Quality of Care in Nursing Homes – a Family's Perspective & Lessons Learned

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- 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, et. al.
- Retired in 2009 after 33 years providing long-term care services
- Advocated for appropriate care & services for her mother with severe dementia

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!

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 HER EFFORTS MANIFEST?

Mother's individuality	Staff's interpretation
• Assertiveness	➢ Combativeness
• ex: Prefers medications given individually and with explanation of their purpose	➢ Refusing medications (they were all crushed together, contrary to doctor's orders)
• Modesty	➢ Resistant to care
• Likes good food	➢ Refusing meals (ground diet)
• Enjoys visiting friends	➢ Wandering / "Eloping"

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

Efforts to Impact Culture of the Facility

- Staff, supervisors, DON, Medical Director, Administrator, CEO, Trustee
- 30+ pages of documentation of these efforts and all events to date
- Family decided to take concerns to SC DHEC
- DHEC found the systemic issues we had identified
- Change began to occur!

Nonverbal Communication

- 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”

What happens when culture change occurs?

- 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

How Did We Get There?

- **REGULATIONS!** Without the power of the federal regulations, CHANGE WOULD NOT HAVE OCCURRED.
- Quality of Care, Quality of Life, and fundamental Resident Rights to a safe and dignified existence mean very little without regulations and strong enforcement. My experience with my mother and in my 33-year "paid" career are ample evidence that providers will NOT police themselves.
- Organizational culture tends toward staff convenience, NOT meeting the needs of each individual care consumer. That's just a fact.
- Long-Term Care is NOT an "industry." It is a CARING PROFESSION.

Regulations & Enforcement? **Essential!**

- The “industry” asserts that regulations are “burdensome” and enforcement is “punitive” when providers need “assistance” “guidance” and “support”. They complain that fines are “too expensive” and they are “losing money.”
- Regulations lay the framework, and enforcement motivates when altruism doesn’t. (And it DOESN’T.)

Competent Service Provision

- ✓ Recruiting
- ✓ Training – sufficient, ongoing, relevant, competency-based
- ✓ Organizing the work – focused on meeting individual needs, not checking off a series of tasks and going home. People ≠ widgets!
- ✓ Ensuring the presence of competent supervision every day on every shift – and that they are overseeing the work to assure staff competency. The Administrator must LEAD this presence.
- ✓ External oversight, compliance, and enforcement are the only tools for assurance we have.

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