Enhancing Well-Being 2: Caring, Communicating and Decoding Distress

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Institutional Model of Care

- Reflects societal views of aging
- Values “doing” over “being”
- Sees aging as decline
- Devalues elders
- Discounts and stigmatizes people living with dementia
- Uses a “hospital” model approach to long-term care
- Provides medical and nursing care, but fails to recognize and cultivate other aspects of life

Institutional Model…

Erodes elder empowerment through:

- *Personal*
- *Operational, and*
- *Physical*

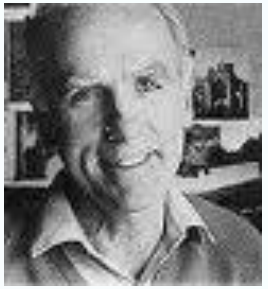
dimensions…

Disempowerment: Personal Dimension

Elaine Brody, MSW (1971)

- “Excess disability”—Disability that is greater than the underlying illness itself would produce
- A function of the care environment
- The good news: potentially reversible!

Tom Kitwood (1997)



- “Positioning”
- “Malignant Social Psychology”

- Deception
- Disempowerment
- Infantilization
- Intimidation
- Labeling
- Stigmatization
- Outpacing
- Invalidation
- Banishment
- Objectification
- Ignoring
- Imposition
- Withholding
- Accusation
- Disruption
- Mockery
- Disparagement

“Positive Person Work”

Recognition

Collaboration

“Timalation”

Relaxation

“Holding”

Creation

Facilitation

Negotiation

Play

Celebration

Validation

Giving

The Danger of Stigmas…

- ***The self-fulfilling prophecy:***

"If you expect less, that's what you will get!"

SFP Examples

- He can’t do that because he has dementia, so we will do it for him.
- She can’t decide that, so we will decide for her
- People with dementia cannot learn
- People with dementia cannot grow
- Frail elders cannot give care, only receive it
- What examples can ***you*** **think of??**

Disempowerment: Operational Dimension

Often expressed through self-fulfilling prophecies

- Doing for
- Deciding for
- Excluding
- Language!
- Regimented living schedules
- Positioning and malignant social psychology

Disempowerment: Physical Dimension

- Long hallways
- Double rooms
- Nursing station
- Med carts
- Uniforms
- Beds, alarms, etc.

…cause excess disability and reinforce the “sick” role

Is “person-centered care” good enough???

- Often viewed and applied paternalistically
- Often retains many aspects of positioning, MSP and SPFs
- Organizational / departmental priorities always trump individual choice
- Positioning and SFPs are often mirrored by how management views/treats staff!!

Dr. Richard Taylor

- “My biggest challenge is to find meaning in *today.*”
- “I need a *purposeful* and *purpose-filled* life.”
- “I need to be *enabled* and *re-abled.*”

What We Often Hear

- “I cannot give him choices – it would be too risky.”

OR

- “I tried to give him choices, but he didn’t seem to know what to do, so I make them instead.”

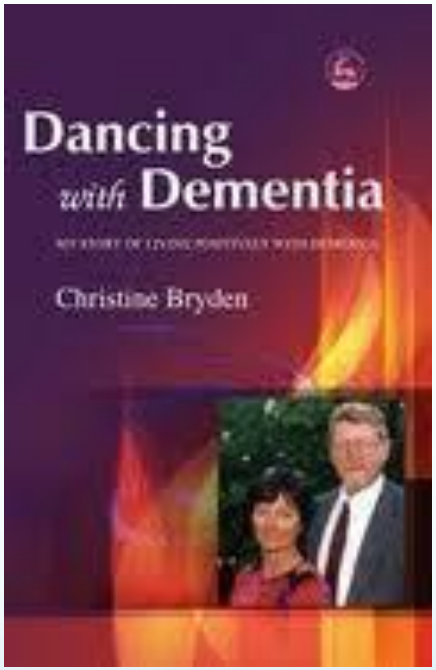
- We hear this about people living with dementia.
- We also hear this about employees!

Five Conditions of Empowerment

- Knowledge
- Parameters
- Training and Skills
- Resources
- Supportive Environment

How Can We Apply the Conditions of Empowerment to People Living with Cognitive Disabilities??

Care Partnerships



Levels of Empowerment

- Face-to-face communication skills
- Working at tasks
- Wording for choices
- Appreciation

Face-to-Face Approaches

At its Most Basic Level…

Good Communication

Is

Empowerment!!!

General Approach: Basics

- At the door → knock, identify, ask permission to enter
- Re-introduce yourself
- Sit down – face to face, eye level
- “Eye of the hurricane”
- Physical space, comfort, quiet
- Optimize hearing and vision
- Center yourself

Basics (cont.)

- Speak slowly and clearly (*not* loudly)
- Allow time for processing and response
- Eye contact, facial expression, non-verbal cues
- Project calm, kindness, empathy
- Appropriate touch
- Active listening (Clarify, Rephrase, Reflect, Summarize)

Other Aids to Communication

- Allow time for people with aphasia to speak
- Don’t cut off, but do help fill in ideas to assist and confirm understanding
- Look for “back doors” to aphasia (music, art, pictures, emotional triggers)
- Look at context and emotional content of statements, not details of words
- Always validate feelings

“Saving Face”

- Asking for info can be frustrating and fatiguing
- Practice the “fine art of asking questions”
- Help fill in gaps while conversing
- “Speak like a sports reporter”
- Recall an event and let elder add as able
- Don’t diminish person’s recollection
- Preserve dignity in social situations

Working at Tasks

Doing *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

Tasks (cont.)

- Present objects in proper orientation and ready for use
- Begin with verbal cue
- Add visual if needed
- May need help with:
  - Initiation
  - Sequencing
  - Problem solving
- Hand-under-hand technique
  - Re-awakens “muscle memory”
  - Ensures gentle approach

Wording for Choices

- Open-ended question – when to use?
- Offer a list
- Offer choices two-at-a-time
- Simplify wording and add emphasis and visual cues
- Offer choices one-at-a-time
- Look for non-verbal acceptance or dismissal
- Re-frame “refusals” and “resistance” as *exercising choice*
- “How do they teach us??”

Appreciation and Self-Esteem

- “Can you please help me with this?”
- “Would you please hold this for me?”
- “What do you think about this?”
- Check for direction through steps of a task
- Give positive feedback and compliment (honestly)
- Give thanks and appreciation
- When all else fails, engage through every task

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

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

Experiential Audit

- Distress as unmet needs
- Life history, job, hobbies, activity patterns…
- Role play, see through his / her eyes
- Look for meaning in behavioral expression
- Look at well-being domains

Experiential Audit: Preparation

Jane Verity's *Spark of Life* steps:

- **Shift your focus**

  Begins with a concerted effort to move from our own perspective and see the world through the eyes of another

- **Share your heart**

  Look into the heart of another, without judgment

- **Shine your light**

  Use your insights to find the unmet need or environmental mismatch

Experiential Audit

Using Well-being Domains

- **Identity** *(Is my story known and understood by my care partners?)*
- **Security** *(Do I feel safe in my surroundings and do I trust those who provide my care?)*
- **Connectedness** *(Do I know my care partners? Do I feel like I belong in my living space?)*
- **Autonomy** *(Do I have opportunities for choice and control throughout the day?)*
- **Meaning** *(Are the daily activities meaningful to me? Are my self-esteem and ability to care for others supported?)*
- **Growth** *(Do I have opportunities to experience life in all its variety and to engage creatively with the world?)*
- **Joy** *(Is life celebrated with me? Am I loved?)*

Filling the Glasses

Approach to Distress

- Consider distress to be legitimate, don't trivialize or challenge,

  (his/her reality is the one that counts!)
- Approach alone, calm, centred
- Caring demeanor – voice, face, body language
- Begin by *validating* emotion
- Words won't be heard till there is an emotional connection
- Move conversation to a less emotional place
- To re-orient or not??
- Investigate triggers

Finding the Calm Center

- Deep breaths
- The slow count
- Imagery
- Look for positive attributes
- Look for positive connections
- Mindfulness practices
- Personal practices (meditation, tai chi, yoga, biofeedback, etc.)

Surplus Safety

Two kinds of risk:

- **Downside Risk**—The risk that things will turn out worse than anticipated
- **Upside Risk**—The risk that things will turn out better than expected

Long-term care tends to focus almost exclusively on **downside risk**

The “Seesaw Effect”

- We can reduce our downside risk by increasing safety, *BUT…*
- As we increase safety, we also tend to reduce the potential for upside outcomes
- Therefore, improving quality of life involves accepting some degree of risk
- Instead of trying to *eliminate* risk, we must *negotiate* risk

Bill Thomas, MD

“The only risk-free human environment is a coffin.”

Negotiating Risk

- Knowing the person
- Individualizing according to personal values
- Understanding perspectives of family, staff, regulators
- Documenting discussions
- Keep decisions based on *principles and values*
- Tie decisions in to domains of well-being

“Failure-Free is Not an Option!”

- Success, failure and meaning
- A story from Tennessee

- ***The most dangerous situation for people living with dementia may well be the self-fulfilling prophecy!***

Thank you! Questions?

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