Why Comfort Matters: Seeing Dementia through a Palliative Care Lens

ALZHEIMER'S DISEASE PROGRAM
ANNUAL CONTRACTORS MEETING

Jed Levine
Executive Vice-President, Director of Programs & Services

Ann Wyatt
Manager, Palliative and Residential Care

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How We Got to Comfort

- Rethinking how organizationally we can be of most 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

How we got to 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 in 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 ‘sun-downing’ symptoms
- Residents receiving active comfort and even enjoyment from meaningful engagement
- Decreased hospitalizations
- Increased family engagement and satisfaction
- Greatly improved staff satisfaction
- Almost no typical staff turnover

Debunking Descartes

"Each individual has social, emotional and spiritual elements which are at least as important as the intellectual. Spending time with people who have dementia challenges us as persons to develop in new ways."

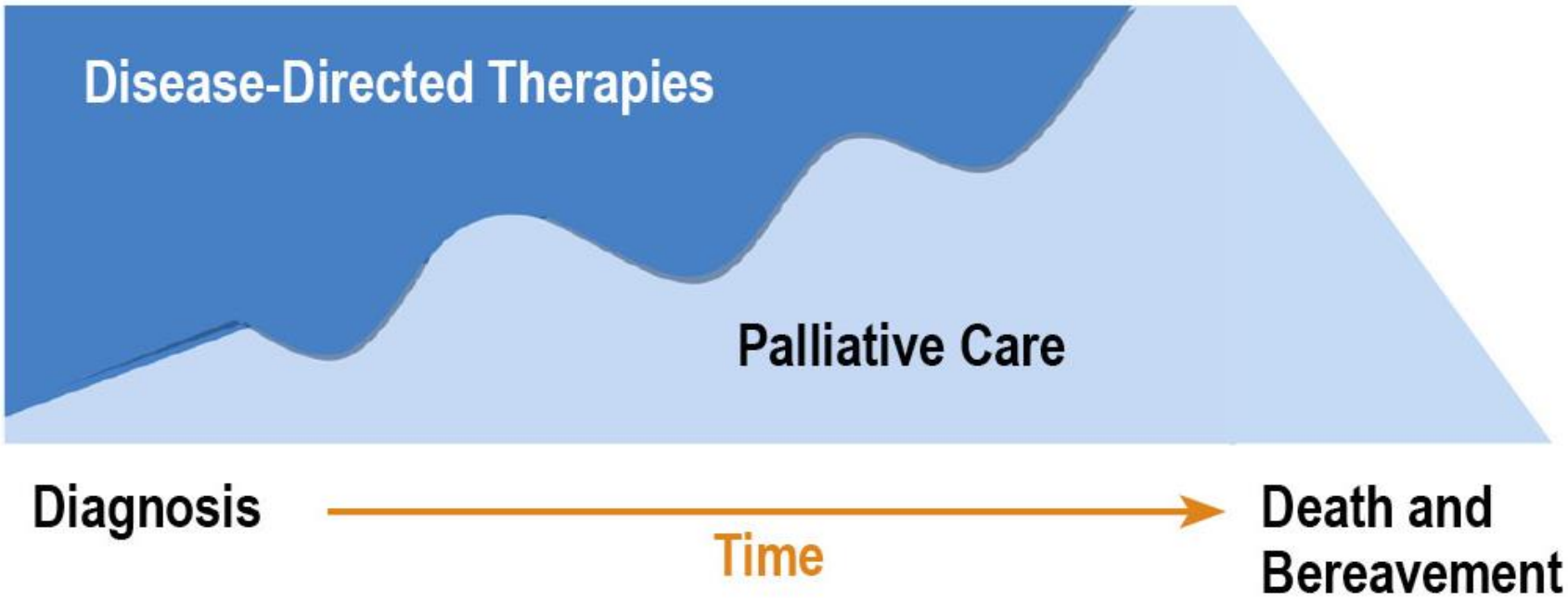
John Killick and Kate Allan

www.dementiapositive.co.uk

Palliative Care & Comfort:
Definition of Palliative Care from the World Health Organization

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Conceptual Shift for Palliative Care



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®* (and all have been re-accredited at this point)

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.

Pain Assessment in Advanced Dementia (PAINAD) Scale

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

*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

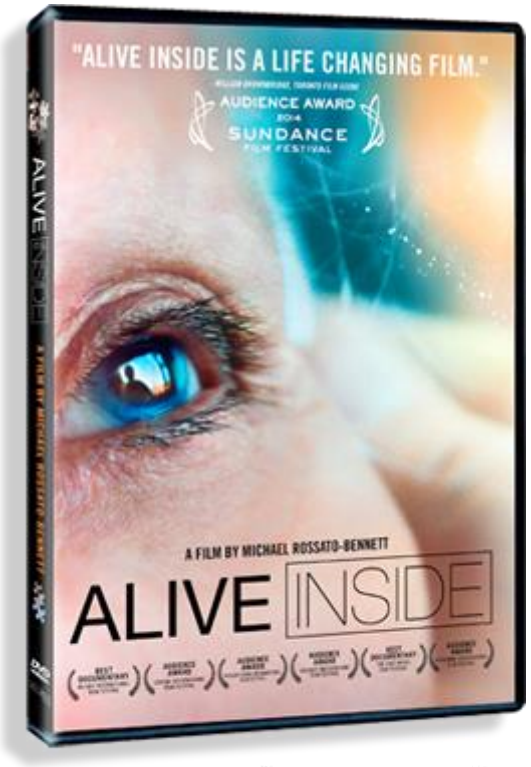
- We are more likely to eat food we enjoy
- A comfortable dining environment makes a big difference
- The Importance of snacks

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

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

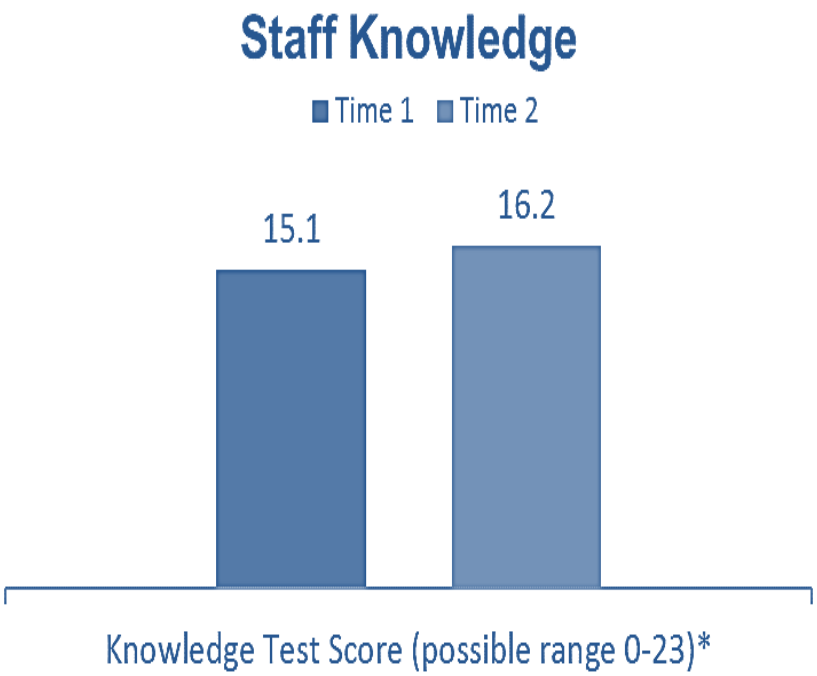
Rethinking Activities: Meaningful Engagement for People with Advanced Dementia

- 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)

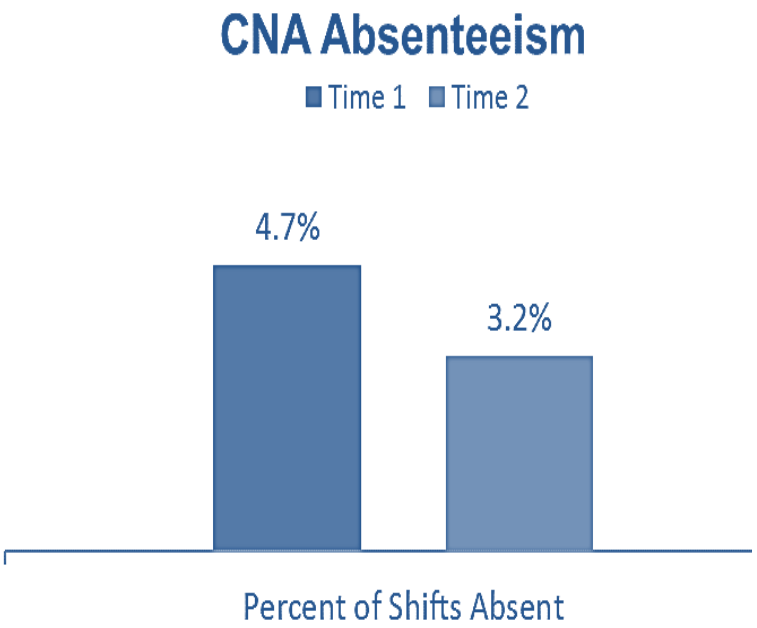

"ALIVE INSIDE IS A LIFE CHANGING FILM."
AUDIENCE AWARD
SUNDANCE
FILM FESTIVAL
A FILM BY MICHAEL ROSSATO-BENNETT
ALIVE INSIDE

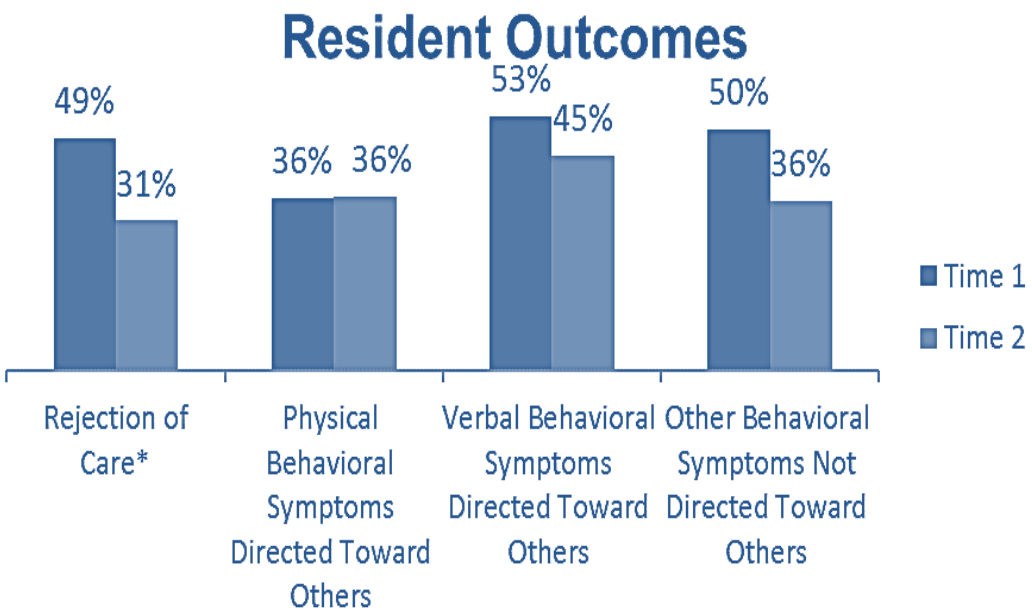
Non-Pharmacological Approaches

- Reposition the resident
- Check temperature in the environment; change clothes if necessary
- Decrease noise level
- Provide rest-nap in bed
- Toilet or hygiene care
- Redirect resident to another area
- Empathize with resident; simple hug or smile
- Know a familiar meaningful name to resident and mention it.

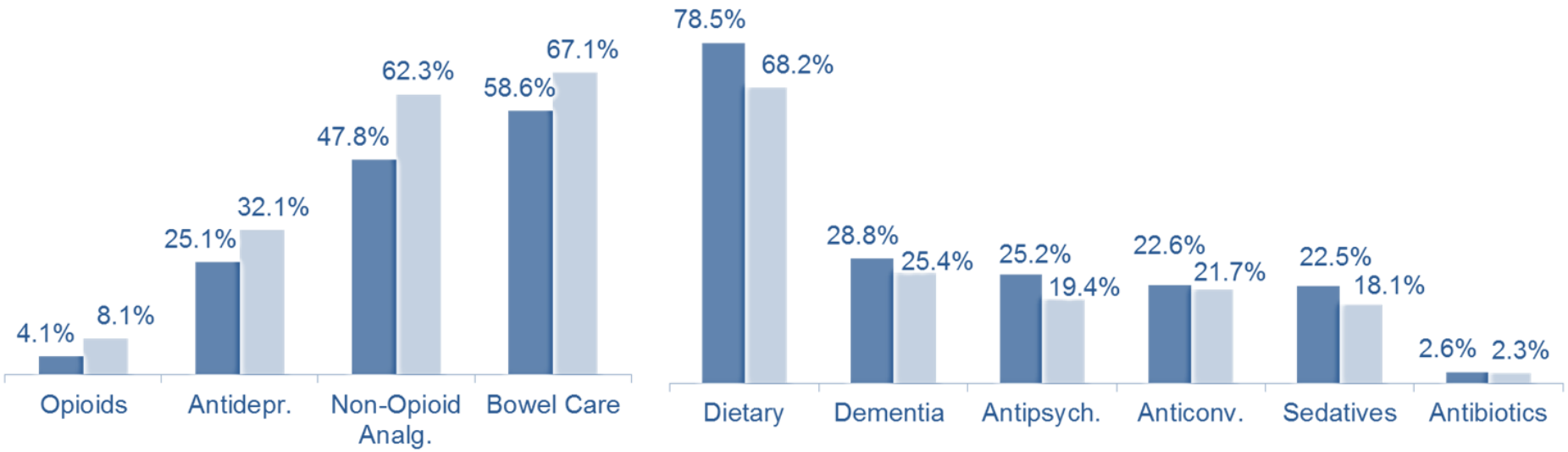

Staff Knowledge
Time 1
Time 2
15.1
16.2
Knowledge Test Score (possible range 0-23)*

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*


CNA Absenteeism
Time 1
Time 2
4.7%
3.2%
Percent of Shifts Absent


Resident Outcomes
49%
31%
36%
36%
53%
45%
50%
36%
Rejection of Care*
Physical Behavioral Symptoms Directed Toward Others
Verbal Behavioral Symptoms Directed Toward Others
Other Behavioral Symptoms Not Directed Toward Others
Time 1
Time 2

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
- PaindAD

Road Map to Comfort: Eliminating Rejection of Care & Distress

Beatitudes Campus Comfort Road Map

ComfortMatters
From Beatitudes Campus
Living Better with Dementia

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

What We Need to Know

ComfortMatters

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:

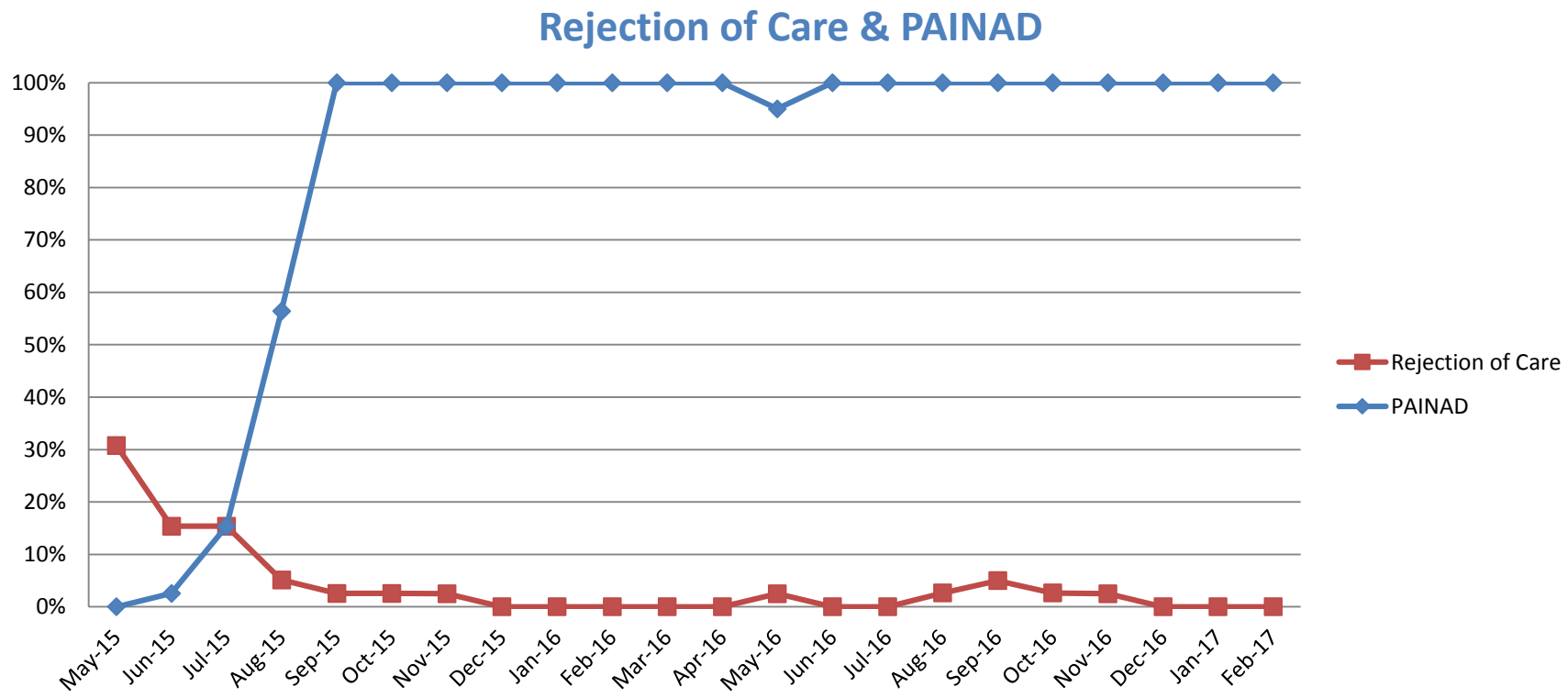
Afternoon routines:

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


Rejection of Care & PAINAD
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
May-15
Jun-15
Jul-15
Aug-15
Sep-15
Oct-15
Nov-15
Dec-15
Jan-16
Feb-16
Mar-16
Apr-16
May-16
Jun-16
Jul-16
Aug-16
Sep-16
Oct-16
Nov-16
Dec-16
Jan-17
Feb-17
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

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

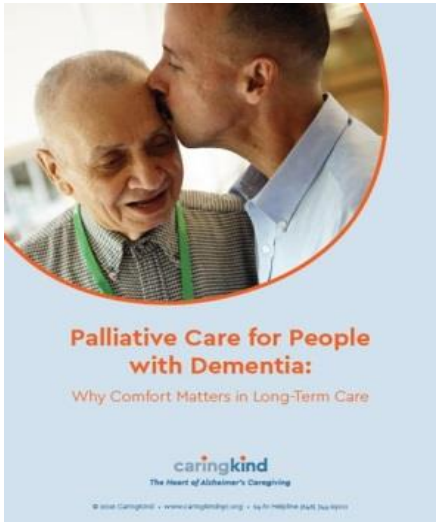
- Artificial Nutrition
- Antibiotic therapy
- Antipsychotic medications
- Cardiopulmonary Resuscitation (CPR)
- Screening Tests
- Hospitalizations
- Medications

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

- jlevine@caringkindnyc.org
- awyatt@caringkindnyc.org
- caringkindnyc.org/palliativecare
- talonzo@beatitudescampus.org
- www.musicandmemory.org