Cultivating Empathy for People Living with Dementia

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Second Wind Dreams
About Us

• Founded in 1997
• 501c(3) non-profit corp. w/ 20+ staff.
• Dreams program
• Revenue from individual contributions, memberships, corporations, eldercare industry associations, and the Virtual Dementia Tour® (VDT®)
• 2000 healthcare facilities in the US and abroad, VDT available in 20 countries
• 200+ colleges and universities
• Other participants include: emergency first responders, police officers, fire fighters, local businesses, community groups, houses of worship
• Over 100+ VDT certified trainers worldwide
• Grant projects: NH-GA, KY, WI, MS, & pending for several other states, family counseling WI.
Groups/Industries Dementia Touches:*

- Clinics
- Hospitals
- Emergency Rooms
- Allied Healthcare
- Long Term Care
- Financial Planners
- Billing Departments
- Telecommunications
- Internet
- Libraries
- Government
- Transportation
- Delivery Services
- Senior Services
- Repair Services
- Restaurants
- Entertainment
- Travel
- Civic Groups
- Architecture
- Legal
- Clubs
- Banks
- Employers
- Travel

*Virtual Dementia Tour: Your Vision, Their World*
The great gift of human beings is that we have the power of empathy.

Meryl Streep
The Challenge

How do we go about understanding a disease that none of us have ever had that affects millions of people who can’t describe what is happening to them?
What is the world like for someone with dementia?
Morning Margaret! Wakey wakey!

Time for a shower. We're a person short today so it'll have to be a quick one!

Looks like she's having one of her difficult days! You wonder what sets them off, don't you...

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Challenging Behaviors (of staff)

Case Examples:

“There is nothing wrong with her. She can talk o.k.”

“We need a psychiatric consult to increase his meds. His hallucinations and delusions are worse – he said that there was mud in his pants.”
Case Examples

“Why were you just feeding into his delusions? He just talks too much about the war he was in, fighting Chinese people. The U.S. was at war with the Japanese in WWII, not the Chinese.”

“The residents are just mean; they know better and just don’t listen.”
If you told someone with dementia a thousand times and he still doesn't understand, then it is not the person with dementia who is the slow learner.
What does it mean to be Dementia-Aware?

• It means that there is a basic understanding of the nuances of dementia and how it impacts the way the person with dementia behaves.

• Simply being aware of dementia in no way suggests that there is an understanding of HOW to provide care and support for the person with dementia.

• However, person-centered care cannot occur without being dementia aware.

• The reaction to dementia can be positive, negative or benign.
em • pa • thy

noun

The ability to step into the shoes of another person, aiming to understand their feelings and perspectives, and to use that understanding to guide our actions.
In my view, the best of humanity is in our exercise of empathy and compassion. It's when we challenge ourselves to walk in the shoes of someone whose pain or plight might seem so different than yours that it's almost incomprehensible.

Sarah McBride
Studies Link Empathy To:

• Greater patient satisfaction
  • Used to calculate Medicare reimbursement under ACA
• Better outcomes
• Less errors
• Decreased burnout
• Lower risk of abuse and neglect
• Empathy is a cognitive attribute not a personality trait.
Simulation Learning: Imperative for Person - Centered Care

- Adult Learners show best outcomes when
  - Involved in experiential learning
  - Given direct feedback
  - Given concrete recommendations
  - In Vivo

- Simulation Learning Improved
  - Competency
  - Employee Satisfaction
  - Sensitivity
    - Core element in quality care delivery

Results above are conclusions of 5 studies comparing simulation training to lecture, video and role playing.
Benefits of the VDT

• Builds staff to resident rapport
• Decreases abuse incidents
• State surveyors look for examples of person-centered care
• Prepares eldercare communities for new CMS guidelines
• Helps staff understand “normal” dementia behaviors
• Onboarding tool during orientation
• Increase satisfaction of family members
• Reduction of psychotropic medication use
• Reduction of inappropriate gero-psychiatric hospitalizations
• Provides the local community with a community edition of the VDT.
Michael on Noise and Focus

• Sensitivity to sound
• Foreign Language
• Intermixed
• Can’t filter
• Distraction
  • Can’t recover
The VDT Brain

**Frontal Lobe**
Tasks read quickly in same decibel as audio and General Instruction memory

**Limbic System**
Tearful
Agitated
“I give up.”

**Left Hemisphere**
Immobile
Poor reasoning
(Only move in the immediate surroundings)

**Cerebral Cortex**
Multi level tasks with secondary process thinking

**Temporal Lobe**
Audio and visual confusion
Interference with memory
Startle response, RAS

**Right Hemisphere**
No abstract use of the environment
“There wasn’t a sweater in there.”

**Parietal Lobe**
Removed ability to get tactile information
“I can’t pick the utensils up and put them in the right place.”

**Occipital Lobe**
“I can’t see anything.”
“Are these the pants?”
Nothing familiar
“Where does this go?”
So What?

• Attitudes changed but...
• It was interesting but...
• Gave me something to think about but...
• Everyone should go through it but...

And what does person-centered care actually mean?
DACE®

• It provides an observable and measurable method of quantifying sensitivity toward the person with dementia and empathy with their plight while ensuring their dignity is preserved and care is provided in a respectful manner.

• It quantifies a staff members competency in the provision of person-centered dementia care.
Empathy is the starting point for creating a community and taking action. It's the impetus for creating change.

Max Carver
The Pledge

-I pledge to seek out a deep understanding of the person with dementia.  
-To build a relationship no matter the depth of the disease.  
-To provide individualized comfort and care.  
-I pledge to anticipate their needs to decrease their stress and view each need from their perspective not mine.  
-To be their advocate and passionately refuse to accept poor care from anyone.  
-I pledge to smile first, hug first, welcome first while always remembering where they dwell.  
-To engage with my eyes, my touch and my tone of voice.  
-To provide supportive attention based on the promise that I am reaching them at a level deeper than cognition.  
-I pledge to be aware of how they forgive me when I’m not “all in” and still look for me every day.