Early through Advanced Dementia: Roles for Social Work with Person and Family Transitions

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Lisa, a clinical social worker with 40 years of experience working with individuals with dementia and families, is an associate professor in the Dept of Psychiatry at Duke School of Medicine and the founder and director of the Duke Family Support Program, and education director of the Bryan Alzheimer’s Disease Research Center at Duke. She has two popular books Caring for People with Alzheimer’s Disease: A Manual for Facility Staff (1985, 2001) from the Alzheimer’s Association and AHCA, and co-author of The Alzheimer’s Action Plan: A Family Guide (2009). She was honored in 1998 as a founder of the national Alzheimer’s Association. She is past president of the Gerontological Society of America, a distinguished social work practitioner of the National Academies of Practice, and producer of a national award-winning documentary on Alzheimer’s care.

Ann Wyatt, MSW
Ann has been working in the field of long term care since 1973, when she worked in Washington Heights in a program that provided assistance to older people living at home. Currently, she is the Project Coordinator for the palliative care project of the Alzheimer’s Association, NYC Chapter, working extensively with Cobble Hill, Isabella and Jewish Home to establish innovative, comprehensive palliative care programs for people with advanced dementia. She has also in recent years worked with the Cobble Hill-Isabella Collaboration Project, concerned with creating more person-centered care environments, and with the United Hospital Fund on their family caregiver project, Next Step in Care.

Objectives
1. List the warning signs of dementia
2. Describe stages of dementia
3. Describe family concerns at each stage
4. Explain advantages of focusing on behaviors
5. Discuss ways social workers can help

More than Memory
“How do I want to be treated? I want to be treated well, just like normal. Alzheimer’s isn’t my whole life. I want to be included. I am more than memory or a diagnosis. I wonder, Am I a case? I thought I was just one of the Ramblers...”

Tommy Thompson, Musician and Founder
NC Red Clay Ramblers (Radio Interview)
We Do Wonder….
“...I get tired of asking when or what is going to be, but I don’t want to keep my mouth shut all the time. I want to be part of something. We people with Alzheimer’s actually do wonder how things happen and why. We want things to be like they used to be — it hurts like hell. Being dense is a big part of it — it’s a very come and go disease.”

Cary S. Henderson, Ph.D.
Harrisonburg, VA

My Dog Helps
“My little dog takes the edge off. He doesn’t talk back or tell you you’re crazy.”

Cary S. Henderson, 1994

“We Want What You Do”
“I want to go to lunch with friends, complain about the local sports teams and talk about the same stuff they do.”

Man living with dementia at Los Angeles Forum

It’s About Fear
• Shame
• Embarrassment
• Stigma/discrimination
• Rejection
• Marginalization
• Social isolation
• Loss of control
• Loss of identity props

“My brain gave up, more or less”

Voices of Dementia Family Caregivers
• There is never enough of me or enough of the quality help I need
• I can’t remember the last time I didn’t worry about...
• I knew I was in trouble when I knew more about mom’s prescriptions than my own
• I will never stop feeling anxious when the phone rings.
What Families Say

I was taking one day at a time, but then several days got together and ambushed me.

Alzheimer’s Is:
- The most common dementia
- A clinical diagnosis
- Complex
- Progressive
- More than memory loss
- Variable in symptoms and duration

The Six Cs of Family Care
- Common
- Chronic
- Complex
- Costly
- Choices
- Conflict

Warning Signs of Dementia
- Repeat same questions?
- Lost on familiar routes?
- Difficulty following directions?
- Confused about time, people, places?
- Not taking care of self, hygiene, responsibilities?
  - www.myhealth.va.gov/

Early Dementia: Family Concerns
- He’s not himself – lost spark, starts nothing, doesn’t care, can’t make decisions
- He goes to the bank every day
- He stopped traveling
- He didn’t pay taxes...he’s a CPA
- It took him an hour to drive to a pharmacy nearby
- He messes up minor repairs

What’s Changed?

He looks fine to me
Early Dementia: Family Concerns

• She can’t follow recipes, won’t change plans
• She constantly checks, searches or hoards
• She wears the same thing, eats only sweets
• She paid a stranger $1700 to clean the gutter
• She insists she takes her meds, but after I set her up for the week, all the meds are gone in two days or none of them are gone.

Money Matters

She didn’t want me to take over.
- Daughter

Who Are You To Question? I’ve Had A Clean Driving Record For 60 Years.

Moderate Dementia: Family Concerns

• He’s up at night for a job he had years ago.
• Her place looks like “What’s wrong with this picture?”
• Neighbors, bankers or pharmacists are complaining.
• She even follows me to the bathroom
• She can read my reminders but doesn’t follow them.
• She thinks I’m her sister or an imposter

Home Alone: But She Fired the Help!

A Crisis Around Every Corner

My good-natured dad, Robert, who has Alzheimer’s disease, finds it’s harder and harder to wait for me while I take care of business.
- Amy Goyer, AARP Bulletin, November 2013
Moderate Dementia: What Changes?

- Confabulation: I showered this morning
- Perseveration: Kleenex, Vitamins
- Disinhibition: Public vs. private behavior
- Delusions: suspicious, theft, infidelity
- Mirror sign
- Spatial relationships problems: falls, balance

It's not that she can’t dress herself – it’s that she won’t let me help, even when she dresses for church in three shirts, a hat, and panties.

– Daughter of a women with AD

How Can Social Workers Prepare the Person with Dementia?

- You will have days when things are easier
- You will retain some skills, knowledge and the capacity to enjoy life
- Ask for reminders, reassurance
- Allow extra time and avoid rushing
- Don’t waste energy hiding from embarrassment
- Rely on trusted family and friends, especially with money and medication management

Social Work Reminders For the Family about the Person with Dementia

- The person is not unhappy or upset because of what you have done. He is living with unwanted dependency.
- People with chronic illness take out their frustration on close family.
- Considering what is best for a family involves compromise among competing needs, loyalties and commitments.

The Power of Pleasant Events

- Evidence-based alternative to “you need to take care of yourself”
- Behavior activation effective for mild depression
- Tailored, personalized strategy
- Adult, dignified, purposive strategy

What Families Need from Social Workers

- Family and person centered information
- Decisional support and acknowledgement
- Compassion re: imperfection, uncertainty
- Help with feelings: failure, loss of control, guilt
- Fresh perspective, appraisal of options, adaptation or coping tips, and problem solving
Prepare for Resistance to Community Service Referrals

- Stigma
- Denial/poor judgment
- Too many changes at once
- Loss of control
- Cost
- Overwhelming disclosure in assessment – privacy issues

Pressure Points in Dementia Care

Transitions:
- Event or change triggers recognition/diagnosis
- Changes in handling money, alcohol, driving, travel, meds
- Changes in safety – fraud, neglect, exploitation, live-alones
- Hospitalization, surgeries, medication and treatment decisions: Determining capacity

Pressure Points in Dementia Care

Transitions:
- Illness, injury or death of caregiver
- Continuous supervision, requests for antipsychotics, sleep medications
- Moves to residential or skilled nursing care
- Palliative/hospice care needs

If Only ...

Decision-making Hazards

- Unrelenting crises
- Old promises
- Chasing ghosts
- Conflicting perceptions, expectations
- Control issues
- Too few good choices

I'm becoming someone scary. I'm not sure what I might do to him.

- A Wife
Almost Home

“Where Someone Cares”
Chandelier Assisted Living

Whereerin Assisted, Assisted Living Resides

- Independent Living for “85 and Better”
- Housing Staff & House Doctors
- House Doctor Work Available to All
- Library–Study/Garden Porch
- Work–Beautify Your Place
- Goal–Pursue Your Interests
- Lake & Beautiful Gardens
- Caring Staff & More...

821-333-2238 or 821-333-1308

She doesn’t belong in a nursing home

Looking at Long-Term Care? What is Home-Like?

Learn About the Person

- Family and friends
- Sleep habits
- Occupation
- Significant events
- Favorite foods
- Childhood experiences
- Spiritual beliefs

- Quirks
- Routines
- Likes/dislikes
- Life achievements
- Hobbies
- Communication preferences


You Catch On

Let me tell you, we love you all, and we’re gonna keep on loving you as long as we can ... What’s good about you all is you catch on, you catch on, you catch on and you know it’s not going to be perfect.

— Jean Walker in her 90s

Four years before her death with Alzheimer’s

Palliative Care & Advanced Dementia in the Nursing Home

alzheimer's association

New York City Chapter

- NYC Chapter working with three NYC nursing homes to adapt model (Comfort First™) developed by Beatitudes Campus in Phoenix, Arizona (30-month project)
- Project includes initial training, ongoing evaluation, implementation and ‘spread’ of practice changes, starting with pilot units

Why the Beatitudes (Comfort First™) Model?

- Behavior as communication
- Training in dementia care
- Training in end-of-life care
- Specific care practices
- Link to hospice
- Active comfort
- Organizational adaptations
Behavior is Communication

*Comfort First™* refers to both specific care practices and the process by which these practices are implemented.

It is about listening, to residents, to families, to staff at all levels, all disciplines.

Getting to the Root of Things

It is about asking everyone, family, nursing assistants, nurses, housekeepers, activities workers, rehabilitation staff, social workers, physicians, dietary staff to be detectives, to find out (1) what has distressed the resident, (2) trying to find out what can we do to eliminate the distress, and (3) being willing to try out new, sometimes very different ideas.

Making Palliative Care Meaningful for People with Advanced Dementia: Identifying Unmet Need

- Pain: Identification and Management (Behavior-based Assessment Tools)
- Food
- Meaningful Engagement: Re-defining Activities
- Sleep and Rest
- Environment
- Education for Families
- Active Comfort

How the MDS (and Social Work!) can Help

- Know the resident, know the resident, know the resident
- Use the information, use the information, use the information
- Individual Care Plans
- QAPI (Quality Assurance/Performance Improvement)

Care Planning & Behavior as Communication—Using the MDS 3.0 to Improve Care

- Physical behavioral symptoms directed toward others
- Verbal behavioral symptoms directed toward others
- Other behavioral symptoms not directed toward others
- Rejection of Care
“Rejection of Care”

It is very common for people with dementia to convey-exhibit signs of distress when care is being provided to them. In the nursing home setting, this is known as ‘rejection of care.’ In reality, usually when someone with dementia is rejecting care, they are really saying, ‘you are upsetting me’ in some way. By rejecting your effort, they are, in fact, protecting themselves, the only way they know how.

Rejection of Care (continued)

However, rejection of care ALWAYS means the person is feeling distressed, and it sometimes means they are in physical pain. Therefore it is essential that every effort be made to find a way to provide the care that is not distressing. As you know, the first step is to simply stop, and come back later (if slowing down doesn’t help).

Put it in the Care Plan!

- If someone prefers to sleep late
- If someone only likes to wear the color pink
- If someone likes listening to baseball games
- If someone does better if they start the day with their iPod
- If someone does better taking their meds with jam instead of applesauce
- If someone doesn’t get along with another resident

What Brings Comfort?

It is as important to know what brings comfort as it is to know what causes distress:

- Peanut butter sandwiches, chocolate, scrambled eggs, back rubs, the color blue, Frank Sinatra, a walk down the hall, holding hands, pictures of cats, listening to a Yankee game, pictures of dogs, holding a baby doll, gospel music, bible reading, sitting on a bench outside, a chocolate lollipop

What information do we have, what information do we need, what information do we collect.....

- Social History
- MDS—preferences and customary routines
- Observation
- Who collects this information?
- How soon after the person comes to live with you?
- Where is the information kept?
- What do you do with the information?
Who needs to know, and how do they find out?

- Staff on the unit
- Different disciplines, different roles
- Different shifts
- “Floating” staff
- Weekend staff
- Supervisors
- Managers

How do we keep the dialogue open?

- Things change

What Do We Need?

- Ongoing Dementia Training
- Ongoing Dementia QAPI (MDS questions)
- Dementia training and orientation for ALL staff on unit
- Regular (weekly) interdisciplinary Meetings
- Care Planning that includes CNAs (and discussion)
- Care Plans that include comfort (and trigger) details

OUR job?

- Set the example, listen, be open to change
- Be a Detective too
- Facilitate group (and care plan) discussions
- Promote Sensible, coherent information sharing
- Help Educate Families

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