



# Our Mother's Voice

• Empowering families to speak for their loved ones in nursing homes who cannot speak for themselves

# Behavior IS Communication!

Presenter: Kathy Bradley

- Founder/CEO, **Our Mother's Voice**
- Member, SC Coalition on Dementia Care, National Consumer Voice for Quality Long-Term Care, SC Adult Protection Coordinating Council, SC Oral Health Coalition, et. al.
- Retired in 2009 after 33 years providing long-term care services
- Advocated for appropriate care & services for her mother with severe dementia
- I'm a SME!





# Behavior IS Communication!



*"Honk-Honk"*

*by Carol J Hay*

*watercolor on art paper*

# My Mother, circa 1983

Kindergarten teacher  
for underserved  
community

Special Education  
teacher

State Education  
Association member &  
officer

Consultant to local and  
state organizations

Political activist

Civil rights activist

Lifelong activist for  
social justice for groups  
without a voice



Gardener (organic  
of course)

Gourmet cook

Artist

Environmental  
steward

Adventurist

Conservationist

Feminist

Daughter AND  
wife of ministers

Elder

## AMAZING WOMAN!



## **DID I MENTION ADVENTURIST???**

My mother took my 10-year-old daughter whitewater rafting when she was in her sixties – and didn't tell me until afterwards!



## **My Mother, 2011, living with severe dementia**

loss of executive skills

loss of expressive language skills

non-ambulatory

difficulty chewing/swallowing

full assistance with daily living activities

She became a member of a group without a voice





## **My Mother, 2011, still herself!**

assertive about her likes/dislikes

enjoyed good food

enjoyed friends

LOVED her only granddaughter!

modest

# HOW DID THOSE QUALITIES MANIFEST?

## Mother's individuality

- Assertiveness
- ex: Prefers medications given individually and with explanation of their purpose
- Modesty
- Enjoys visiting friends
- Likes good food

## Staff's interpretation

- Combativeness
- Refusing medications (they were all crushed together, contrary to doctor's orders)
- Resistant to care
- Wandering / "Eloping"
- Refusing meals (ground diet)



# FLOSS Curriculum

<https://prezi.com/mpon3cvbck85/floss/>



# My Job



**"Glass Mosaic"**  
by Carol J Hay

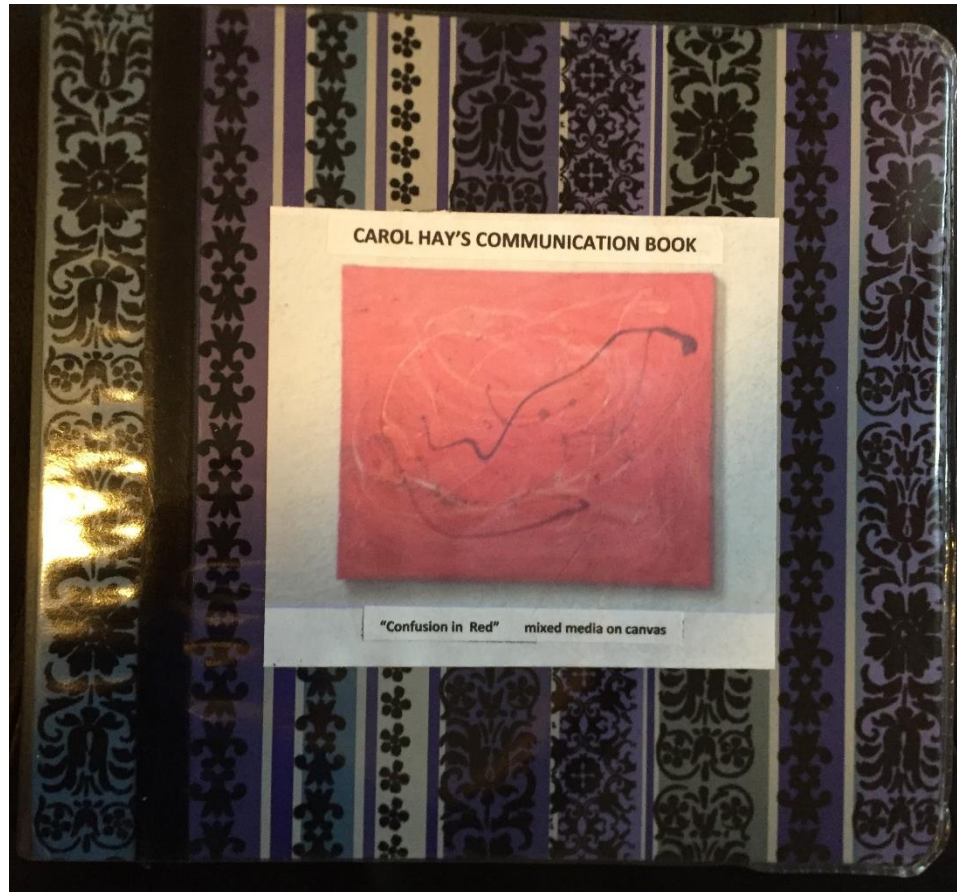
- Interpret Mother's nonverbal behavior
- Help staff understand that her "acting out" was her only means of communicating her dissatisfaction with what was happening around her or to her
- Work with staff to include important information, preferences, and techniques for providing care and activities in Mother's care plan
- Remember that, while Mother's core personality had not changed, her cognitive and executive abilities had.

# What this meant for Mother's care

- The early days were very difficult.
- Staff were not accustomed to adjusting their behavior to respond to nonverbal communication. They saw Mama as someone who needed to be controlled.
- Resistance = “acting out”
- Medication
- Tying her in a wheelchair so she wouldn't wander and “risk falling”
- Illness was misinterpreted as “lethargy”
- Repeated hospitalizations
- Psychiatric hospitalization



# Mama's Communication Book



# Alzheimer's Special Care Disclosure Act

SECTION 44-36-520 Information respecting form of Alzheimer's care or treatment provided.

A nursing home, community residential care facility, or day care facility for adults licensed by the Department of Health and Environmental Control which offers to provide or provides an Alzheimer's special care unit or program must include in its policies and procedures and disclose to the responsible party seeking a placement within the Alzheimer's special care unit or program, the form of care or treatment provided that distinguishes it as being especially applicable to or suitable for persons with Alzheimer's disease. The information that distinguishes the form of care or treatment shall include criteria for admission, transfer, and discharge; care planning; staffing patterns; staff training; physical environment; resident and participant activities; family role in care; and unique costs to the resident or participant associated with specialized service delivery.

# Federal Regulations – Oral Care

## §483.24 Quality of life.

Quality of life is a fundamental principle that applies to all care and services provided to facility residents. Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being, consistent with the resident's comprehensive assessment and plan of care.

(a) Based on the comprehensive assessment of a resident and consistent with the resident's needs and choices, the facility must provide the necessary care and services to ensure that a resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that such diminution was unavoidable. This includes the facility ensuring that:

(1) A resident is given the appropriate treatment and services to maintain or improve his or her ability to carry out the activities of daily living, including those specified in paragraph (b) of this section,

(2) A resident who is unable to carry out activities of daily living receives the necessary services to maintain good nutrition, grooming, and personal and oral hygiene, ....

(b) *Activities of daily living.* The facility must provide care and services in accordance with paragraph (a) of this section for the following activities of daily living:

(1) Hygiene—bathing, dressing, grooming, and oral care, ....



# State Regulations – Oral Care

## **SECTION 900--RESIDENT CARE/SERVICES**

### **901. General.**

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B. The facility shall coordinate with residents to provide care, including diet, services, i.e., routine and emergency medical care, podiatry care, dental care, counseling and medications, as ordered by a physician or other authorized healthcare provider. Such care shall be provided and coordinated among those responsible during the process of providing such care/services and modified as warranted based upon any changing needs of the resident. Such care and services shall be detailed in the ICP. (I)

C. The facility shall render care and services in accordance with orders from physicians or other authorized healthcare providers and take precautions for residents with special conditions, e.g., pacemakers, wheelchairs, dementia, etc. The facility shall assist in activities of daily living as needed and appropriate. Each facility is required to provide only those activities of daily living and only to the levels specifically designated in the written agreement between the resident, and/or his/her responsible party/guardian, and the facility. (I)

D. The facility shall provide necessary items and assistance, if needed, for residents to maintain their personal cleanliness, e.g., soap. (II)

# Lessons Learned



*"After the Storm"*  
by Carol J Hay

***Moving into a nursing home changes everything! But life should be good, even if different than before.***

The early months were turbulent. But changes began to take place, and staff learned some important concepts.

# Ten Commandments of Care

1. Care for each resident the way you would want your family members to be cared for.
2. Remember we are guests in the residents' home and have the privilege to work in their home each day.
3. Always respect the privacy, opinions and choices of all residents.
4. Take time to listen to all resident concerns and treat each concern with compassion and importance.
5. Be a good listener and communicate honestly and clearly to others, including all residents, family members, and co-workers.
6. Always smile and welcome everyone you come in contact with.
7. Be a problem solver by taking ownership of issues and finding solutions.
8. Keep all residents safe, secure, and free of harm at all times.
9. Go above and beyond each day by giving more care than expected.
10. Always have a positive attitude towards all residents, family members, and co-workers.



# Nonverbal Communication



*"The Journey"*  
by Carol J Hay

- Walking up the hall = "I want to visit my friends"
- Pulling away from staff = "You're being too rough with me" or "You're moving too fast for me"
- Striking out = "I don't like this situation" (too loud, too many people, what you're doing)
- Lethargy = "I don't feel well"
- Refusing medication = "I don't know what this is" or "I don't like the way this tastes"
- Resisting getting up = "I want to sleep longer"

# Let Mama know what's going to happen before it happens

- ✓ Speak at eye level and close enough so she can see you
- ✓ Smile, and use a calm and reassuring voice
- ✓ Find out – and use – her preferred salutation: Ms. Last Name, first name, nickname, etc. Peers call Mama “Carol”; students call her “Ms. Hay”. If you were her student, she may remember you if you call her “Ms. Hay” and tell her who you are!
- ✓ Ask her if she's ready to do what you want her to do – and honor the answer, whether verbal, gestural, or behavioral
- ✓ Tell her you're going to move her wheelchair before you do it
- ✓ Let her know it's bath time before you start to undress her

# Let Mama Know, cont'd.

- ✓ Explain her medications and what they are for, and give them one at a time instead of all crushed together. If you must crush them, do it individually, and explain that you do that to make it easier for her to swallow (not trying to trick her into taking something suspicious)
- ✓ If she spits out medication, try putting it in something she likes, like pudding, ice cream, a small spoonful of peanut butter
- ✓ Identify each food before putting it in her mouth
- ✓ If she seems resistant, back off and come back later to try again – or try another way
- ✓ Remember tactile sensitivity – use a gentle touch and tell her first what you are going to do
- ✓ Consider all her behavior as trying to communicate something – pleasure, dissatisfaction, need, preference

# What happens when culture change occurs?

*True Quality of Life makes every day more enjoyable for every resident*

- ❖ Staff are happier
- ❖ Residents are happier
- ❖ Work is easier
- ❖ Days are more enjoyable for everyone
- ❖ Staff and residents feel valued and empowered
- ❖ Behavioral challenges decrease
- ❖ Use of psychotropic / sedating medications declines



*"Joy Cometh In the Morning"*

*by Carol J Hay*



# QUALITY OF LIFE



*Individual preferences for activities should be honored.*

*"Whitewater" by Carol J Hay*

Actively promoting quality of life includes not just medical care and meeting physical needs; it also means honoring each individual's personal preferences about activities, day-to-day schedules, personal space, how personal care is provided, and all the "little things" the rest of us take for granted every day. When residents cannot participate in groups, are not physically active, or cannot make choices on their own, those who know them well can help them.

# Quality of Life Means:

- Different things to different people! It's individual.
- A positive, encouraging environment that adds value to each resident's day, every day (not just when there's lots of staff).
- Respect for each resident's individuality.
- Recognizing where the resident is "in the present" and meeting them there (preferences change, sometimes moment to moment)
- A variety of interesting activities available at times residents can access them (NOT just TV and music players, and not during appointment time!) Remember the brownie debacle!
- If staff approach activities with enthusiasm, so will residents!

# MOMENTS OF QUALITY

When a person has severe dementia, “quality of life” is measured in moments. Much time is spent disengaged from the rest of the world. But if one’s alert moments have quality, then that person has “quality of life”. Here are some examples of “moments of quality” for someone with severe dementia.



**TIME WITH FAMILY**



**GOOD FOOD & GOOD FRIENDS**





# TIME WITH GOOD FRIENDS







Even those with special dietary needs can enjoy a variety of foods, including “old favorites.” If they are alert and able to manage different food textures and consistencies, these diet modifications can add value to the quality of their everyday experiences. Experiment and find out!

## **GOOD FOOD**



## **SPECIAL OCCASIONS**

Festive lights and familiar celebrations can trigger positive emotions. Special food, visits from children and family, and “mood music” can stimulate memories of fun times. These activities create “moments of quality” for people whose lives are changed by the limits of severe dementia.



**THIS is what Quality of Life looks like!**



# Quality of Life is personal and individual



Photo courtesy Pioneer Network





## **Trudy, a “community dog” at one nursing home**

Photo courtesy Pioneer Network



**Even end of life care can bring quality for our loved ones**

Photo courtesy Pioneer Network

# **It's Important to Recognize**

**Quality of Life changes over time!**

My “quality menu” when I was working & raising my child: no crisis at work, no migraine, no trip to school mid-workday, no car wreck, no call from the police (She turned out great, BTW!)

My menu now: sleep late, breathe deep, walk, cook good food, eat dinner with friends, SING!



## **Mother's Day Tea 2013**

Though the glint in her eye was fading, and her alert moments were fewer, Mother still enjoyed good food and friends. Her health remained good. She lived to benefit from the culture change her nonverbal advocacy had brought about for all the residents in her facility.



**Our Mother      Carol J. Hay, circa 1983**

“If someone had asked Mama 20 years ago if she would go through these experiences if the outcome would be better quality of life for nursing home residents, she would have said Yes. It’s who she was.”

“What do families who don’t have a ‘You’ do?”

---- Carol Makemie Hay, March 2010





# Our Mother's Voice

Empowering families to speak for  
their loved ones in nursing homes  
who cannot speak for themselves

[www.ourmothersvoice.org](http://www.ourmothersvoice.org)  
[contact@ourmothersvoice.org](mailto:contact@ourmothersvoice.org)



# ABOUT the artist, Our Mother



All artwork featured in this presentation is taken from original paintings © Carol J Hay, our mother; used with permission. “The Sentry Box”, “The Gift”, “Confusion in Red” – mixed media on canvas; “Whitewater”, “Joy Cometh in the Morning”, “After the Storm”, “Irrational Exuberance” – oil on canvas. Photos of “The Gift” and “Whitewater” taken from giclee prints on canvas.

*“Irrational Exuberance” by Carol J Hay*

Our mother developed her interest in abstract art in the years shortly preceding her diagnosis. She was able to enjoy artistic expression during the early stages of her dementia, even after her language began to fade. We chose these paintings to represent the major tenets upon which Our Mother’s Voice is founded, both as a visual connection to each of the concepts, and as a celebration of our mother’s talent and the joy she found in her work.

## **Our Mother's Voice**

### **Mission Statement**

Our Mother's Voice provides information to families of nursing home residents to empower and equip them to advocate for quality of life and quality of care which goes beyond traditional custodial care to encompass the achievement of maximum physical, spiritual, social, mental, and emotional health for each resident.

### **Vision**

Families will be empowered to require services that respect and nurture all aspects of each individual's unique character regardless of age or infirmity. All nursing home residents will live a life of quality and dignity.

### **Values**

- ❖ We value all people, regardless of age or loss of capacity, as human beings worthy of respect and deserving of dignity.
- ❖ We value self-determination as achievable for every person.
- ❖ We value the support of families in enabling each person to express one's rights, needs, choices, and preferences, when that person is no longer able to do so for oneself.
- ❖ We value nursing facilities which strive to achieve true quality of life and quality of care for each individual resident, founded on the concepts of self-determination and family advocacy in the exercise of each resident's rights.
- ❖ We value honesty, integrity, and good stewardship of all resources, human and material; in the conduct of both professional and personal business.

*"Life's most persistent and  
urgent question is, 'What are  
you doing for others?'"*

**MARTIN LUTHER KING, JR.**

