Why Comfort Matters: Seeing Dementia through a Palliative Care Lens

ALZHEIMER’S DISEASE PROGRAM
ANNUAL CONTRACTORS MEETING

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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

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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

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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
The Heart of Alzheimer’s Caregiving

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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

Disease-Directed Therapies

Palliative Care

Diagnosis

Time

Death and Bereavement

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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

<table>
<thead>
<tr>
<th>Items*</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low-level speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
<td></td>
</tr>
</tbody>
</table>

*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").

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**CaringKind** The Heart of Alzheimer’s Caregiving

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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

"ALIVE INSIDE IS A LIFE CHANGING FILM."

A FIlM BY MICHAEL ROSSATO-BENNETT

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The Heart of Alzheimer's Caregiving

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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

<table>
<thead>
<tr>
<th>Knowledge Test Score (possible range 0-23)*</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>15.1</td>
<td>16.2</td>
</tr>
</tbody>
</table>

### Staff Commitment

<table>
<thead>
<tr>
<th>Will Look for Different Job</th>
<th>Often Think About Quitting</th>
<th>Recommend Care at My Facility*</th>
<th>Recommend Job at My Facility*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1</td>
<td>Time 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-1.27</td>
<td>-1.12</td>
<td>1.26</td>
<td>1.56</td>
</tr>
<tr>
<td>-1.31</td>
<td>-1.23</td>
<td>1.14</td>
<td>1.43</td>
</tr>
</tbody>
</table>

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CNA Absenteeism

- Time 1: 4.7%
- Time 2: 3.2%

Percent of Shifts Absent

Resident Outcomes

- Rejection of Care*: 49% (Time 1), 31% (Time 2)
- Physical Behavioral Symptoms Directed Toward Others: 36% (Time 1), 36% (Time 2)
- Verbal Behavioral Symptoms Directed Toward Others: 53% (Time 1), 45% (Time 2)
- Other Behavioral Symptoms Not Directed Toward Others: 50% (Time 1), 36% (Time 2)

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Medication Use (% of Resident Days on Therapy)

- **Opioids**: 4.1%, 8.1%
- **Antidepressants**: 25.1%, 32.1%
- **Non-Opioid Analgesics**: 47.8%, 62.3%
- **Bowel Care**: 58.6%, 67.1%
- **Dietary**: 78.5%, 68.2%
- **Dementia**: 26.8%, 25.4%
- **Antipsychotics**: 25.2%, 19.4%
- **Anticonvulsants**: 22.6%, 21.7%
- **Sedatives**: 22.5%, 18.1%
- **Antibiotics**: 2.6%, 2.3%

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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

24-hour Helpline 646-744-2900  www.CaringKindNYC.org
# Road Map to Comfort: Eliminating Rejection of Care & Distress

## Beatitudes Campus Comfort Road Map

<table>
<thead>
<tr>
<th>Dementia-related Behavior</th>
<th>What is the Person Communicating</th>
<th>Possible Remedies</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Consider all possible meanings of the person's actions</td>
<td>Consider all possible options that could help</td>
</tr>
</tbody>
</table>

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

### Contact Information:
- 24-hour Helpline: 646-744-2900
- www.CaringKindNYC.org
What We Need to Know

What Caregivers Should Know About Persons with Dementia

Basic information about this person that allows caregivers to provide better 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: ___________________________
Grandchildren's names: ___________________________
Places lived: ___________________________
Educational accomplishments: ___________________________

Occupation(s): ___________________________
Favorite job(s): ___________________________
Leisure activities: ___________________________
Spiritual affiliation/practices: ___________________________
Favorite spiritual song: ___________________________
Favorite holiday: ___________________________
Favorite vacation activity/location: ___________________________
Favorite music: ___________________________
Favorite time to listen to 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: ___________________________
Cleaning preferences: ___________________________
Footwear preferences: ___________________________
Beauty/barbering usage: ___________________________
Frequency: ___________________________
Manicure/pedicure usage: ___________________________
Frequency: ___________________________

Shaving needs and razor type: ___________________________
Time of day for shaving: ___________________________

Morning routines: ___________________________

Afternoon routines: ___________________________

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Some other considerations

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

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QAPI and the Usefulness of Data

- Implementation Strategies
- Accessibility
- For use by managers and by direct care staff
The Heart of Alzheimer’s Caregiving

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The Heart of Alzheimer’s Caregiving

Rejection of Care & PAINAD

Rejection of Care
PAINAD

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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
<table>
<thead>
<tr>
<th>DATE</th>
<th>PROBLEMS/NEEDS/SPECIAL INTERESTS</th>
<th>GOALS/EXPECTED OUTCOME</th>
<th>DATE</th>
<th>INTERVENTIONS</th>
<th>DISC.</th>
<th>DATE</th>
<th>EVALUATION / OUTCOME</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/14/14</td>
<td>I have difficulty hearing so I like it when people look directly at me when speaking to me. I like to have a cup of coffee with a donut every day and I like to drink a lot of water. I like to be well groomed each day. I am very social and like to be with people and like to listen to music. I like to walk around the unit and like when people let me hold their arm and talk to me as we walk. I need help being redirected back to my room as I need to want to lie down in bed throughout the day. I like to take naps throughout the day.</td>
<td>I will have difficulty hearing so I like it when people look directly at me when speaking to me. I like to have a cup of coffee with a donut every day and I like to drink a lot of water. I like to be well groomed each day. I am very social and like to be with people and like to listen to music. I like to walk around the unit and like when people let me hold their arm and talk to me as we walk. I need help being redirected back to my room as I need to want to lie down in bed throughout the day. I like to take naps throughout the day.</td>
<td>03/14/14</td>
<td>□ Staff will look directly at Ms. A when speaking to her. □ Staff will offer Ms. A coffee and donuts as indicated as well as water on a daily basis. □ Staff will groom and dress Ms. A as she likes on a daily basis. □ Staff will engage Ms. A in TR programs with her peers and play music she likes on a daily basis. □ Staff will socialize with Ms. A as she walks on the unit on a daily basis.</td>
<td>T</td>
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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