

# Opportunities and Strategies to Improve Care of Patients with Dementia

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### Disclosure

I have no relevant financial relationships with commercial interests to disclose.



### **OBJECTIVES**

Participants will be better able to:

- Implement improved non-pharmacologic care of patients with dementia in the nursing home
- Develop a clinical program, with specific interventions, to reduce inappropriate use of anti-psychotic medications in the nursing home.



### The bottom line

- Patients with dementia are suffering and dying in high numbers in our SNFs
- We are not optimizing their patient/person centered care and communication
- We are not discussing goals of care or optimally managing behavior
- Too many toxic meds are prescribed and too many burdensome transitions occur
- Tools exist to do a better job
- We need to resolve to use them and be the change we want to see



### Recognizing the Opportunity

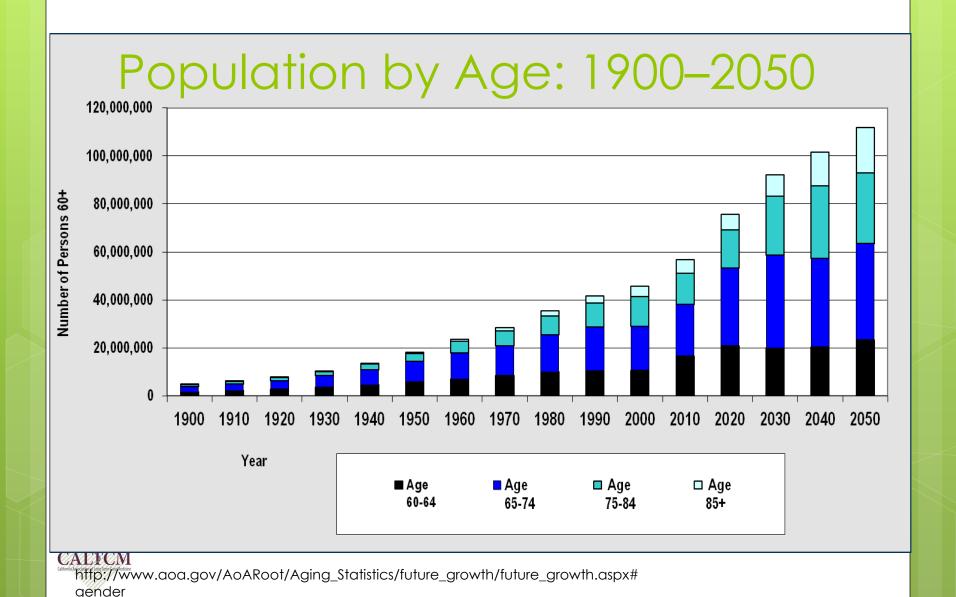
The first step to making something better is recognizing you have a problem worth fixing!



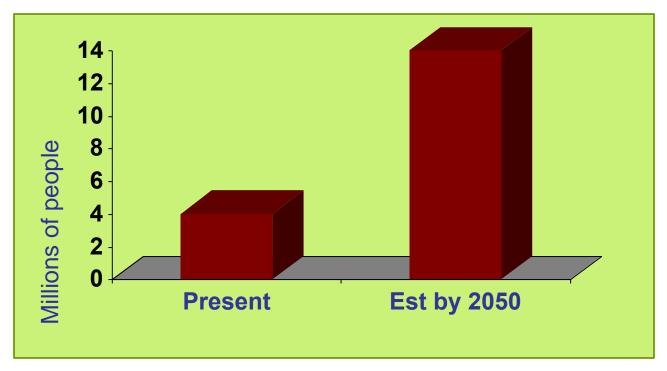
## Management of Dementia: Opportunities for Improvement

- Reduction of antipsychotic medication
- Improvement in advance care planning
  - reduction of burdensome interventions
  - Improvement in end of life care
- Restraint reduction
- Many other opportunities





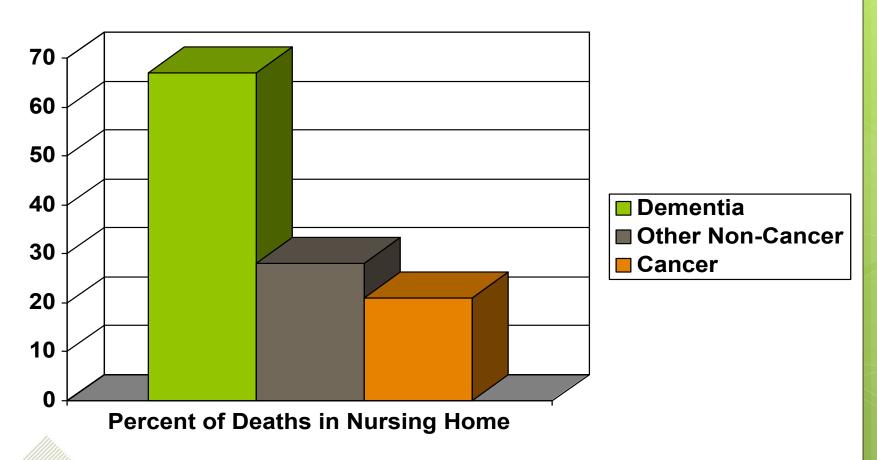
### Prevalence of Alzheimer's Disease



- o 4 million in the United States currently (14 million by 2050)
- Life expectancy of 8–10 years after symptoms begin

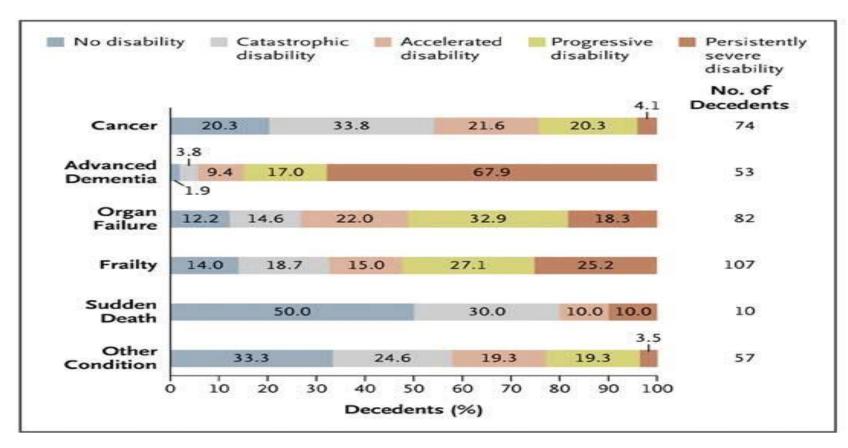


### Patients with Dementia Much More Likely to Die in Nursing Homes Than Those with Other Diagnoses



Mitchell, SL et al "A national study of the location of death for older persons with dementia," J Amer Geriatr Soc 2005:299-305.

## Dementia Trajectory is Persistent Severe Disability and Death



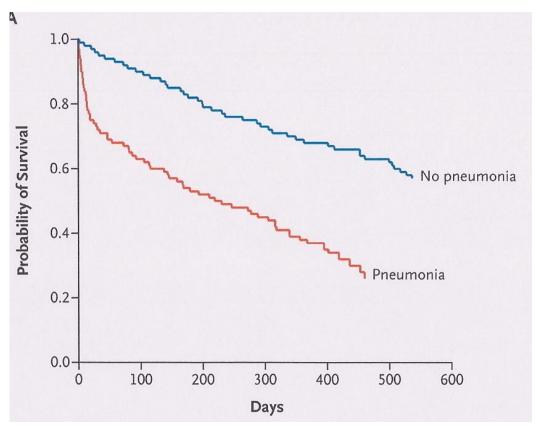
### Dementia is a Terminal Illness: Survival Poor in Following Acute Illness

- Prospect cohort study with 6 months of follow-up advanced dementia of patients without cancer > 70 years old hospitalized with hip fracture or pneumonia
- o 53% with pneumonia were dead at 6 mo.
- 55% with hip fracture were dead at 6 mo.
- Mortality of similar patients without dementia 13% and 12%.



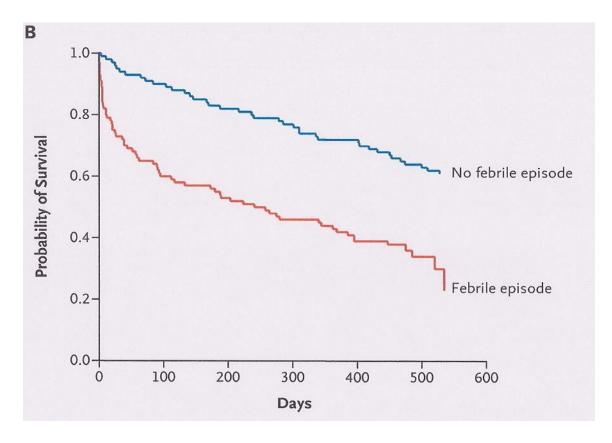
Morrison, RS and Siu, AL, "Survival in End-Stage Dementia Following Acute Illness, JAMA. 2000:47-52.

## Advanced Dementia: Death After Episode of Pneumonia



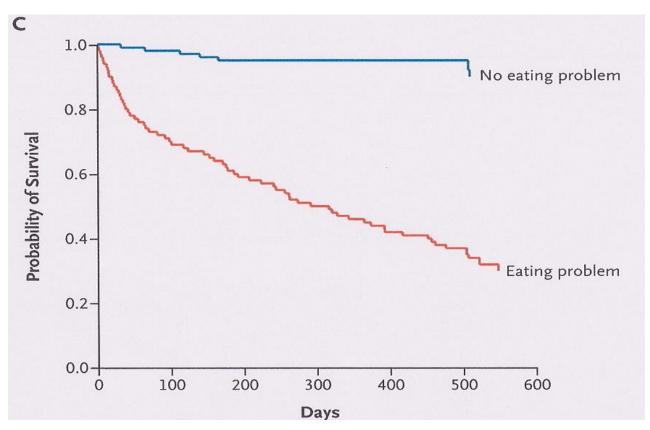


## Advanced Dementia: Survival After Febrile Episode



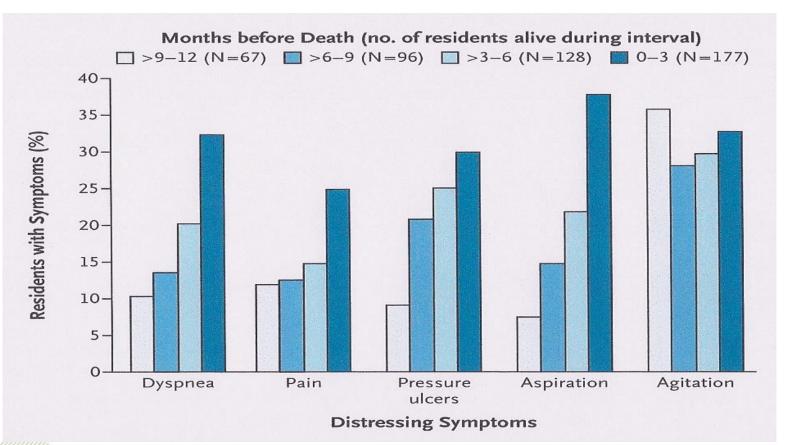


## Advanced Dementia: Survival After Onset of Eating Problem





## Suffering is High in Patients with Advanced Dementia





## Typical Hospice Eligibility Criteria (Local Coverage Determinations)

**Table 4.** Hospice Eligibility Guidelines for Dementia Among Nursing Home Residents With Advanced Dementia (N = 606)

Hospice Eligibility Guidelines	No. (%) of Nursing Home Residents
FAST stage 7c	215 (35.48)
Medical conditions in prior 12 mo Aspiration pneumonia	43 (7.10)
Pyelonephritis or another upper urinary tract infection	3 (0.50)
Septicemia	8 (1.32)
Multiple stage 3 or 4 decubitus ulcers	6 (0.99)
Recurrent fevers after antibiotic treatment	49 (8.09)
Insufficient oral intake or tube feeding with impaired nutritional status <sup>a</sup>	59 (9.74)
Any of the above medical conditions	135 (22.28)
FAST stage 7c and ≥1 medical condition	65 (10.73)

Abbreviation: FAST, Functional Assessment Staging. <sup>a</sup> Indicates 10% weight loss within the prior 6 months or serum albumin of less than 2.5 g/dL.

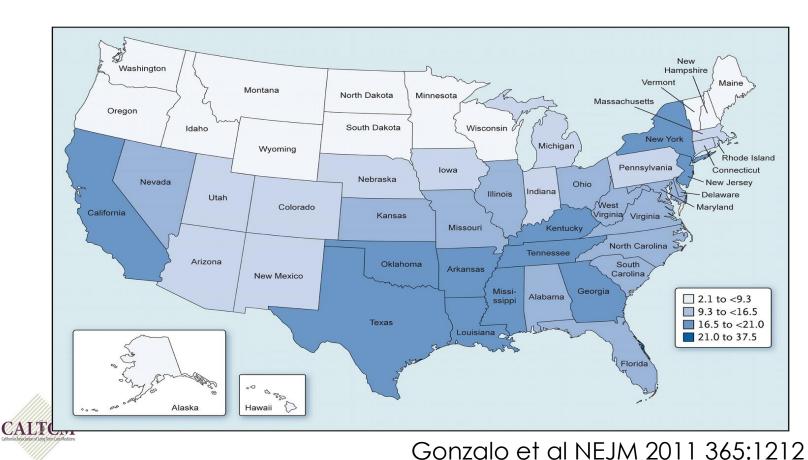
#### Functional Assessment Staging

- No difficulties
- Subjective forgetfulness
- 3. Decreased executive function
- 4. Difficulty with complex tasks
- 5. Requires supervision with ADLs
- 6. Impaired ADLs with incontinence
- 7. Stage Seven
  - A. Ability to speak limited to 6 words
  - B. Ability to speak limited to a single word
  - C. Loss of ambulation
  - D. Inability to sit
  - E. Inability to smile
  - F. Inability to hold head up

### High Rates and Variation in Burdensome Interventions in Dementia Patients in SNF

- Tenfold variation in feeding tube in advanced dementia in US across states in the United States
- Parts of CA are in the highest quintile
- Patients with high rates of tube feeding insertion 2.5 higher rate of burdensome transition in last 6 months of life
- 20% of patients had transition in last 3 days of life, multiple hospitals or different nursing homes in last 3 months of life

### Burdensome Transitions in Last 90 Days in Patients with Advanced Dementia



### Feeding Tubes in Advance Dementia

- Studies show <u>no impact</u> of feeding tubes in advanced dementia on:
  - Survival(Median survival 56 days)
  - Pressure ulcer healing
  - Aspiration pneumonia
- Likely <u>increase</u> in burdens
  - Loss of experience/connection of feeding
  - Restraints
  - Complications are common
  - Dehydration is not painful
- Use associated with decreased satisfaction with end of life care

Sampson EL, Candy B, Jones L, "Enteral tube feeding or older people with advanced dementia. Cochrane Database Syst. Rev. 2009;(2):CD007209

## End of Life Decision Making: Feeding Tubes in Dementia

- Telephone survey of 450 relatives of SNF patients with advanced dementia who had feeding tubes
  - 85% of decisions were made in hospital
  - 47% reported discussion lasted <15 minutes</li>
  - 1/3 family members recalled that no risks of tube feeding presented
  - 50% felt hospital physician was "strongly in favor of tube insertion"
  - 13% "felt pressured to put in a feeding tube"
  - Approx. 25% regretted the feeding tube decision



Kuo, Sylvia, Poster Presentation, American Geriatrics Society Annual Meeting, May 12, 2010, Orlando, FL

## Antipsychotics Associated With Increased Death Rate

- Warning: Increased Mortality in Elderly Patients with Dementia-Related Psychosis
  - Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at and increased risk of death. [Name of Antipsychotic] is not approved for the treatment of patients with dementia-related psychosis.

#### WARNING

Increased Mortality in Elderly Patients with Dementia-Related Psychosis — Elderly patients with dementia-related psychosis treated with atypical antipsychotic drugs are at an increased risk of death compared to placebo. Analyses of seventeen placebo-controlled trials (modal duration of 10 weeks) in these patients revealed a risk of death in the drug-treated patients of between 1.6 to 1.7 times that seen in placebo-treated patients. Over the course of a typical 10-week controlled trial, the rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group. Although the causes of death were varied, most of the deaths appeared to be either cardiovascular (e.g., heart failure, sudden death) or infectious (e.g., pneumonia) in nature. [this drug] is not approved for the treatment of patients with dementia-related psychosis.



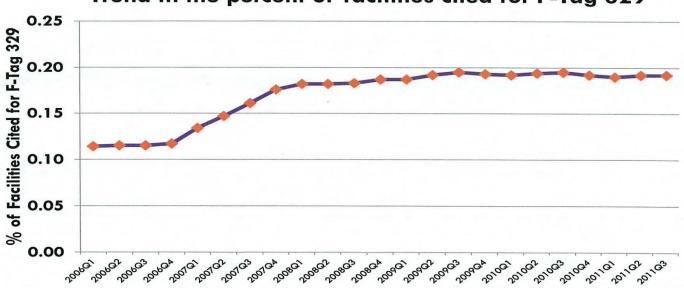
## Increasing F-329 Antipsychotic Medication Deficiencies

- F-Tag associated with off-label use
- F-Tag 329: Unnecessary Drugs
- Residents should have drug regimens that are free of unnecessary drugs defined as
  - There in an excessive dose including duplicate therapy
  - There is an excessive duration of being on the drug
  - There is inadequate monitoring of the drug
  - There is inadequate indication for the use of the drug
  - There are adverse consequences
  - A combination of the reasons above
- D Specific conditions for antipsychotic drugs
  - The facility must ensure that residents have not used antipsychotics previously, are not given these drugs unless the drug therapy is necessary, and recorded in the clinical record
- In an effort to decrease the use of antipsychotics residents must receive gradual dose reduction and alternate therapies, unless they are counter-indicated



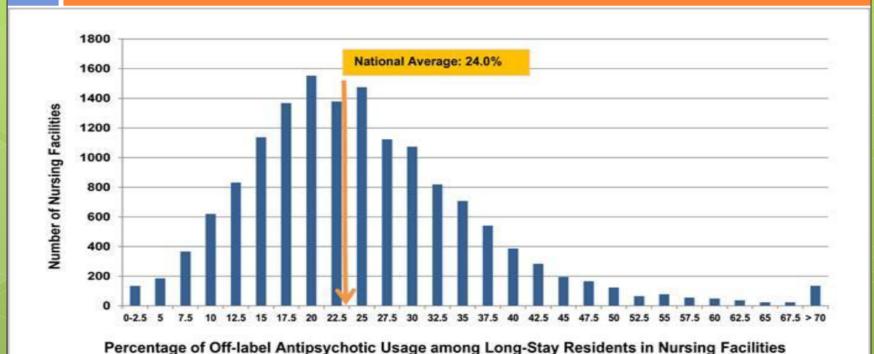
### Trends in F-Tag 329 unnecessary Meds







# Variation Suggests Opportunity for Improvement: Off-Label Use of Antipsychotic Meds



Source: CMS analysis of MDS 3.0 data, 4th Quarter 2011.

## Goal 1: Reduction of Antipsychotic Medication

• In 2011, the Department of Health and Human Services Inspector General found that high rate of nursing home residents were prescribed antipsychotics for non-approved purposes.



## CMS Partnership to Improve Dementia Care In Nursing Homes

- Launched on March 29, 2012
- Aimed to improve behavioral health and minimize the use of antipsychotic medications to manage individuals with dementia
- Established a goal is to reduce avoidable antipsychotic use by 15 percent by December 31, 2012
- Move from 23 percent to 19.6 percent.



## Reducing Antipsychotic Medication: The Challenge

- No simple non-pharmacologic approach has compelling evidence for effectiveness
- The SNF culture and historical mandate; warehousing patients instead of culture change (But there is progress)
- No FDA approved medication with significant regulatory pressure to reduce
- Medications with solid evidence of effectiveness are toxic and can be lethal



## Medication for Behavior Problems in Dementia: Data Challenges

- Multiple reviews and meta-analyses.
  - JAMA 306: 1359-69 2011(Meta-analysis of 38 RCTs)
  - Cochrane reviews 2012
  - Agency for Health Care Quality and Research 2011
  - Ballard C et al Expert Opin Drug Saf. 2011 Jan. 1;10(1):35-43.
- Many classes of medications have been tried
- Only antipsychotics better than placebo
- The data for other medications—antidepressants, cholinesterase inhibitors, valproate, are weaker-- either no randomized study, isolated positive studies, or mixed and negative studies
- One randomized positive trial for prazosin is being replicated
- Data don't really address patients who may have dementia and another diagnosis such as depression



### Adverse Effects of Antipsychotics

- Atypical antipsychotics associated with cognitive decline consistent with 1 year's deterioration
- $\circ$  Odds ratio of death increased approx 1.5 1.7x
- Increased rate of gait disorder, gait, falls, strokes, diabetes, speech, swallowing, somnolence, other functional decline
- Data suggest impacts the same or worse with typical antipsychotic medications
- Adverse impacts may vary significantly between different agents, but data are limited.
- E.g. Studies suggest quetiapine may have lower adverse effects, but at doses which may have no antipsychotic effect

## Antipsychotic Effectiveness in Dementia

- Not all meta-analyses agree on all points
- Olanzapine, Risperidone and Aripiprazole have statistically significant effect compared to placebo (12 -20% better)
- Quietiapine with less significant impact (no statistical impact per JAMA review)
- No conclusive evidence related to comparative effectiveness
- AHQR conclusion is that data do not justify concept of "class effect"



## Anti-psychotic Net Effectiveness

 "For every 100 patients with dementia treated with an anti-psychotic medication only 9 to 25 will benefit and 1 will die"

Drs. Jerry Avorn et al.

From Independent Drug Information Service "Restrained use of antipsychotic medications: rational management of irrationality. 2012

### The SNF Culture of Prescribing

- "Post hoc ergo propter hoc" (After the event therefore because of the event) means we over-interpret regression to the mean as a drug effect.
- Then, when the behavior flares, we add more medication. A vicious cycle.
- "If you're a hammer, things look like a nail" and physicians want a quick solution.
- My belief: we need a countervailing more aggressive skeptical eye to reduce meds, especially antipsychotics.



### Antipsychotic Medication Withdrawal in Patients with Dementia

- Multiple studies have shown no adverse impact of medication withdrawal
- One RCT study showed significant increase in relapse of patients who had documented improvement to Risperdal after abrupt discontinuation
- One study does show ongoing increased death rate in patients on anti-psychotics
- Thus, it is generally safe to withdraw anti-psychotics, with caution suggested for those with proven response to medication and/or severe behavioral problems
- Scant data to support general practice of very slow (e.g. q3 month adjustment) gradual tapers of medication.



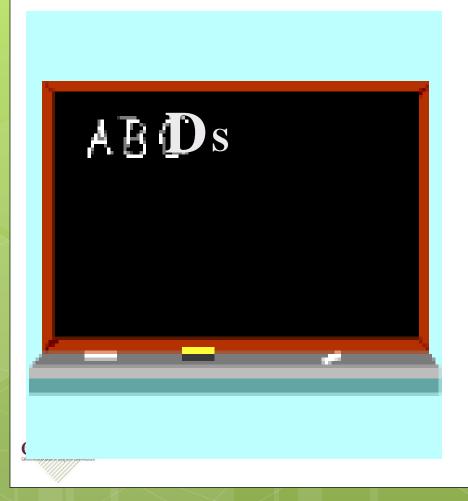
### Non-pharmacologic Interventions for Behavioral Problems

- Many programs have worked, but difficult to generalize as to what can be dispensed or spread
- Pain and symptom control
- Exercise
- Music/Recordings
- Optimal level of activity
- Environmental changes: light, reassuring picture
- Treating each patient with personalized care



See also extensive materials below from IA Adapt, Interact, Hand in Hand

### **ABCDEs** of Neurobehavioral Care



- OAntecedents
- OBehaviors
- Consequences
- Documentation
- Emotion
- Systematic

Adapted from Teri, L. (1997)

### ABCDs Examples



E= Emotional Engagement

### Antecedents

Diagnoses (What is the cause of dementia?)
What other diagnoses exist?

Fatigue, hunger, pain Levels of stimulation

Restraint

Staff or resident

approaches

Gender & Cultural

Lack of exercise

### Behaviors

What exactly is the behavior?

Crying

Yelling

**Biting** 

Hitting

Grabbing

Fecal play

Time of day

Exact setting and details as possible

Consequences

Attention

Isolation

Abuse

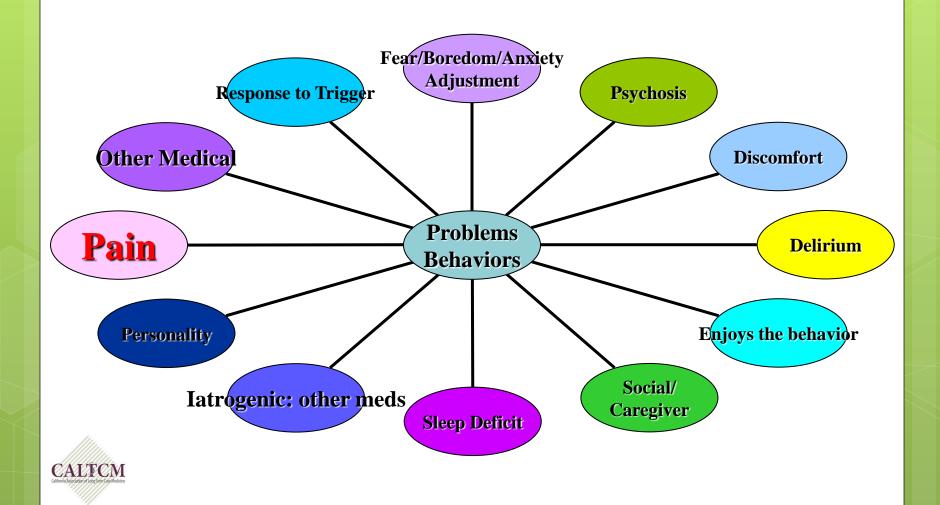
Injury

Medication response

Other positive

reinforcement

### Common Reasons for Difficult Behaviors in Patients with Dementia



#### Goal 2:

Better Align Goals of Care with Actual Care Received and Avoid Ineffective Burdensome Procedures



# Advance Care Planning: Clear Opportunities to Improve Care

- Most families of patients with dementia do not understand the prognosis
- Early discussions reduce burdensome treatments near end of life
- Feeding tubes are ineffective and not recommended by major physician groups
- POLST can improve rate at which care follows patient wishes



### Association of End-Of-Life Conversations with Clinical Outcomes

- No change in depression or anxiety
- Lower rate of ventilation (1.6% vs. 11%)
- Lower rate of CPR (0.8% vs. 6.7%)
- ICU admission (4.1% vs. 12.4%)
- Earlier hospice enrollment (66% vs. 45%)
- Less aggressive care = better quality of life (6.4 vs. 4.6)
- Longer hospice with better quality of life (6.9 vs. 5.6)
- Improved caregiver outcomes and bereavement

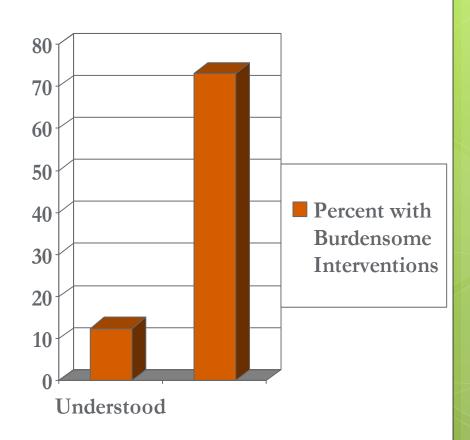


Wright, AA et al, "Association between endof-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment, JAMA. 2008;300(14): 1665-1673.

#### Late Stage Dementia: Impact of Family Understanding of Prognosis

Proxy understanding of poor prognosis was greatest predictor of reduced burdensome interventions:

- Hospitalizations
- Emergency Department Visits
- Parenteral Therapies
- Tube Feedings





Mitchell, SL. The clinical course of advanced dementia. NEJM 2009. 361(16):1529-1538.

# Hospice Care Improves Care of Patients with Dementia

Families of patients with advanced dementia in a SNF who received hospice:

- 49% less likely to report unmet pain management
- 51% less likely to report unmet needs and concerns with quality of care
- 50% less likely to have wanted more emotional support before their loved one's death
- Rated peacefulness of dying and quality of dying more positively than families of those who did not receive hospice care

Teno JM, Gonzalo PL, Lee IC, "Does hospice improve quality of care for persons dying from dementia? J Am Geriatr Soc. 2011 Aug:59(8):1531-6.

CALTCM

#### Impact of Hospice on Nursing Home Patients with Dementia

- Fewer unmet needs
- More appropriate scheduled medications
- More recognition and treatment of dyspnea

Hospice Use and Outcomes in Nursing Home Residents with Advanced Dementia Dan K. Kiely, MPH, MA, Jane L. Givens, MD, MSCE, Michele L. Shaffer, PhD, Joan M. Teno, MD, MS, Susan L. Mitchell, MD, MPH J Am Geriatr Soc. 2010;58(12):284-2291.



#### Strategies and Actions

- Define the Mission
- Develop a Vision
- Build a Leadership Team
- Develop Strategies
- Take Action



#### The Mission

To develop nursing homes that maximally support the dignity, safety and quality of life for every patient with dementia while minimizing the adverse and deadly effects of antipsychotic medications

Focus on patients as persons: focus on their goals not just diseases and regulations



#### Person Centered Care!

- Focus on quality of life—personhood
  - not just mitigating challenging behaviors
- Programs to enhance quality of life
  - Exercise
  - Art
  - Music
  - Appreciation of patients as persons
  - Minimize potentially toxic medications
- Understand patient goals & align care & goals
  - Advance care planning and POLST
  - Hospice



#### The Vision

A team of providers working together using their full range of skills, in an optimal environment, using the best approaches to enhance the dignity and life of each patient with dementia.



# Build a Core Team Committed to Change

- Educate Staff: Get Buy In
  - Use extraordinary resources available
- Get medical director to CALTCM
- Identify a champion for improvement
- Engage family
- Participate in CALTCM change process
- Engage with other efforts led by QIO,
   CAHF, CA Culture Change et al



# Staff Development Resources are There!

- Materials are available for the taking!!
- IA Adapt program with training resources for all types of staff, including physicians, pharmacists, nurse's aides etc.
- Hand in Hand training series for nursing homes



# Excellent Video Training Tools for Nursing Homes from CMS

A Training Series for Nursing Homes







# IA ADAPT Site has extensive video training and tools

The purpose of this website is to help clinicians, providers, and consumers better understand how to manage problem behaviors and psychosis in people with dementia using evidence-based approaches. This includes resources such as brief lectures, written content, quick reference guides for clinicians and providers, and information for families or patients on the risks and benefits of antipsychotics for people with dementia (a.k.a. Alzheimer's disease and others). We're offering continuing education credit for physicians and physician assistants. You can also request laminated quick reference guides to use in your practice, which can help you put the strategies you learn about into action. This program is supported by the Agency for Healthcare Research and Quality (R18 HS19355-01).

Use the links on the right to view the videos, products, and other information available as part of this program. The information below describes the objectives, brief lectures, products, and faculty that are included in the program. Brief lectures average 15 minutes each.

This program is sponsored by the University of Iowa College of Public Health, the Iowa Geriatric Education Center, and the University of Iowa Roy J. and Lucille A. Carver College of Medicine.

#### **Disclosure Statement**

Planners and speakers involved in creating and delivering this program do not have any disclosures that create a conflict of interest.

#### **Technical Requirements**

Physician Home

#### Videos

Introduction/Overview
Assessment
Delirium
Non-Drug Management
Shared Decision Making
Antipsychotic Selection
Antipsychotic Monitoring

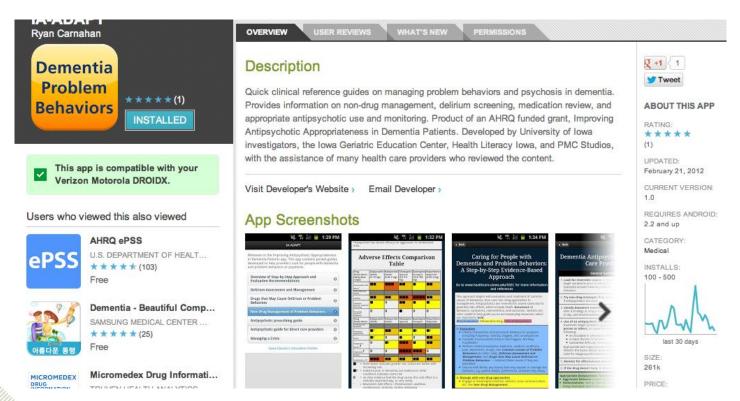
#### **Products**

**Pocket Guides** 

- Overview of evidence-based approach + evaluation of problem behaviors
- Delirium
   assessment and
   management
- Non-drug management
- Drugs that may

CALTEMITES://www.healthcare.uiowa.edu/IGEC/IAAdapt/physician

#### "Dementia Behavior Management: There's an app for that"



https://play.google.com/store/apps/details?id=edu.uiowa.IAADAPT

## Strategy 2: Change Your Processes

"Every system is perfectly designed to get exactly the results it achieves"



# Advancing Excellence Tools: Comprehensive System for Use

- Medication Performance Improvement Cycle Delineated and Detailed
- Baseline Medication Use and Tracking Tool
- Multiple Resources to Identify Strategies for Improvement
- Consumer and Staff Fact Sheets



### Quality Improvement Plans with Advancing Excellence





# Useful Interact Advance Care Planning Tools for Staff

#### Advance Care Planning Communication Guide: Overview



The INTERACT Advance Care Planning Communication Guide is designed to assist health professionals who work in nursing homes to initiate and carry out conversations with residents and their families about goals of care and preferences at the time of admission, at regular intervals, and when there has been a decline in health status.

The Guide can be useful for education, including role-playing exercises and simulation training.

#### Communicating about advance care planning and end-of-life care involves all facility staff

 Physicians must communicate with residents and families about advance directives, but <u>all staff</u> need to be able to communicate about goals of care, preferences,



# Advance Care Planning Resources



PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT



#### POLST – Physician Orders for Life-Sustaining Treatment

POLST (Physician Orders for Life-Sustaining Treatment) is a form that states what kind of medical treatment patients want toward the end of their lives. Printed on bright pink paper, and signed by both a doctor and patient, POLST helps give seriously ill patients more control over their end-of-life care.

\*POLST Trainers and Physician Champions may access the POLST Education Website here - you will need your login and password.





#### **Videos**

Related videos, click on the video thumbnail below to watch. Video will open in a new window so please allow pop-ups from this site.



#### POLST at Work in California

This 12-minute video provides a detailed look at the POLST form and how it works in a community as a patient is transferred between health care settings. The video is designed for health care providers, but can also



### Excellent Advance Care Planning Staff Training is Available





# When Thursday May 9, 2013, 9:30 AM - 4:30 PM Breakfast is provided at 9:00AM Friday May 10, 2013, 8:30 AM - 3:30PM Breakfast is provided at 8:00AM Add to Calendar Where O'Connor Hospital Medical Office Building Auditorium 2101 Forest Avenue San Jose, CA 95128 Driving Directions Contact: Suzanne Richards Coalition for Compassionate Care of California info@coalitionccc.org (916) 489-2222

#### POLST: It Starts with a Conversation

Register Now!

#### California POLST Education Program





**Program Description** 

POLST: It Starts with a Conversation - The California POLST Education



### Additional Goals of Care/Advance Care Planning Resources

- Palliative Care Providers
- Medicare Hospice Evaluation (Free for Medicare pts.)
- Alzheimer's Association materials
  - www.Alz.org
- Multiple other resources



# Suggestions for care planning to reduce antipsychotic use

- Improve care planning meetings to include systematic consideration of the ABCs
- 2. New patient review includes detailed understanding of medication use and consideration of rapid d/c/taper of medication
- 3. Include pharmacist in care planning process
- 4. All new antipsychotic and all prn antipsychotic medication orders reviewed by pharmacist and medical director
- 5. Biweekly meetings with medical director to review all patients on antipsychotics. Discuss quality of life and overall goals of care.
- 6. Monthly review of total number and percentage of patients on antipsychotics without schizophrenia, Tourette's syndrome, Huntington's syndrome
- 7. Compare data with CMS antipsychotic data



## Approach to Medications for Behavioral Problems in SNF IV

- First try:
  - Behavioral interventions (at least 2 trials)
  - Medication toxicities minimized (e.g. anticholinergic medications)
- Require (As per Title 22 and CMS)
  - Behavior causes significant impairment of quality of life or danger to self or others
  - Informed consent for serious risks (including death) obtained
  - Avoid prn antipsychotics in dementia



# Advance care planning for patients with dementia

- Educate physicians, families and staff about trajectory of illness of dementia
- Elicit patient's goals of care based on advance directives and prior values
- 3. Educate families and physicians about burdens and benefits of interventions, including lack of benefit for tube feeding.
- 4. Complete POLST documents: assess not only completion but quality of the conversations
- 5. Consider hospice if appropriate



### Possible Action Steps and Resources

- Schedule family meetings with knowledgeable nurse practitioner or medical director to discuss realistic options and choices and document decisions on POLST
- Be sure that all physicians and nurses understand the criteria for hospice referral
- Engage physician/medical director in evaluation of every patient with dementia
- Review every patient on anti-psychotic medication every month
- Track all patients with dementia on anti-psychotic medication in a "real time" number and percentage of patients on anti-psychotic medications



# One Antipsychotic Reduction Action Plan Results

- Identify all patients on antipsychotics without schizophrenia, Tourette's, Huntington's (8/140)
- Spoke with all major physicians in SNF and with nurses in training session
- Detailed case review, development of improved non-medication care plan and call to physicians led to immediate removal of 4 (Diagnosis of significant pain and pseudo-bulbar affective disorder, 1 each)
- Initiated successful rapid taper of 2 others with questionable indications
- All patients on admit with antipsychotic meds considered for either d/cing the order on admit or in first week of care (if started in hospital)
- Most patients do fine with rapid taper; 2 patients had truly strong indications for the medication and approach of very cautious GDR taken
- Monthly review of all non-schizophrenic patients on antipsychotics
- Seem to be stabilizing at about 10% with CMS data at about 13%
- Plan is to continue focus and enhance with additional training to stabilize results
- Consider use of materials from Advance Excellence
- ?? What is optimal rate-perhaps 5-10% -- not clear from literature



#### Conclusion

- The Need (Opportunity) is Huge
- The tools are there for the taking
- Look at your baseline, decide your best opportunity and design a change (Plan)
- Make the change (Do)
- Measure the impact (Study)
- Continue to work until you have achieved excellent patient centered care (Act)
- Start NOW

