Psychosocial Interventions that aim to Comfort Persons with Dementia

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Nursing Home Social Work Network
Webinar Series

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Tena Alonzo

- Tena Alonzo is the Director of Education & Research and the Director of the Comfort First, a dementia care education program at Beatitudes Campus in Phoenix, Arizona. She has spent more than 25 years working to enhance the lives of persons with dementia. Her work has appeared in the book Palliative Care for Advanced Alzheimer’s and Dementia, the Gerontologist, the Journal of Hospice & Palliative Nursing, the American Journal of Alzheimer’s Disease & Other Dementias, the Annuals of Long Term Care. She received a Bachelor of Science (1983) and Master of Arts degree (1985) both in Psychology from Northern Arizona University.

Deirdre Downes

- Deirdre Downes, LCSW is the Corporate Director of Social Work Initiatives at Jewish Home Lifecare in New York and has worked in the field of aging for over twenty years. She received her undergraduate degree from Barnard College and her master’s degree from Hunter College School of Social Work. She is currently a Ph.D candidate at City University of New York Graduate Center.
Session objectives

1. Identify three characteristics of mild, moderate and advanced dementia
2. Identify three advanced care planning choices that can be made by older adults
3. Describe a basic framework social workers can use when discussing advanced care planning with surrogate decision-makers

Progression of Dementia

<table>
<thead>
<tr>
<th>Mild</th>
<th>Moderate or Mid-Stage</th>
<th>Severe or Late Stage</th>
<th>Terminal</th>
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</thead>
<tbody>
<tr>
<td>Impaired memory; Personality changes; Spatial disorientation</td>
<td>Confusion; Agitation; Insomnia; Aphasia; Apraxia</td>
<td>Resistiveness; Incontinence; Eating difficulties; Motor impairment</td>
<td>Bedfast; Mute; Intercurrent infections; Dysphagia</td>
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(Hurley & Volicer, 1998)
Mild Brain Deterioration Due to Alzheimer’s Disease

Memory and Thinking
• Difficulty with short-term memory
• Poor concentration
• Poor decision-making

Language
• Problems remembering the right word or name

Mood
• May become depressed or socially withdrawn

Function
• Difficulty organizing and managing household affairs, such as cleaning, cooking and yard work.
• Trouble handling finances
• Difficulty initiating activities
• Gets lost/mixed up when driving in familiar places

Moderate Brain Deterioration Due to Alzheimer’s Disease

Memory and Thinking
• Difficulty with short- and long-term memory
• Forgets own personal history
• May begin to forget friends and family members

Language
• May not understand what is being said
• Loses ability to express self and make needs known

Mood
• Easily upset and frustrated
• May appear to lack emotion

Function (needs help with the following)
• Dressing
• Grooming
• Bathing
• Bowel & bladder elimination
Advanced Brain Deterioration Due to Alzheimer’s Disease

Memory and Thinking
• Severely impaired memory for recent and past events

Language
• Unable to carry on a meaningful conversation

Mood
• Appears withdrawn
• Difficult to engage

Function
• Has difficulty interacting/responding to surroundings
• Forgets how to walk without help; may lead to eventual loss of body movement
• Relies totally on caregivers for: dressing, grooming, bathing, feeding, bladder/bowel
• May forget to chew food or swallow
• May lose ability to sit up, hold head up and/or smile

Source: Hospice of the Valley, 2005; revised 2012

The Resilient Human Brain

➢ People with dementia are experts on their own comfort
➢ Our emotions are intact and we can receive information from the world into our limbic system
➢ Information is transferred through our senses
➢ When verbal communication is compromised we communicate through our behavior/actions
Psychosocial Interventions that aim to comfort persons with dementia

• Most types of dementia cannot be cured: families need help understanding the course of the illness and what to expect. Don’t assume families know this...

• Social Workers can provide education through: Family council meetings, Support Groups, Care Plan Meetings - important to be proactive and not wait for the crisis point.

Things to consider when the goal is comfort -

• How are goals of care addressed at your facility?
• Who discusses advance care planning and when? Is it a one time discussion or on-going?
• Who is the resident’s family? How are decisions made in this family?
• What is the family member’s understanding of the illness? Be prepared to ask this question and listen for the responses.
• What does the family understand about the person’s wishes for End of Life Care?
• What supports does the family need? (Pastoral Care, Hospice, Support Groups, a good listener...)
• What are the laws/regulations in your state?
Goals of Care Discussion

• Attention to detail: should take place in quiet area (no distractions);
• Everyone should have a place to sit
• All staff involved should understand dementia and the course of the illness and comfort as the goal
• Families need time to take in information – understand benefits/burdens
• Ask for feedback: what did family hear? What do they understand?
• What can the family expect to happen next?

What do families want?

• The resident to be pain and symptom free
• Sense that their loved one is receiving good care
• Good lines of communication with the nursing home staff – families want information
• Being able to say goodbye

(Munn, 2006, Beila, et al 2007)
Comfort-Focused Care for persons with advance dementia

- Focuses on recognizing and relieving pain
- Addressing distressing symptoms: signs of agitation, loneliness, boredom, anxiety, poor appetite
- Is an active approach to care – not “nothing can be done…”

Behavior as a Form of Communication

- Social workers can help develop cohesive teams: everyone’s observations help decipher what the resident is trying to tell us through their behavior. (questions: who attends your team meetings?, how is information gathered and shared?)
- First Meet Basic Needs, then ask:
- What makes this person comfortable? Naps, Quiet, Going outside, Music, Dining, Exercise, Gentle Massage, Relationships…..how can we aid in comfort
- Think about Spiritual Comfort: Prayer, Hymns, and more
- Engage the family – team efforts bring the family comfort

(Kitwood, 1997; Volicer & Hurley, 2003; Kolansker & Ustaker, 2006)
Families as Partners

• Families provide the history and help us get to know each person: social work role includes documenting the history and sharing with the community (About Me, bulletin boards, creative ways of sharing).
• Creating tools – an activity for families: Memory Books, Ipods
• This information can guide end of life care

Tools

• compassionandsupport.org
• See your State Guidelines
• Five Wishes
  • Encouraging Comfort Care: A guide for Families of People with Dementia Living in Care Facilities – Alzheimer’s Association Greater Illinois Chapter 847 – 933-2413
  • MusicandMemory.org
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Thank you.

A recording of this webinar is available through the National Nursing Home Social Work Network website:

http://clas.uiowa.edu/socialwork/nursing-home/webinars