DEMENTIA BEYOND DISEASE:
CARING COMMUNICATING, AND DECODING DISTRESS

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OPENING EXERCISE

If a time should come when you could not speak for yourself, what are 2-3 important things that you would want others to know about you?

A NEW APPROACH RESTS UPON THREE PILLARS

- 'Experiential model of dementia'
- Well-being as a primary outcome
- Transformation of the living/care environment

A NEW DEFINITION

"DEMENTIA IS A SHIFT IN THE WAY A PERSON EXPERIENCES THE WORLD AROUND HER/HIM."

A NEW PRIMARY GOAL: ENHANCE **WELL-BEING**

HELPING RESTORE WELL-BEING FOR PEOPLE LIVING WITH DEMENTIA

Figure 2. The well-being pyramid illustrates the hierarchy of domains to be addressed for restoring well-being. (From *Dementia Beyond Disease: Enhancing Well-Being*, by G. Allen Power. Published by Health Professions Press. Copyright (c) 2014 by Health Professions Press, Inc. All rights reserved. Reprinted by permission.)

TRANSFORMATION

- **Personal**: Both *intra-personal* (how we see people living with dementia) and *inter-personal* (how we interact with and support them).
- **Physical:** Living environments that support the values of home and support the domains of well-being.
- **Operational:** How decisions are made that affect people with dementia, fostering empowerment, how communication occurs and conflict is resolved, creation of care partnerships, job descriptions and performance measures, etc., etc.

PERSONAL TRANSFORMATION

- Positive view of aging
- Valuing elders
- **Valuing and prioritizing relationships**
- Experiential learning about aging and dementia
- Education of *all*
- Mission, vision, values
- Enlightened communication, facilitation techniques
- Language…

CAUTION…

Words Make Worlds!

AT ITS MOST BASIC LEVEL…

Good Communication

Is

Empowerment!!!

YOUR TURN…

What are some basic communication tips we should always try to keep in mind?

KNOCK!

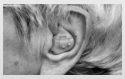
F24

THIS IS THEIR HOME.

FIRST STEPS…

- Re-establish the relationship

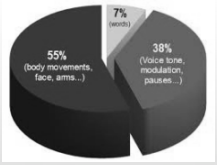
- Optimize comfort, hearing, and vision

3 REASONS TO SIT DOWN…

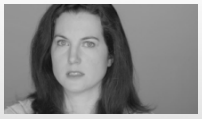
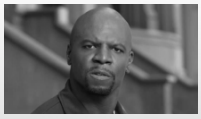
PRESENCE

BODY LANGUAGE



Mehrabian, A. *Silent Messages*. c.1972 Wadsworth Publishing (now Cengage).

THE "VERBAL-NONVERBAL CONNECTION"

SPEAKING

- Slowly and clearly, mirror pace of person
- Don't talk down or patronize
- Don't address like a child
- Be genuine
- Enunciate consonants if hard of hearing—don't speak too loudly
- Speak as to any normal person

LISTENING

- Mindfulness
- Focus on the person
- Open, accepting presence, body language
- Pay attention to the person's emotional content and body language
- Always validate feelings
- Watch for "embodied expressions" of choice

OTHER COMMUNICATION TIPS

- Give people the time to speak
- Don't cut them off, but do help fill in ideas to help and confirm understanding
- Rephrase questions to help get people "unstuck"
- Speak to the underlying feelings
- "Speak like a sports interviewer"

WORKING AT TASKS

Doing ***To*** or ***For***

Vs.

Doing ***With***

TASKS

- Approach from the front
- Use "face-to-face" communication skills
- Make a connection
- Use name and/or light touch to focus attention
- Prepare and explain, verbal *and visual cues* as needed
- Check for understanding and acceptance

PHYSICAL TRANSFORMATION

- Creating living environments that reflect the values of home, rather than institutions
- Awareness of sensory challenges in dementia
- Attention to lighting and acoustic environment
- Maximizing familiarity, accessibility, comfort and meaning
- How do we reinforce the "sick role"??

OPERATIONALIZING DOMAINS OF WELL-BEING:
A FEW SIMPLE (AND NOT-SO-SIMPLE) EXAMPLES…

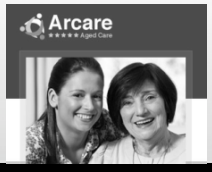
EXAMPLE: IDENTITY

"Sundowning," "Elopement," and natural rhythms and activity patterns

CONNECTEDNESS

Dedicated Staff Assignments

"It Takes A Community - A relationship-centred approach to celebrating and supporting old age"
(https://www.youtube.com/watch?v=IUJWFWXz-wY)



Daniella Greenwood
Strategy and Innovation Manager

ARCARE AGED CARE

- 33 residential care communities in Victoria and Queensland
- Some "sensitive care" areas for people living with dementia
- Daniella Greenwood (Dementia Strategy and Innovation Manager) – appreciative inquiry survey of 80 elders, staff and family members
- Identified four main categories, including "connections"
- Many comments highlighted the importance of continuous relationships
- Began to formulate a pathway for dedicated staff assignments in all areas where people live with dementia

ARCARE (CONT.)

- Staff education sessions
- Re-application process for all hands-on staff, must work at least 3 shifts/week with the same 6-8 residents every time
- Positive feedback from most staff and managers
- Within 6 weeks, staff spending more time with elders, without sacrificing task completion

ARCARE (CONT.)

- One early-adopting community (38 residents):
  - 69% decrease in chest infections
  - 90% decrease in pressure injuries
  - 100% decrease in formal complaints from families
  - 45% increase in family satisfaction
  - Decrease in staff in one area from 48 → 26
  - Decrease in avg. day/evening care partners in a month from 28 → 5!!

RESULTS (CONT.)

- 25% reduction in skin tears
- 12.9% reduction in falls
- 2.92 kg average weight gain
- 51.6% reduction in PRN psychotropic medication use
- 27.5% reduction in sick leave
- 50.2% reduction in staff turnover
- 19.8% increase in job satisfaction for CNAs
- 30% increase in job satisfaction for nurses

CASTLE & ANDERSON,
(2011, 2013)

- **Study 1: 2839 UD nursing homes**

  - Significant decreases in pressure sores, restraints, urinary catheters, and pain in home with >80% dedicated staff

- **Study 2: 3941 US nursing homes**

  - Significantly fewer survey deficiencies in several QOL & QOC categories with >85% dedicated staffing

  - Follow-up study also showed significantly lower CNA turnover and absenteeism

TWO RECENT STUDIES
(KUNIK, ET AL. 2010; MORGAN, ET AL. 2013)

- Factors leading to "aggressive behavior"
- Both studies found a major factor to be a decrease in consistency and quality of staff-elder relationships

OPERATIONALIZING WELL-BEING
A FEW MORE EXAMPLES

- Preferred name, Evolving and bridging identity, Move-in process (Identity)
- Knocking, Alarm removal (Security)
- Continual consent (Autonomy)
- Rituals (Meaning, Growth, and Joy)
- Opportunities to care and share wisdom, Volunteerism (Meaning, Growth)
- Simple Pleasures (Joy)

EXPERIENTIAL APPROACH TO DECODING DISTRESS

DEMENTIA IS A CONDITION IN WHICH A PERSON'S ABILITY TO MAINTAIN HER/HIS WELL-BEING BECOMES COMPROMISED

GENERAL APPROACH: THREE "AUDITS"

- Medical Audit (not always necessary)
- Environmental Audit
- **Experiential Audit**

CONSIDER A MEDICAL EVALUATION WHEN…

- There is an expression that is very unusual for the person
- There is an expression in conjunction with physical signs or symptoms (low-grade fever, grimacing, change in breathing, etc.)
- Other suggestion of discomfort
- A person is more *lethargic* than usual

MEDICAL CONSIDERATIONS

- Pain
- Infection
- Drug side effect
- Other medical illnesses (heart failure, abdominal problems, etc.)

PHYSICAL DISCOMFORT

- Does not have to be due to severe pain or injury
- May be seen during personal care or movement, and/or after periods of immobility
- May be more prevalent later in the day
- Can see recent falls or signs of injury

PHYSICAL DISCOMFORT (CONT.)

- Untreated pain can be a cause of delirium
- Can be related to medication side effects
- Can be related to bowel/bladder needs
- Many people, even with advanced cognitive changes, can still answer when asked about pain
- If unable to answer, use an observational scale such as PAINAD

PAIN ASSESSMENT IN ADVANCED DEMENTIA SCALE (PAINAD)

Behavior	0	1	2	Score
Breathing independent of vocalization	• Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	• None	• Occasional moan or groan • Low-level speech with a negative or disapproving quality	• Repeated troubled calling out • Loud moaning or groaning • Crying	
Facial expression	• Smiling or inexpressive	• Sad • Frightened • Frown	• Facial grimacing	
Body language	• Relaxed	• Tense • Distressed pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling or pushing away • Striking out	
Consolability	• No need to console	• Distracted or reassured by voice or touch	• Unable to console, distract, or reassure	
			TOTAL SCORE	

(Warden et al., 2003)

Source: Warden V, Hurley AC, Volicer, L (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc, 4*(1), 9-15.

PERSONAL EXPRESSIONS MAY REPRESENT…

- Unmet needs / Challenges to well-being*
- Sensory Challenges*
- New communication pathways*
- New methods of interpreting and problem-solving*
- Response to physical or relational aspects of environment*
- May be perfectly normal reactions, considering the circumstances!*
- Actions that are threatening to one's dignity*

(*NO medication will help these!)

ENVIRONMENTAL AUDIT

Second, look at the environment. Are there other things that are influencing how the person is and whether she is feeling distressed? (This is the point where a lot of people quit looking and go to medication instead.)

ENVIRONMENT

- Over- or under-stimulation
- Bowel bladder issues
- Hunger/thirst
- Environmental sounds
- Heat/Cold
- Interactions with others
- Getting "stuck"

EXPERIENTIAL AUDIT

The Experiential Model teaches that we need to go deeper into the Domains of Well-Being and find out how they are being challenged or eroded.

The Experiential Model states that distress is more likely due to a person's attempt to cope, problem-solve, or communicate her/his needs.

Are there aspects of well-being that the person is trying to fulfill that we're not satisfying, that may be leading to the distress?

REFRAMING "RESISTANCE"

A QUESTION FOR YOU…

If someone were helping you complete a personal task, what are some things that would make you want to resist them?

IS DEMENTIA REALLY THE *CAUSE* OF THE PERSON'S ACTIONS??

People with dementia become distressed for largely the same reasons that you and I do!

The *difference* is that they may be less able to:

- express their feelings and needs in a way we understand,
- remember the information that helps them feel secure and in control, or
- cope with stressful situations

A WELL-BEING APPROACH

Figure 2. The well-being pyramid illustrates the hierarchy of domains to be addressed for restoring well-being. (*From Dementia Beyond Disease: Enhancing Well-Being*, by G. Allen Power. Published by Health Professions Press. Copyright (c) 2014 by Health Professions Press, Inc. All rights reserved. Reprinted by permission.)

WHEN YOU MEET "RESISTANCE"…

Think first about the domains of

Autonomy

and

Security

SECURITY

People are more likely to resist if they feel insecure, frightened, or threatened.

- Unfamiliar care staff or locations
- Being awoken suddenly
- Not knowing what comes next
- Being unclothed and/or receiving personal care
- Being dependent
- Difficulty comprehending words
- Nonverbal signals!

AUTONOMY

Many people resist when approached to do something…

- They do not wish to do
- At a time they do not wish
- At a pace they do not wish
- With too little explanation of the process
- With little or no input into the process

ENHANCING SECURITY (24/7!)

- Dedicated staff assignments, especially during personal care
- Respecting boundaries (room and personal)
- Connecting before starting a task
- Carefully explaining each step of each task
- Preserving modesty and dignity
- Body language
- Attention to physical environment

ENHANCING AUTONOMY (24/7!)

- Doing *with*, not doing *to* or *for*
- "Continual consent" – explain and wait for understanding and acceptance *with each step (Greenwood, D. 2014)*
- Frequent requests for input throughout the task
- Appropriate pace to enable participation
- "The least that I can do; the most that you can do." (Greenwood, D. 2014)
- Think **"SEE"**: **S**low down, **E**ngage, **E**mpower (Power, A. 2010)
- Change times, techniques, or break up tasks as needed

ENHANCING OTHER WELL-BEING DOMAINS

- **Identity** – know the person, share stories during care, use preferred term of address, know personal rhythms and style
- **Connectedness** – dedicated staff assignments, relationship building during tasks, familiar objects can bring comfort
- **Meaning** – tie in to past history, ask for input and guidance, understand different ways of communication and symbolic words, creating rituals out of routines
- **Growth** – relationship-building, doing with, don't infantilise
- **Joy** – simple pleasures, TLC/spa approaches, stimulate all the senses, use of personalised music (which helps all seven domains!)

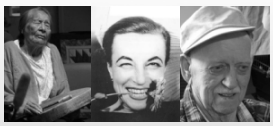
THE KEY…

Turn your backs on the "behavior," and build the "ramps" to well-being!

DR. RICHARD TAYLOR

*'I believe that as people progress with dementia, their humanity **increases**.'*

THANK YOU!! QUESTIONS??



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