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
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
→ 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.
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

- DISEASE-DIRECTED THERAPIES
- PALLIATIVE CARE

Care Required

DIAGNOSIS

Time

SURVIVORSHIP OR HOSPICE
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

<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></td>
<td>inexpressive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>console</td>
<td></td>
<td></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").
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)
Data for Staff Knowledge and Commitment

**Staff Knowledge**

<table>
<thead>
<tr>
<th>Time</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time 1</td>
<td>15.1</td>
</tr>
<tr>
<td>Time 2</td>
<td>16.2</td>
</tr>
</tbody>
</table>

**Staff Commitment**

- Will Look for Different Job: Time 1 = -1.27, Time 2 = 1.26
- Often Think About Quitting: Time 1 = -1.31, Time 2 = 1.56
- Recommend Care at My Facility*: Time 1 = 1.14, Time 2 = 1.43
- Recommend Job at My Facility*: Time 1 = 1.14, Time 2 = 1.43
Data for Absenteeism and Outcomes

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

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

<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 would help</td>
</tr>
</tbody>
</table>

Beatitudes Campus Comfort Road Map
# What We Need to Know

**What Caregivers Should Know About Persons with Dementia**

Anecdotal information about the person that allows caregivers to personalize his/her care: we are aware questions that would violate privacy.

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

Rejection of Care & PAINAD

- 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

### Resident's Name: Ms. A
**Resident's Strengths:** Involved Daughter and Son

<table>
<thead>
<tr>
<th>Date</th>
<th>Problem/Needs</th>
<th>Goal/Expected Outcome</th>
<th>Interventions</th>
<th>Date</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.</td>
<td>I will be spoken to face to face by others over the next 10 days.</td>
<td>Staff will speak directly at Ms. A when speaking to her.</td>
<td>01/14/14</td>
<td>T</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I like to have a cup of coffee with a donut every day and I like to drink a lot of water.</td>
<td>I will have my cup of coffee and donut every day as indicated over the next 10 days.</td>
<td>Staff will offer Ms. A coffee and donuts as indicated as well as water on a daily basis.</td>
<td>01/14/14</td>
<td>T, T</td>
<td>D</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I like to be well groomed each day.</td>
<td>I will be assisted with dressing in the clothes I prefer everyday over the next 10 days.</td>
<td>Staff will groom and dress Ms. A as she likes on a daily basis.</td>
<td>01/14/14</td>
<td>N</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I am very social and like to be with people and like to listen to music.</td>
<td>I will hear music as indicated and be encouraged to engage with my peers as appropriate over the next 10 days.</td>
<td>Staff will engage Ms. A in TR programs with her peers and play music she likes on a daily basis.</td>
<td>01/14/14</td>
<td>N, T</td>
<td>N, SW</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I like to walk around the unit and like when people let me hold their arm and talk to me as we walk.</td>
<td>I will be engaged with by staff as I walk in the unit over the next 10 days.</td>
<td>Staff will socialize with Ms. A, as she walks on the unit on a daily basis.</td>
<td>01/14/14</td>
<td>N</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I need help being redirected back to my room as I tend to want to lie down in bed throughout the day.</td>
<td>I will be redirected as needed to my room to lay down every day over the next 10 days.</td>
<td>Staff will redirect Ms. A, back to her room as indicated on a daily basis.</td>
<td>01/14/14</td>
<td>N</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I like to take naps throughout the day.</td>
<td>I will get as much sleep as I need over the next 10 days.</td>
<td>Staff will encourage resident to sleep in her own bed as appropriate on a daily basis.</td>
<td>01/14/14</td>
<td>T</td>
<td>T</td>
<td></td>
</tr>
</tbody>
</table>

**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
Questions?

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