<td>1:00pm</td>
<td>Increased wandering - looking for bathroom, Confused</td>
</tr>
<tr>
<td>2:00pm</td>
<td>Continued using phone, going to bathroom. Alzheimer’s day</td>
</tr>
<tr>
<td>3:00pm</td>
<td>Did not sleep well</td>
</tr>
</tbody>
</table>

Go over the care log and determine how you would instruct LuAnne’s caregiver and/or Jessica.

Explain your rationale.

What suggestions might you give to this family for the future?
Reducing Hospitalizations and Readmissions

• Proactive assessment/early detection of acute illness
  • Teach caregivers about sudden and unusual changes and recognizing baseline
• Effective management of co-existing conditions
• Teach caregivers how to use IDEA!
• Support and education to caregivers
  • Minimize risk of elder abuse

PART III
Caring for the Family
Diversity Considerations
Cultural Perspectives of Alzheimer’s

Views of aging

• Dementia = normal
• Aging to be managed within the family (not to be shared with outsiders)
Cultural Perspectives of Alzheimer’s

Views of Alzheimer’s

• Mental disease (not physical)
• Stigma/shame
• Dementia terminology/labeling person as having dementia
• Diagnosis may be seen as shaming family for doing something wrong/causing disease
Family roles

- Caregiving = family responsibility
- Shameful to admit that caregiving is demanding
- Filial roles/responsibilities
- Caregiver vs. decision-making
- Person lives with family
Use of formal healthcare services

- Delayed diagnosis
- Lack of early treatment for cognitive symptoms
- Prolonged caregiver “burden”
- Delay in using formal services until completely overwhelmed
Cultural Perspectives of Alzheimer’s

Linguistic considerations

• Lack of information/materials in various languages
• Unaware that services exist that are linguistically and culturally appropriate
• Providers unable to communicate with patients/families
Lesbian, Gay, Bisexual, Transgender (LGBT) Considerations

- LGBT patients and care partners should have medical, legal, and financial documents completed and on file.
- Early diagnosis allows more time for planning and making sure affairs are in order.
- Who is “immediate family?”
- Family dynamics may need to be considered.
Caring for Caregivers
“Nobody ever asks ‘How’s Waldo?’”
What is the Toll on Caregivers?

- Depression
- Fatigue
- Burnout
- Emotional stress
Physical and emotional “burden” of ADRD caregiving costs $9.3 billion in additional health care for caregivers.

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

More than 1/3 report symptoms of depression.

Alzheimer’s Association, Alzheimer’s Disease Facts and Figures 2014.
HBO: The Alzheimer’s Project

http://www.hbo.com/alzheimers/the-films.html

[Show a short clip related to caregiving]
What to Look for

10 warning signs:
1) Denial
2) Anger
3) Social withdrawal
4) Anxiety
5) Depression
6) Exhaustion
7) Sleeplessness
8) Irritability
9) Lack of concentration
10) Health problems
Unique Caregiver Considerations

• Caregiving is more demanding as disease progresses
• Caregivers need to learn whole new language (behavior & communication)

• Person with dementia cannot change (only caregiver can adapt)
• Role changes may occur
Caregiver Referrals and Support

Referrals and support for caregivers:

• Identify support groups and support systems
• Self-care
• Respite
• Caregiver education
Caregiver Referrals and Support

Referrals and support for caregivers:

• In-Home Supportive Services (IHSS)
• Community-Based Adult Services (CBAS)
• Multi-Purpose Senior Services Program (MSSP)
• Other resources within your health plan?
PART IV
Resources/Support Services
Given everything we have discussed today, why are referrals to support services and community resources so important in dementia care management?
Going the Extra Mile =
Seamless Transition =
Coordinated Care =
Better Outcomes

• **Reduce** hospital readmission
• **Prevent/delay** institutionalization
• **Improve** quality of life
Dementia Care Specialist

• Resource within health plan
• Expertise on Alzheimer’s disease and related dementias
• Provide guidance/additional support
Making Referrals
Considerations Before Making a Referral

- Clarify service need
- Be specific
- Carefully match caregiver to agency
Alzheimer’s Greater Los Angeles
Alzheimer’s Greater Los Angeles

• Serving diverse communities
• Multi-lingual services
• Culturally competent services
Alzheimer’s Greater Los Angeles

• Website www.alzgla.org
• 24/7 Helpline 844.HELP.ALZ | 844.435.7259
• Care counseling
• Family caregiver education; psycho-educational classes
• Early stage services
• Support groups
• MedicAlert® safety program
• Professional training
Care Counseling & Support

• Clinical expertise
• Bilingual in English and Spanish
• Triage to determine immediate needs or whether ongoing support is needed
• Services and support offered throughout the course of disease
• No cost
Care Counseling & Support

24/7 Helpline
844.HELP.ALZ
Information & Referrals

Care Counseling
Ongoing Support

All cases are kept confidential

Staff are mandated reporters

Staff are mandated reporters
Medic Alert®

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

ALZ DIRECT CONNECT
Direct Healthcare and Aging Service Providers to identify and link patients, clients & families to Alzheimer’s Greater Los Angeles for:

- Access to case coordination and psychosocial support
- Referrals to support services (at no cost)
- Help with understanding the disease & navigating its progression
- A 360° approach to care through feedback to the referring provider

HELPs
- Enhance understanding
- Offer resources

CONNECTS
- families to resources & support networks

IMPROVES
- communication & care coordination

Additional Questions?
Contact (323) 830-6207

ALZ DIRECT CONNECT REFERRAL FORM

- Name/Email
- Address
- City/State/Zip
- Phone
- Email
- Relationship to Patient/Guardian
- Referral Source
- Other

To the provider/client: I hereby certify that I have reviewed and signed this form and authorize the release of any information necessary for the care of the above patient. I agree to the terms of the service and understand that I will receive care coordination with access to support programs and services, and will be kept informed of any changes made to the care plan.

Signature
Date

Reason for Referral (If applicable):
- Support for newly diagnosed
- Support group
- Mental health
- Emotional support
- Financial assistance
- Other

Additional information:

Required Information:
- Referral Provider Name
- Provider Organization
- Address
- Tel.
- Email

How would you prefer to receive follow-up?
- Phone
- Email
- Fax
- Other (Specify):
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
“What maybe a physician should do is... prescribe something that would give you the opportunity to learn about [Alzheimer’s] and have the interaction...that would probably be the biggest help.”

- Focus Group Participant
Mr. Lopez is a 78-year-old man with moderate/middle stage Alzheimer’s disease and type 2 diabetes. Mr. Lopez lives with his 75-year-old wife who is his primary caregiver. Mr. Lopez and Mrs. Lopez have been married for 50 years and used to enjoy dancing, singing, and going to church. Mrs. Lopez often gets impatient with Mr. Lopez and yells at him when he is too slow in getting dressed and eating. She also gets easily frustrated when he wanders around the house and follows her. Mr. Lopez frequently misplaces things, like his Bible, and accuses his wife of stealing these items. Mrs. Lopez is tired of being a caregiver and feels like she has no time to herself. Mr. and Mrs. Lopez have two children who call regularly to check in. Mrs. Lopez tells them that everything is fine because she does not want to burden them.
Directions: Develop a care plan for Mr. Lopez that includes:

• Anticipatory guidance for managing the diabetes and potential refusal of care
• Use IDEA! to manage Mr. Lopez’s behavioral symptoms
• Cultural considerations for Mr. and Mrs. Lopez
• Suggestions for Mrs. Lopez for her self-care
• Referrals to home and community based services
• ALZ Direct Connect Referral (specific needs)
Connect with us
844.HELP.ALZ | alzgla.org
24/7