CA Alzheimer's GREATER LOS ANGELES

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

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Director, Professional Training & Healthcare Services

Dementia Cal MediConnect Project



California Coordinated Care Initiative

Cal MediConnect
Dual
Demonstration

Dementia Cal MediConnect Project

Three-way contract

Dementia
Capable System
of Care

Improve quality of care for people with dementia & family caregivers

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



Care Manager Training 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



Alzheimer's Disease in the USA 2015



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

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

Slide courtesy of Cordula Dick-Muehlke, PhD 15.5
million unpaid caregivers

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

a new case every

67 seconds

5.3 *million people have Alzheimer's*

6thleading

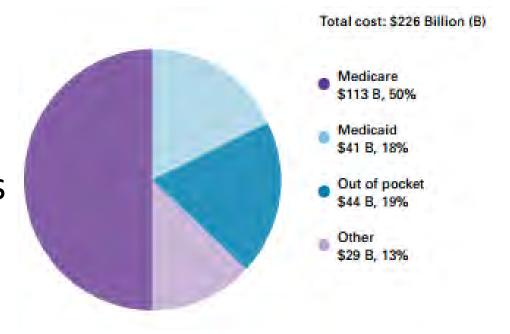
cause of death

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

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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 Association. 2015 Alzheimer's Disease Facts and Figures.

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

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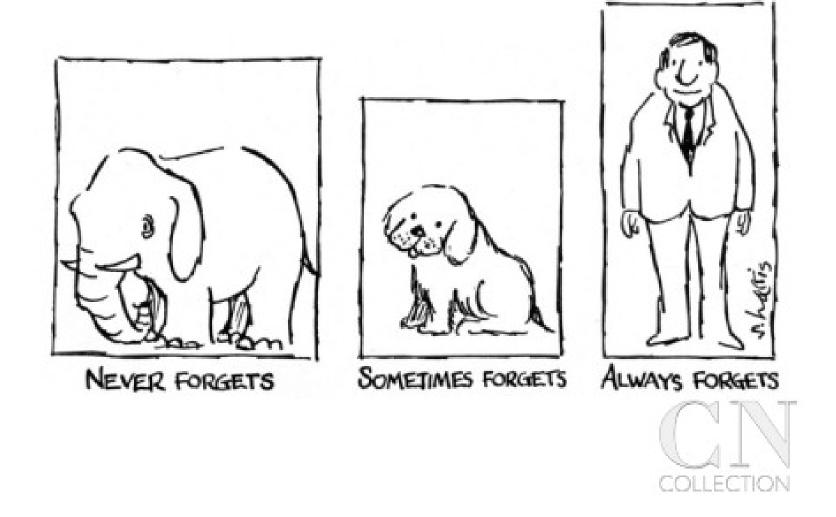
Implications for Health Care

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





Normal Aging

Alzheimer's is *not* a normal part of aging

Typical age-related changes can include:

Missing a monthly payment

Losing things from time to time

Sometimes forgetting a word

Making a bad decision once in a while

Forgetting the day and remembering it later

Early Signs of Alzheimer's Disease

- 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.

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

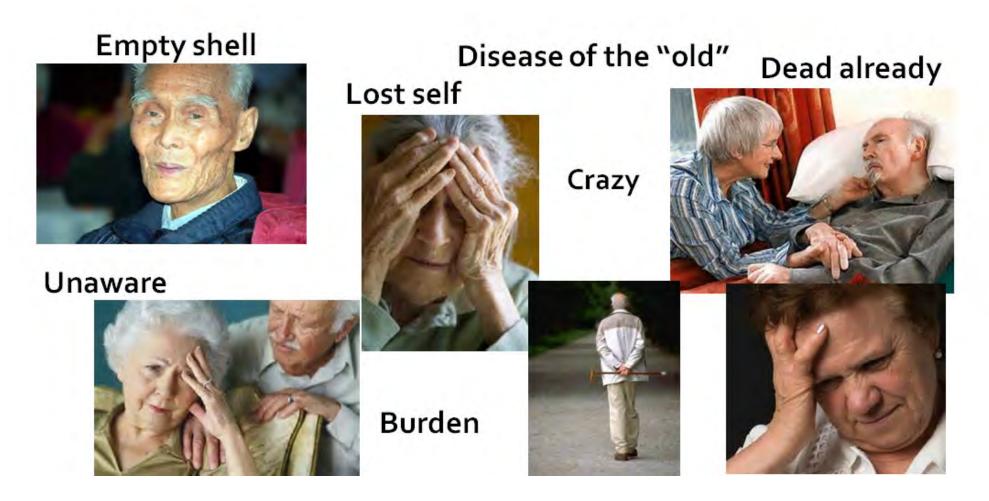
Dementia



Stigma and Labeling



The Many Faces of Dementia: Moving Beyond Stereotypes



The Many Faces of Dementia: Moving Beyond Stereotypes



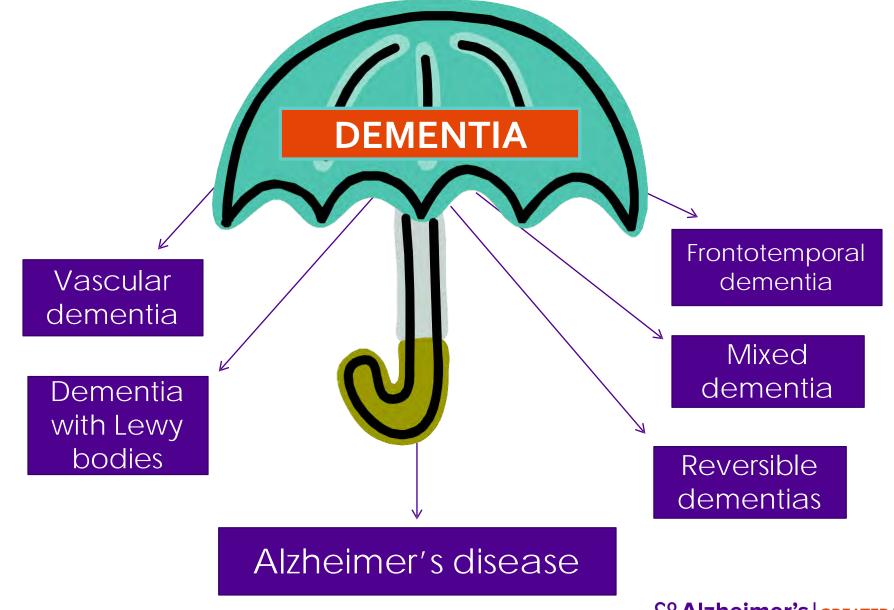
Video: The Unspoken Impact of Dementia



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



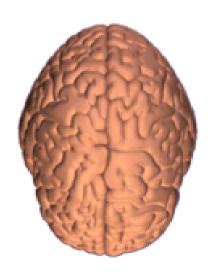


What is Vascular Dementia?

- 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

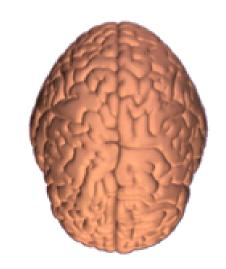
What is Frontotemporal Dementia?

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



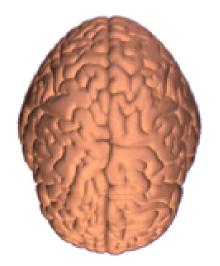
What is Dementia with Lewy Bodies?

- Wide variations in attention and alertness
- May include:
 - Hallucinations
 - Tremors
 - Rigidity
- Potential for adverse reaction to antipsychotic 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 Association. The Basics.

Alzheimer's Disease



Did You Know?



Not everyone with dementia has Alzheimer's disease

BUT

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



Activity: Through the Eyes, Head, and Heart of a Person with Alzheimer's



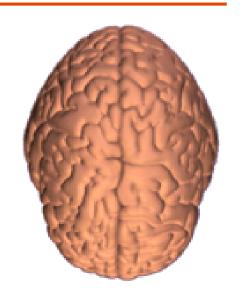
4 favorite memories

3 most important people in your life

2 things you love to do 1 hope for your future

What is Alzheimer's Disease?

- Most common form of dementia
- Neurocognitive disorder
- Must be diagnosed by physician
- Onset is gradual
- Progressive
- Symptoms: memory impairment, problems with thinking and planning, and behaviors which interfere with daily life
- Leads to death



Healthy Brain vs. Brain with Alzheimer's

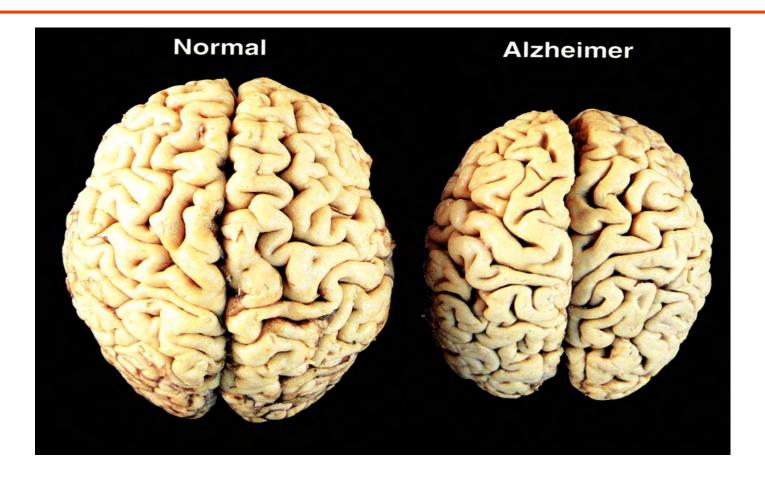
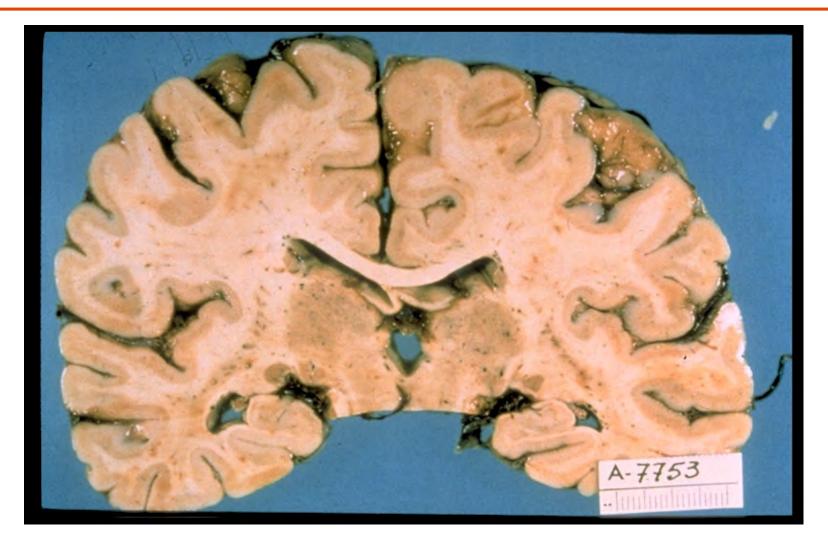


Image appears courtesy of Dr. Richard E. Powers, Director of the Alabama Bureau of Geriatric Psychiatry, alzbrain.org

Healthy Brain



Alzheimer's Brain



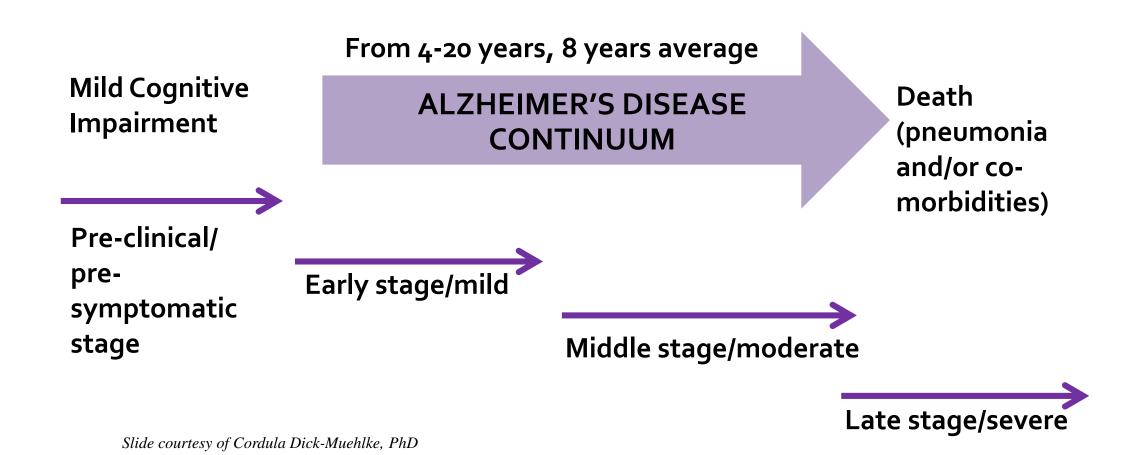
Video: What is Alzheimer's Disease?



Disease Progression



Alzheimer's Disease Progression



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



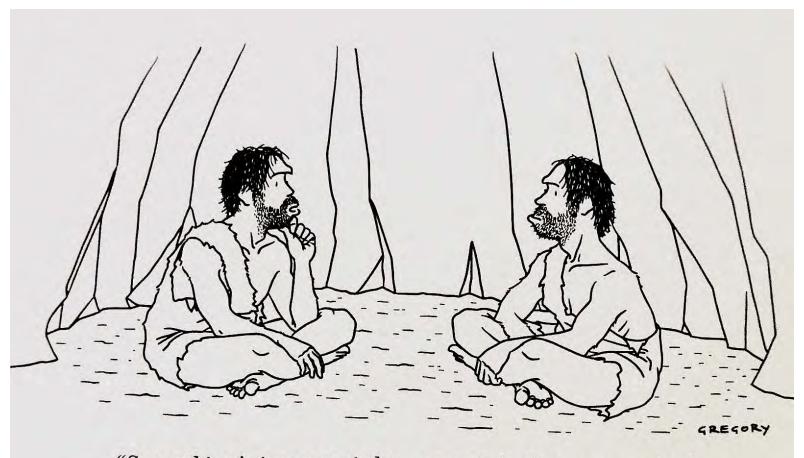
Disease Continuum



- 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

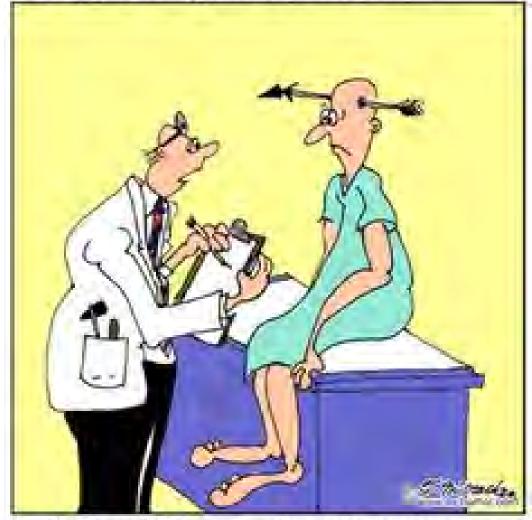
- Evidence links brain health to heart health
- Factors that increase risk of cardiovascular disease are associated with higher risk of developing ADRD
 - Smoking
 - Obesity
 - Diabetes
 - High cholesterol
 - Hypertension



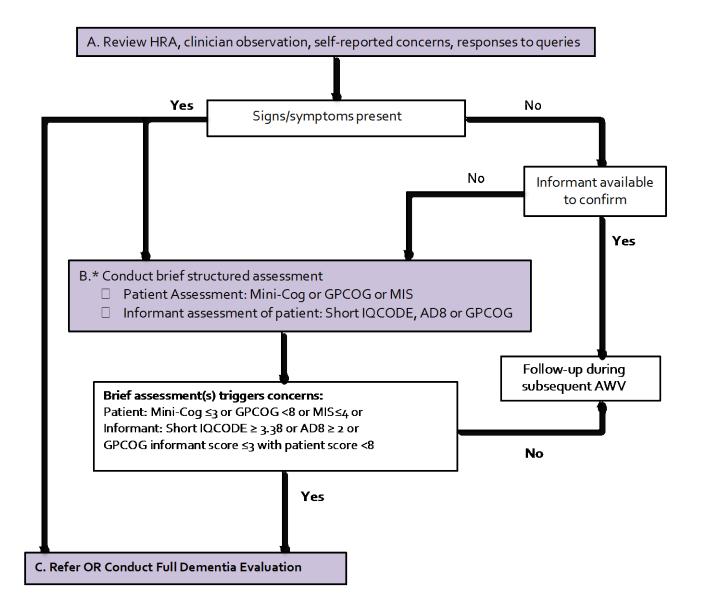
Screening and Diagnosis



MGHUMOR, COM by T. McCracken



"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."



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

ADOD		
AD8 Dementi	a Screening	i Interview
7 DO Demend	a sercenniq	111661 416 44

Patient ID#:	
CS ID#:	
Date-	

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

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

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

Document can be found in Care Manager Manual page 14

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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:
 - o-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

atient ID#:_	
S ID#:	
Date:	

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

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Alzheimer's Evaluation

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

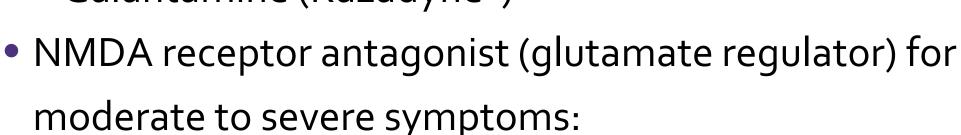


Treatment



Medications to Treat Symptoms

- Treatment should be individualized
- Cholinesterase inhibitors:
 - Donepezil (Aricept[®])
 - Rivastigmine (Exelon[®])
 - Galantamine (Razadyne[®])



Memantine (Namenda®)

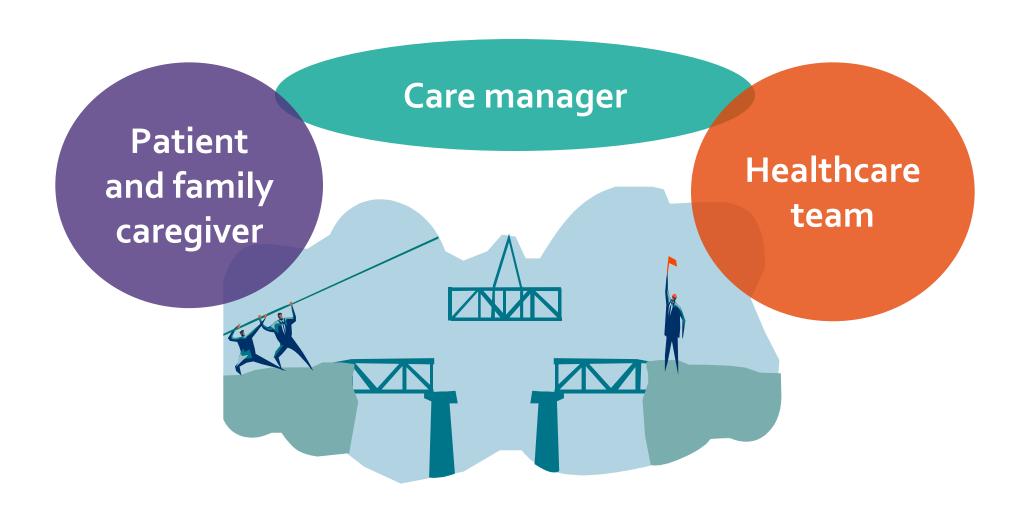


PART II Practical Dementia Care Management

The Unique Role of Care Managers in Dementia Care Management



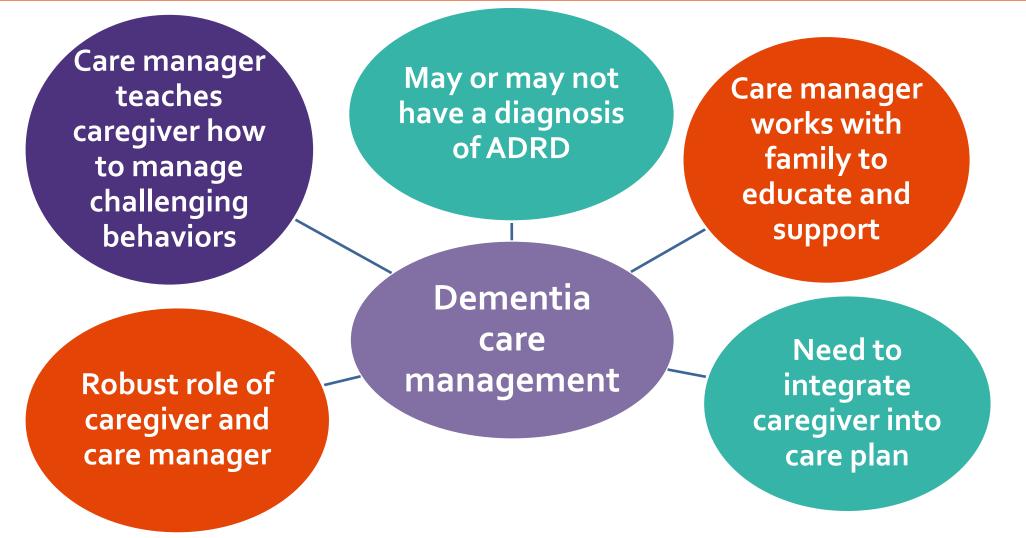
Care Manager Role



What Makes <u>Dementia</u> Care Management Unique?



What Makes Dementia Care Management Unique?

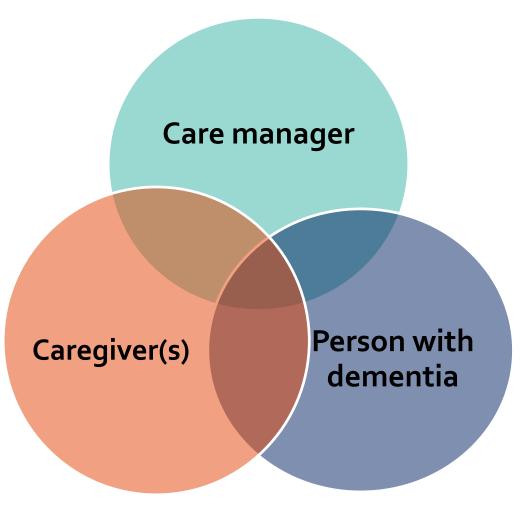


Engaging Caregivers



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

Monitor Changes

ASSESSMENT

TREATMENT

Conduct and document an assessment and monitor changes in:

- Daily functioning, including feeding, 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 sudden worsening in cognition, function, or as change in behavior
- Behavioral symptoms, psychotic symptoms, and depression
- Medications, both prescription and non-prescription (at every visit)
- Living arrangement, safety, care needs, and abuse and/or neglect
- Need for palliative and/or end-of-life care planning.

Reassess Frequently

Reassessment should occur at least every 6 months, and sudden changes in behavior or increase in the rate of decline should trigger an urgent visit to the PCP.

Identify Support

Identify the primary caregiver and assess the adequacy of family and other support systems, paying particular attention to the caregiver's own mental and physical health.

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.

Develop Treatment Plan

Develop and implement an ongoing treatment plan with defined goals. Discuss with patient and family:

- Use of cholinesterase inhibitors, NMDA antagonist, and other medications, if clinically indicated, to treat cognitive decline
- Referral to early-stage groups or adult day services for appropriate structured activities, such as physical exercise and recreation

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 Alcheimer's Association's MedicAlert® + Sale Return® program for patients who may wander

Non-Pharmacological Treatment First

IF non-pharmacological approaches prove unsuccessful, THEN use medications, targeted to specific behaviors, if clinically indicated. Note that side effects may be serious and significant.

Treat Co-Morbid Conditions

Provide appropriate treatment for comorbid medical conditions.

Provide End-of-Life Care

Provide appropriate end-of-life care, including palliative care as needed.

Integrate Medical Care & Support Integrate medical care with education and support by connecting patient and caregiver to support organizations for linguistically and culturally appropriate educational materials and referrals to community resources, support groups, legal counseling, respite care, consultation on care needs and options, and financial resources.

 Alzheimer's Association (800) 272-3900 www.alz.org

Organizations include:

Family Caregiver Alliance
(800) 445-8106 www.caregiver.org

Discuss Diagnosis & Treatment

Discuss the diagnosis, progression, treatment choices, and goals of Alzheimer's Disease care with the patient and family in a manner consistent with their values, preferences, culture, educational level, and the patient's abilities.

Involve Early-Stage Patients

Pay particular attention to the special needs of early-stage patients, involving them in care planning, heeding their opinions and wishes, and referring them to community resources, including the Alzhairae's Association

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 intensity of care and other end-of-life care decisions with the Alzheimer's Disease patient and involved family members while respecting their cultural preferences.

Document can be found in Care Manager Manual page 18

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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



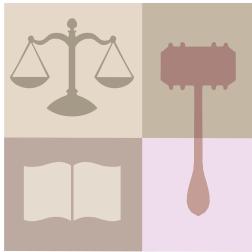
Patient and Family Education and Support

- 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



Making Plans for the Future After an Alzheimer's Diagnosis

#ENDALZ, Advocacy, Voices of Alzheimer's January 22, 2014

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

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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





Physical abuse

Financial abuse

Abduction



Isolation

Neglect



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

Reporting Driving

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

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."

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AllPosters

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



More Tests...What for?

Anonymous August 12, 2014

"I would have done just about anything to prolong my grandma's life; however, when you know someone has 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?"

Monitoring Co-Existing Conditions



Congestive heart failure	Challenge of Alzheimer's disease	Potential adaptation strategies for caregiver
Monitoring weight		
Taking diuretic		
Compression stockings		

Safety



Safety Considerations

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



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



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



is always a potential risk

Assessing Home Environment

- Medications
- Hazards
- Weapons
- Fire



Alzheimer's Home Safety



<u>Instructions</u>:

Use the Home Safety
Assessment on page 47
of the Care Manager
Manual to complete the
Alzheimer's Home Safety
worksheet

I times, of a person with memory loss.

© 2016 Alzheimer's Greater Los Angeles

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24/7 844.HELP.ALZ | alzgla.org



Behavioral Symptoms



What are Behavioral Symptoms?

Expressions of the disease

EXAMPLES may include:

- Agitation
- Aggression
- Wandering
- Hallucinations

- Paranoia
- Disinhibition
- Sundowning





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?

Is something wrong?

Why are they communicating this?

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

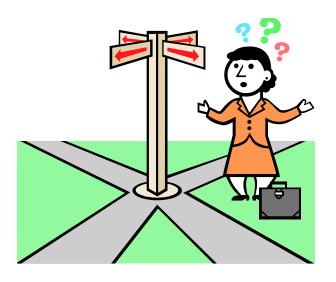
- What is the specific difficult/ challenging behavior?
- Is it observable?
- Is it measurable?
- Can others see it?



Educate Yourself: Understand the Causes/Triggers

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

doctor if sudden and unusual changes are present

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

Fact Sheets on challenging behaviors located throughout Care Manager Manual



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 quiet and calm when you can
- speak slowly and try not to say too much at one time

Make a Change

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

Be Safe

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

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.





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





Educate Yourself:

Understand the meaning of the behavior

Dad is anxious; responsibility as a parent



<u>A</u>dapt

- 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

Penrod, J., et al. (2007). *Res Theory Nurs Pract*, 21(1), 57-72. Gitlin, LN., et al. (2012). *JAMA*, 308(19), 2020-2029.

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



Risks Associated with Hospitalizations

Hospitalizations of elderly with dementia increase:

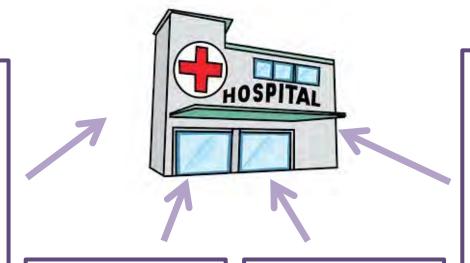
- Subsequent cognitive decline,
- latrogenic complications.
- Risk of delirium,
- Functional decline,
- Risk for institutionalization,
- Risk for death,



Reasons for Hospitalizations

Physical

(top reasons: pneumonia, congestive heart failure, UTI₁, syncope, fall, trauma₂)



Mental

(i.e. delirium, psychoses)₄

Behavioral

(i.e. agitation, wandering)₃

Environmental

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

¹ Phelan, EA, et al. (2012). *JAMA*, 307(2), 165-172.

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

³ Toot, S, et al. (2013). J Am Med Dir Assoc, 14(7), 463-470.

⁴ Targum, SD. (2001). Primary Care Companion J Clin Psychiatry, 3(4), 156-163.

Case Study: Using a Care Log to Determine Medical Needs



Dementia Care Manager Training
Part II: Practical Dementia Care Management

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 inhome 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.

Care Log

WELL.	THE	
5/19/14	8:05am	Seemed upset/moody; otherwise okay
5/20/14	9:45pm-	Got up several times at night; wandering Thru house
5 20 14	day	Agitated Throughout day; going to bathroom more often
5 2 14	8:30am	Did not finish breakfast
5/21/14	12:30pm	Light lunch - refused to eat side salad
5 21 14	3:45pm	Increased wandering - looking for bathroom; confused
5 22 14	8:00pm	Cirimacing while going to bathroom
5 22 14	night	Did not Sleep well

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

□ Explain your rationale.

SAlzheimer's GREATER LOS ANGELES

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



Views of aging

- Dementia = normal
- Aging to be managed within the family (not to be shared with outsiders)



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



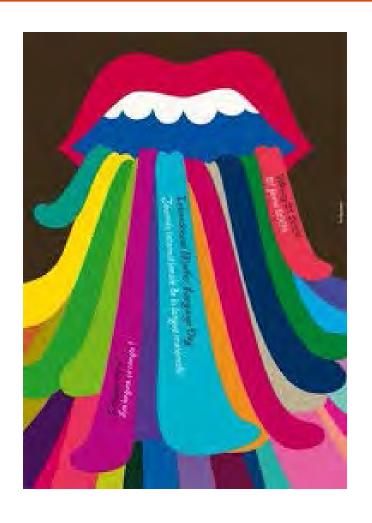
Use of formal healthcare services

- Delayed diagnosis
- Lack of early treatment for cognitive symptoms
- Prolonged caregiver "burden"
- Delay in using formal services until completely overwhelmed



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



Toll on Alzheimer's Caregivers

Physical and emotional "burden" of ADRD caregiving costs \$9.3 billion in additional health care for caregivers

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

More than 1/3 report symptoms of depression

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

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?

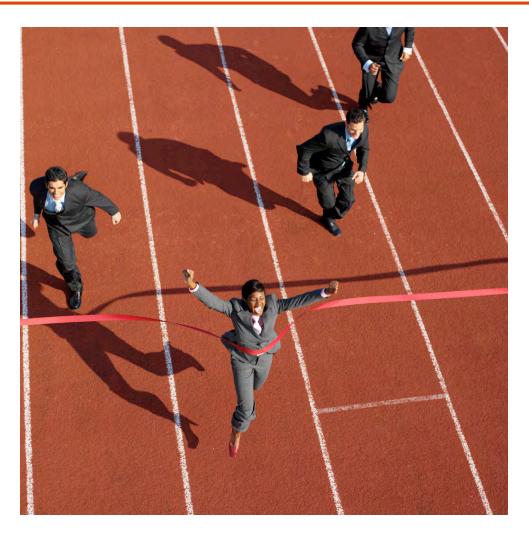
PART IV Resources/Support Services

Given everything we have discussed today, why are referrals to support services and community resources so important in dementia care management?

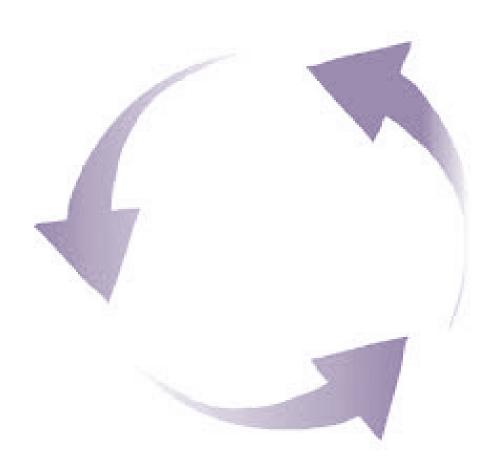




Going the Extra Mile =



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 <u>www.alzgla.org</u>
- 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

All cases

are kept

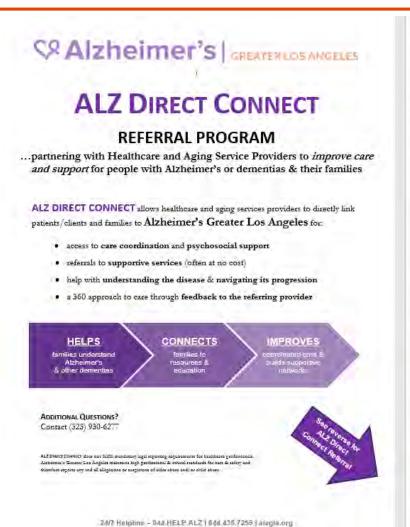


Medic Alert®

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

Wandering is always a potential risk

ALZ Direct Connect Referral Program



Fax or email this form to Alzheimer's Greater Los A	- The control of the
Fax # 323.686.5106 Email alzdi	rectconnect@alzla.org Date
Check if primary contact	Check if primary contact
PATIENT/CLIENT NAME	FAMILY CAREGIVER NAME (if available)
Address	Address
City Zip_	CityZip
Phone#_	Phone#
Email	Email_
Primary Language: English Spenish Other (specif	Relationship to Patient/Client: Spouse/Partner Child Professional Caregiver Other (specify)
Is the patient/client on Medi-Cal <u>AND</u> Medicare? □ Yes □ No	Primary Language: English Spanish Other (specif
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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

& 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

Culminating Activity: Problem-Based Scenario/Case Study



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.

Culminating Activity: Problem-Based Scenario/Case Study



<u>Directions</u>: 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

