

# Bringing Comfort to People with Advanced Dementia

Ann Wyatt, Consultant in Palliative & Residential Care

CaringKind. The Heart of Alzheimer's Caregiving

New York, New York

October 17, 2018



## Practical Tools for Making Change • November 8-10 • Orlando, FL

### Pre-Conference Workshops • November 7

- **Boot Camp:** Designing Palliative Care Programs in Community Settings
- **NEW! Payment Accelerator:** Financial Sustainability for Community Palliative Care

### Seminar Keynote Lineup



**Diane E. Meier, MD,  
FACP**  
Director, Center to  
Advance Palliative Care



**Edo Banach, JD**  
President and CEO,  
National Hospice  
and Palliative Care  
Organization



**Elisabeth  
Rosenthal, MD**  
Author, *An American  
Sickness* and  
Editor-In-Chief,  
Kaiser Health News



**Jay D. Bhatt, DO**  
President, HRET and  
Senior VP and CMO,  
American Hospital  
Association



**Christy Dempsey,  
MSN, MBA, CNOR,  
CENP, FAAN**  
Author, *The Antidote to  
Suffering* and CNO,  
Press Ganey  
Associates



**Edward  
Machtinger, MD**  
Director, Women's  
HIV Program,  
University of  
California, San  
Francisco

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# NEW “Best Practices in Dementia Care and Caregiver Support” CAPC Curriculum

Check out the new curriculum of courses to train *all* clinicians in dementia care and caregiver support. The first three courses are already available, with four more launching in early 2019:

- Discussing Your Patient’s Dementia Diagnosis
- Communicating About What to Expect as Dementia Progresses
- Understanding and Responding to Behavioral and Psychological Symptoms of Dementia
- Planning for the Future with People Living with Dementia and their Caregivers
- Supporting the Caregivers of People Living with Dementia
- Addressing Mood & Sleep Disturbances for People Living with Dementia
- Addressing Swallowing Disorders, Pain, and Medical Decision-Making for People Living with Advanced Dementia



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# Why a Comfort Approach?

- CaringKind rethinking how to best be of assistance to LTC facilities
- 75% of people with dementia will spend time in a nursing home, most typically in the moderate and advanced stages
- Dementia is progressive and eventually terminal
- The average time between diagnosis and death is 8 to 10 years; extreme variability with some dementias lasting up to 20 years or more

# Why Comfort ?(continued)

- Typically, about 40% of time spent living with dementia means living in the advanced stages
- Someone who reaches the age of 80 and does not have dementia has an approximately 5% chance of spending time in a nursing home
- Someone who reaches the age of 80 and has dementia has an approximately 80% chance of spending time in a nursing home

# Treatment & Caregiving

- There are some treatments available that will help some people with Alzheimer's for a period of time. There is no treatment yet that will prevent, modify or cure the disease.
- In the absence of an effective therapy to prevent, treat or cure Alzheimer's disease and related dementias, the best medicine is good care.



# Therefore...

- There can be no more important role for long-term care providers than that of bringing comfort to people with advanced dementia, and by extension, to their families and friends.

# How We Got to Comfort Matters®

- Review of literature, efforts around the country
- Finding Beatitudes Campus and *Comfort Matters®*



# What Comfort Matters® Does

- Delivers a comfort-focused model of care for people with dementia which can be used in any setting
- Targets necessary change in individual staff/ family practice and organizational systems to ensure individualized comfort for each person
- Bringing comfort is a combination of (1) adoption of specific care practices, and (2) the process used for assessment and implementation for specific individuals

# Evidence-Based Comfort Matters® Assumptions

- Comfort is a benefit to people with dementia
- People with dementia are experts on their personal comfort
- People with dementia communicate comfort and discomfort through their actions
- Everyone with dementia can be comfortable
- Comfort is NOT just for end-of-life circumstances

“Cure sometimes, treat often, comfort always.”

Hippocrates



# Beatitudes Campus Care Evolution

## Traditional Model

- All people used physical restraints
- All people received antipsychotic and anxiolytic medications
- 25-40% of population lost weight every month
- Strict adherence to therapeutic diets
- Spent \$30,000 annually on supplements
- Most people rejected care
- Sleep/wake were staff-driven
- Everyone showed Sundown symptoms
- Total focus on medical needs

## Comfort Model

- No physical restraints
- Antipsychotic & anxiolytic medication use is minimal
- Weight loss is rare
- NO therapeutic diets
- NO supplements used
- Resisting care/service is rare
- People sleep, wake & eat as they desire
- NO ONE exhibits Sundown symptoms
- Total focus on mind, body, spirit

# What the Comfort Matters® model looks like

People with dementia:

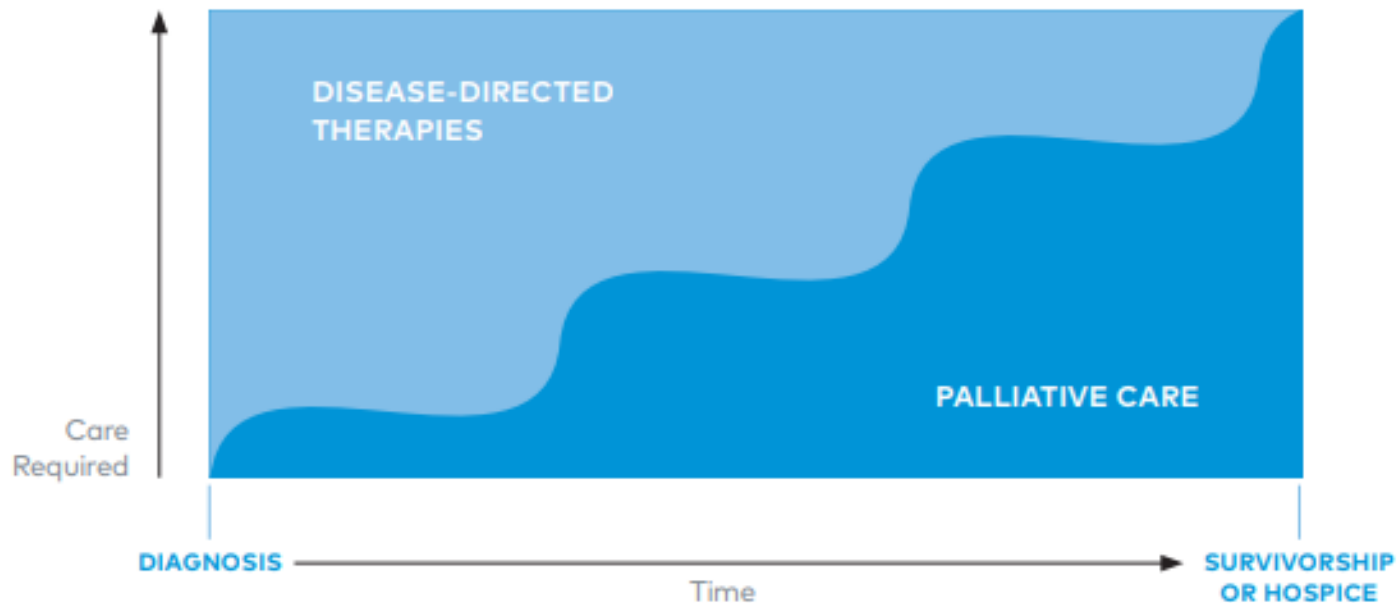
- Sleep when they're tired and wake when refreshed
- Eat what they enjoy when they're hungry
- ADLs delivered on each person's terms
- Participate in engagement events as they wish
- Experience an environment which meets their needs at every level

# Results Include

- Liberalized diets contributing to stable weights (almost no use of supplements)
- Increased toileting and reduced incontinence
- No use of physical restraints (including alarms)
- Almost no anti-psychotic, anxiolytic and sedative medications
- Increase in pharmacologic and non-pharmacologic methods for treating pain
- Decrease in total number of medications prescribed
- Elimination of 'sundowning' symptoms
- Residents receive active comfort and even enjoyment from meaningful engagement
- Decreased hospitalizations
- Increased family engagement and satisfaction
- Greatly improved staff satisfaction
- Almost no typical staff turnover

# Conceptual Shift for Palliative Care

**Palliative Care Is Appropriate at Any Point in a Serious Illness**





# Why do we need to look at palliative care through a dementia lens?

- Behavior is communication: it is not the dementia that causes the behavior, it is the dementia which prevents the person from expressing the cause of their distress
- Anti-psychotics may remove the person's only means of communication (and not be responsive to the underlying problem)
- Care settings/providers tend to want the person to conform to the needs of the setting, which means not only that the person's needs may not be met adequately or in a timely manner, but that the setting itself may be causing the person's distress
- Comfort will often not reach people with dementia unless dementia-specific adaptations are made in how care is delivered

# Behavior vs. Distress

- Use the word 'distress' rather than 'behavior'
- 'Behavior' suggests the person has control over their actions and can change if we tell them to
- 'Distress' suggests we should seek the reason for the person's discomfort and address it on their behalf (do for them what they cannot do for themselves)

# Bringing Comfort Matters® to NYC: Project Overview

- 30-months (starting 7/1/12 through 12/31/14)
- Nursing Homes: Cobble Hill Health Center; Isabella Geriatric Center; The New Jewish Home (Manhattan)
- Hospice Programs: Calvary Hospital Hospice; MJHS Hospice and Palliative Care of Greater New York, and Visiting Nurse Service of New York Hospice and Palliative Care (VNSNYHPC)
- Four phases initially: Training; Piloting; Sustaining & Spreading; Final Document (“Palliative Care for People with Dementia: Why Comfort Matters”)
- Final (fifth) phase: All three homes accredited by Comfort Matters®

# Project Components

- Training/Education (initial and ongoing)
- Weekly Meetings
- Evaluation
- Care Practices
- Communication with Families

# Care Practices

- Pain
- Environment
- Sleep/rest (sundowning)
- Food/Nourishment
- Balance/Stimulation
- Meaningful Engagement (Use of Day Rooms)
- Heat/Cold
- Toileting
- Ambulation

# Pain

- Pain is what the person says it is
- People experience pain differently
- Pain does affect cognition
- Research indicates people with dementia more likely not to have pain identified/treated
- Person with dementia who is experiencing pain may (1) deny pain, and (2) express their distress through their behavior.

# PAINAD Scale

**Pain Assessment in Advanced Dementia (PAINAD) Scale**

Items*	0	1	2	Score
<b>Breathing independent of vocalization</b>	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
<b>Negative vocalization</b>	None	Occasional moan or groan. Low-level speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
<b>Facial expression</b>	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
<b>Body language</b>	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
<b>Consolability</b>	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
<b>Total**</b>				

\*Five-item observational tool (see the description of each item below).

\*\*Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

# The Care Environment

- Noise
- Activities, shift-change, etc.
- Comfortable Places to Be
- Uncomfortable Places to Be
- Visitor Experience
- Sundowning





# Making the Most of Meals

- We are more likely to eat food we enjoy
- A comfortable dining environment makes a big difference
- The Importance of snacks

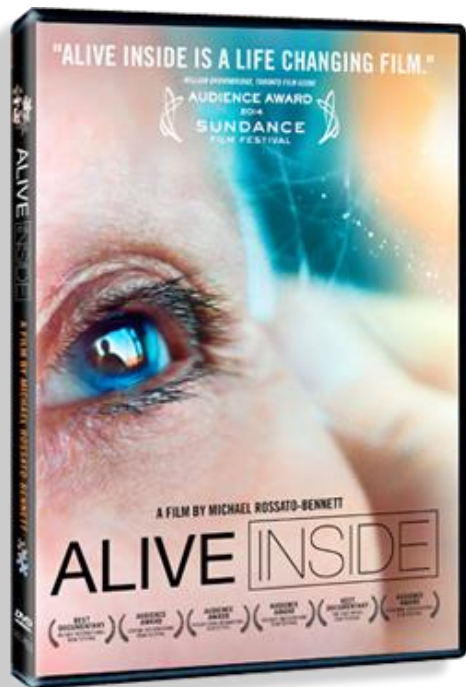


# Rest and Sleep/Wake Routines: The Importance of Resting When Tired

- Customary routines
- Changes in routine
- Frequency
- Finding what works for someone

# Rethinking Activities: Meaningful Engagement for People with Advanced Dementia

- People with advanced dementia can still feel lonely, bored or frustrated
- Every interaction holds the potential for meaningfulness (or its absence)
- Importance of one-on-one and small groups
- All staff involved
- Music & Memory, Inc. ([www.musicandmemory.org](http://www.musicandmemory.org))



# Data for Staff Knowledge and Commitment

## Staff Knowledge

■ Time 1 ■ Time 2

15.1

16.2

Knowledge Test Score (possible range 0-23)\*

## Staff Commitment

■ Time 1 ■ Time 2

strongly disagree----strongly agree

-1.27

-1.12

-1.31

-1.23

1.26

1.56

1.14

1.43

Will Look for  
Different Job

Often Think  
About Quitting

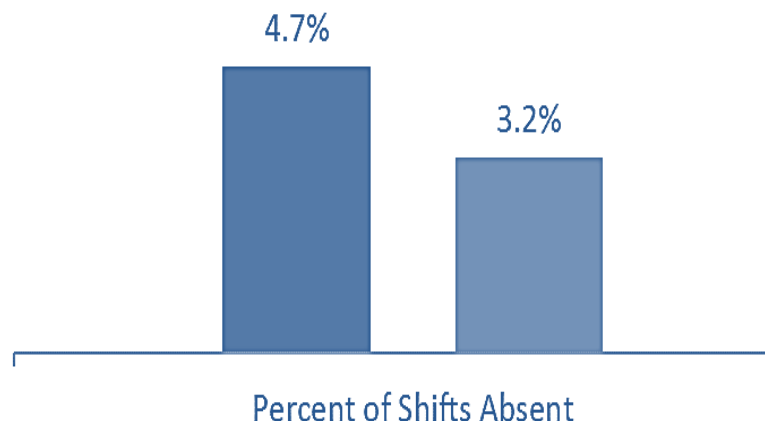
Recommend Care  
at My Facility\*

Recommend Job  
at My Facility\*

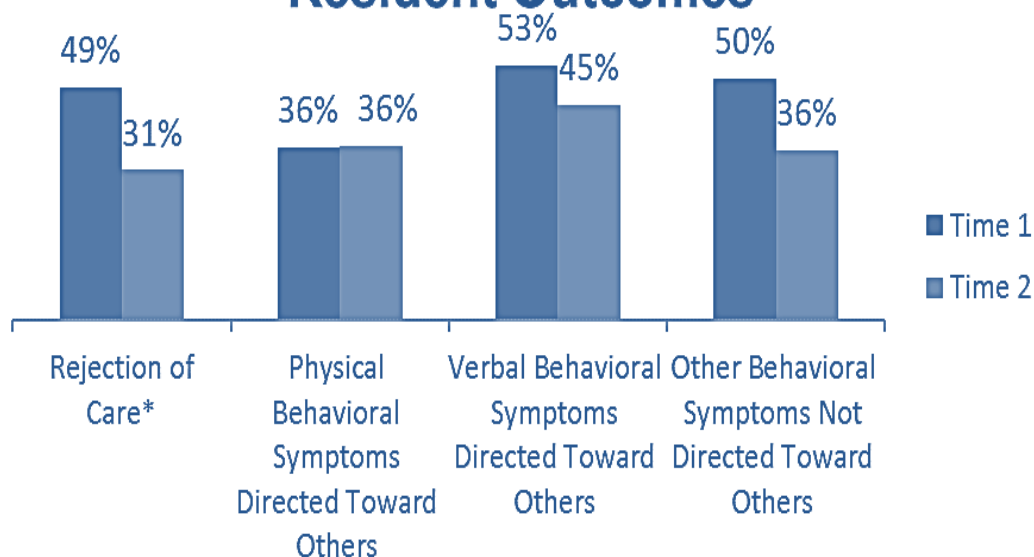
# Data for Absenteeism and Outcomes

## CNA Absenteeism

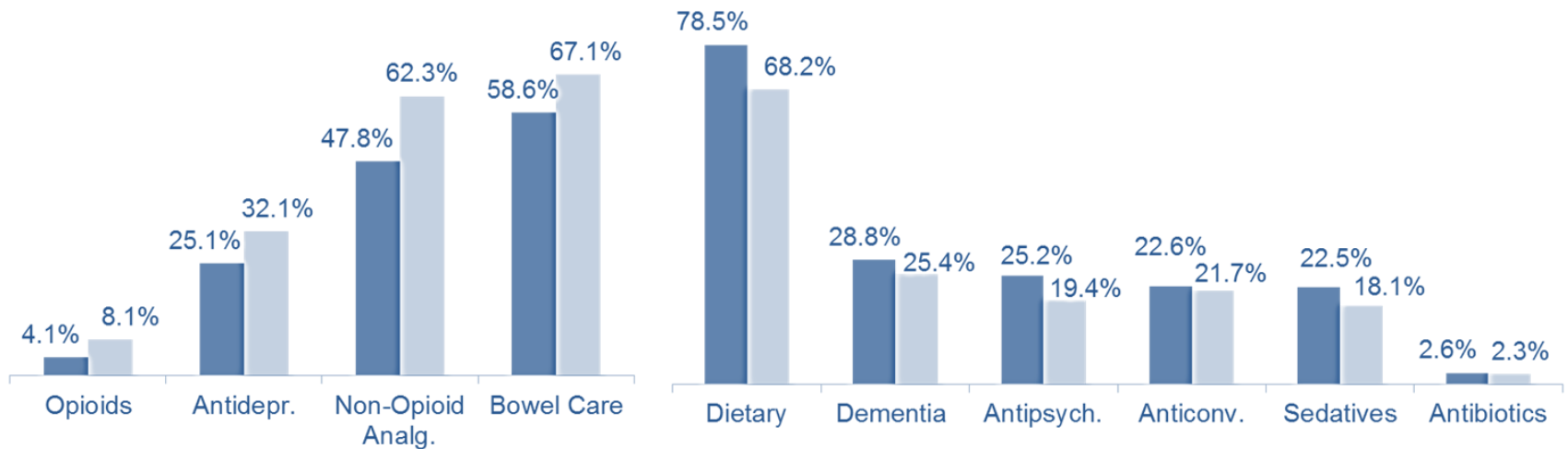
■ Time 1 ■ Time 2



## Resident Outcomes



# Medication Use (% of Resident Days on Therapy)



# Processes

- Weekly interdisciplinary meetings on-unit
- At time of admission, comprehensive assessment of care needs, habits, and comforts
- Education for families (Advance Directives)
- Care Plans (What Comforts Me)
- Roadmaps for Distress
- PAINAD



# Road Map to Comfort: Eliminating Rejection of Care & Distress

## Beatitudes Campus Comfort Road Map



<b>Dementia-related Behavior</b> <i>Describe what the person is actually doing, avoid using words such as agitated or combative</i>	<b>What is the Person Communicating</b> <i>Consider all possible meanings of the person's actions</i>	<b>Possible Remedies</b> <i>Consider all possible options that could help</i>

# What We Need to Know



## What Caregivers Should Know About Persons with Dementia

*Record information about this person that allows caregivers to personalize his/her care. Do not answer questions that would violate privacy.*

Name:	Preferred name:
Birthplace (city and state):	
Parents' names:	
Parents' occupation(s):	
Names of brothers:	
Names of sisters:	
Important information about brothers/sisters:	
Name of spouse/partner:	
Special memories of wedding day/honeymoon:	
Children's names:	
Grand-/great grandchildren's names:	
Places lived:	
Educational accomplishments:	
Occupation(s):	
Favorite job(s):	
Leisure activities:	
Spiritual affiliation/practices:	
Favorite spiritual songs:	
Favorite holiday:	
Favorite vacation activity/location:	
Favorite music:	
Favorite pet:	
Special rituals observed:	
Favorite food and drink:	
Favorite smells:	
Tobacco use—type:	frequency:
Wine or spirits use:	frequency:
Food dislikes:	
Coffee/tea use:	served with: frequency:
Special food preferences while ill:	
Preferred forms of comforting touch:	
Easily subject to temperature changes: cold/hot	
Preference for bathing:	time of day:
Clothing preference(s):	
Footwear preference(s):	
Beauty/barbershop usage:	frequency:
Manicure/pedicure usage:	frequency:
Shaving needs and razor type:	time of day for shaving:
Usual bed time and wake up time:	
Morning routines:	
Afternoon routines:	

# Some other considerations

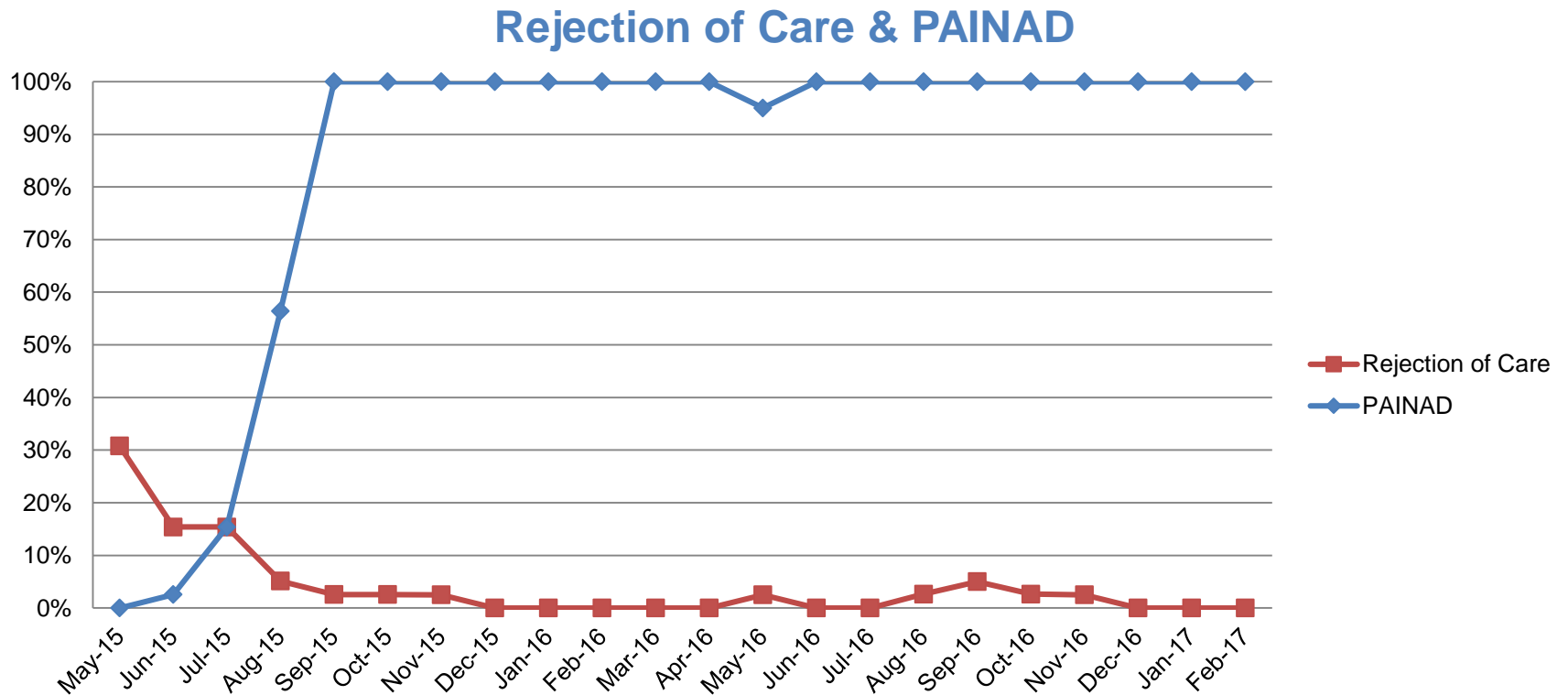
- Anticipation of Need
- Slow Down
- Consistent Assignment (replacement staff)
- Risk
- Falls
- Day Rooms
- QAPI
- Policies and Procedures

# QAPI and the Usefulness of Data

- Implementation Strategies
- Accessibility
- For use by managers and by direct care staff



# Data for Rejection of Care & PAINAD



# Care Planning & Advocacy

- Resistance to Care
- Verbal behavioral symptoms directed to others
- Physical behavioral symptoms directed to others
- 'Other' behavioral symptoms not directed to others
- **Avoid** using 'agitation' and 'combative'---instead, find out specifics about potential contributing factors to the distress

# Put it in the Care Plan

- Not just problems
- Comforts: Frank Sinatra; peanut butter; Mets games; the color pink; walking up and down the hall holding hands; naps after lunch; hot tea first thing in the morning; lollipops; pizza; walk around the block; sitting somewhere besides day room; wearing make up every day; hugs; memory books



# Comprehensive Care Plan

COBBLE HILL HEALTH CENTER  
COMPREHENSIVE CARE PLAN  
What Brings Me Comfort Care Plan

RESIDENT'S NAME: Ms. A

UNIT: B5

ROOM #

RESIDENT'S STRENGTH: Involved Daughter and Son

DATE	PROBLEMS/NEEDS /STRENGTHS	GOALS/EXPECTED OUTCOME	DATE	INTERVENTIONS	DISC.	DATE	EVALUATION / OUTCOME
03/14/14	<input type="checkbox"/> I have difficulty hearing so I like it when people look directly at me when speaking to me.  <input type="checkbox"/> I like to have a cup of coffee with a donut every day and I like to drink a lot of water.  <input type="checkbox"/> I like to be well groomed each day.  <input type="checkbox"/> I am very social and like to be with people and like to listen to music.  <input type="checkbox"/> I like to walk around the unit and like when people let me hold their arm and talk to me as we walk.  <input type="checkbox"/> I need help being redirected back to my room as I tend to want to lie down in bed throughout the day.  <input type="checkbox"/> I like take naps throughout the day.	<input type="checkbox"/> I will be spoken to face to face by others over the next 90 days.  <input type="checkbox"/> I will have my cup of coffee and donut every day as indicated over the next 90 days.  <input type="checkbox"/> I will be assisted with dressing in the clothes I prefer everyday over the next 90 days.  <input type="checkbox"/> I will hear music as indicated and be encouraged to engage with my peers as appropriate over the next 90 days.  <input type="checkbox"/> I will be engaged with by staff as I walk on the unit over the next 90 days.  <input type="checkbox"/> I will be redirected as needed to my room to lay down over the next 90 days.  <input type="checkbox"/> I will get as much sleep as I need over the next 90 days.	03/14/14	<input type="checkbox"/> Staff will look directly at Ms. A. when speaking to her.  <input type="checkbox"/> Staff will offer Ms. A. coffee and donuts as indicated as well as water on a daily basis.  <input type="checkbox"/> Staff will groom and dress Ms. A as she likes on a daily basis.  <input type="checkbox"/> Staff will engage Ms. A in TR programs with her peers and play music she likes on a daily basis.  <input type="checkbox"/> Staff will socialize with Ms. A. as she walks on the unit on a daily basis. .  <input type="checkbox"/> Staff will redirect Ms. A. back to her room as indicated on a daily basis.  <input type="checkbox"/> Staff will encourage resident to sleep in her own bed as appropriate on a daily basis.	T   N,TR,D   N   TR,N,SW   T   T   T		

N=Nursing MD =Physician D=Dietary SW=Social Work TR=Therapeutic Recreation PT/OT/ST=Physical/Occupational/Speech Therapy T= Team

# Palliative Care Decision Points: Maximizing Comfort

- Artificial Nutrition
- Antibiotic therapy
- Antipsychotic medications
- Cardiopulmonary Resuscitation (CPR)
- Screening Tests
- Hospitalizations
- Medications

# Hospice and End-of-Life Care

- Last six months
- Can be difficult to predict with dementia
- Need for palliation arises well before last six months in most cases
- Care plan considerations in residential care

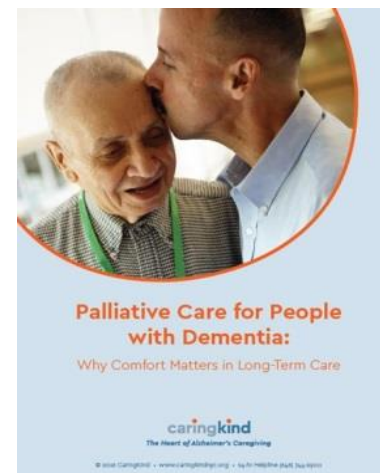
**“You matter because you are you and you matter to the end of your life.”**

-Dame Cicely Saunders, Nurse, Physician, and founder of the hospice movement



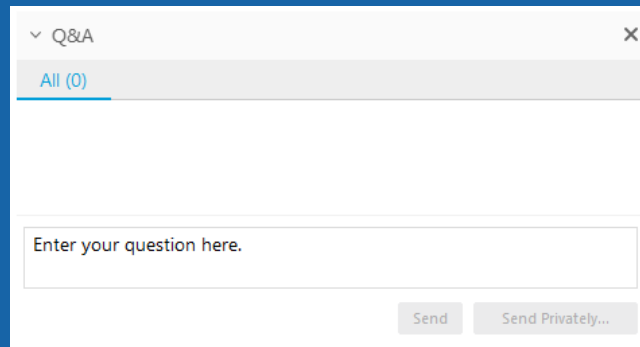
# Contact Information

- [www.caringkindnyc.org](http://www.caringkindnyc.org)
- [awyatt@caringkindnyc.org](mailto:awyatt@caringkindnyc.org)
- [talonzo@beatitudescampus.org](mailto:talonzo@beatitudescampus.org)
- [www.musicandmemory.org](http://www.musicandmemory.org)



# Questions?

Please type your question into the questions pane on your WebEx control panel.

A screenshot of the WebEx Q&A interface. The window has a title bar with a dropdown arrow, the text "Q&A", and a close button. Below the title bar is a tab labeled "All (0)". The main area is empty. At the bottom, there is a text input field with the placeholder text "Enter your question here." and two buttons: "Send" and "Send Privately...".

Q&A

All (0)

Enter your question here.

Send Send Privately...