

## A Well-Being Approach to Decoding Distress in People Living with Dementia



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## Outline

- Disempowerment and self-fulfilling prophecies
- Reframing interpersonal interactions as empowerment
- Communication and working through tasks
- Three “audits” for distress
- The Well-Being Approach
- Discussion

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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 and well-being

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**Institutional Model...**  
Erodes elder empowerment through:

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

dimensions...

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**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!

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**The Danger of Stigmas...**

- *The self-fulfilling prophecy:*

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

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### 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??

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### Disempowerment: Operational Dimension

Often expressed through self-fulfilling prophecies

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

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### Disempowerment: Physical Dimension

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

...cause excess disability and reinforce the "sick" role

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

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

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### 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*.”

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### 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!

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### Five Conditions of Empowerment

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



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### How Can We Empower People Living with Cognitive Disabilities??



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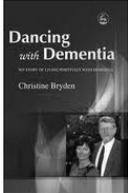
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### Care Partnerships



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## Levels of Empowerment

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

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## At its Most Basic Level...

*Good Communication  
Is Empowerment!!!*



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## 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

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### 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)

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### 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



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### "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

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Working at Tasks  
Doing *For*  
Vs.  
Doing *With*



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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

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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

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### 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??”

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### 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

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### Experiential Approach to Decoding Distress

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



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## General Approach

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

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## 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

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## The Experiential Pathway to Well-Being



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A well-being approach can be used for both:

- Ongoing support and care, and
- Decoding distress



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### Filling the Glasses



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The Key...



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



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## Experiential Audit

Using Well-being Domains  
(Sample questions)

- **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?)

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## Václav Havel



*Hope is not a prognostication—it's an orientation of the spirit. . . . Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well but the certainty that something makes sense, regardless of how it turns out. . . . life is too precious a thing to permit its devaluation by living pointlessly, empty, without meaning, without love, and, finally, without hope.*

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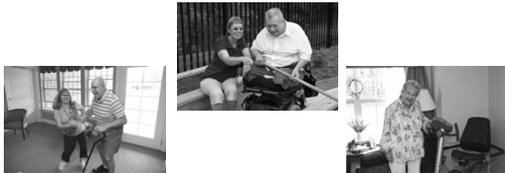
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## Thank you! Questions?



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