



## Dementia Beyond Disease: *Enhancing Well-Being*

G. Allen Power, MD, FACP  
WI FOCUS 2014 conference  
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### Disclosures

- I am an Eden Alternative board member (unpaid) and a contracted educator (paid)
- I have books and DVDs
- No other relevant financial interests

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### Outline

- Review demographics of psychotropic drug use
- Explain drawbacks of the biomedical model of dementia
- Envision an experiential approach
- Well-being as the ultimate outcome
- The culture change connection
- "Why nonpharmacological interventions don't work"
- Discussion

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## Perspectives

*“The only true voyage of discovery . . . would be not to visit strange lands, but to possess other eyes, to behold the universe through the eyes of another, of a hundred others, to behold the hundred universes that each of them beholds, that each of them is . . .”*  
- Marcel Proust

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## U.S. Antipsychotic Prescriptions Since 2000

- U.S. sales, (2000→2011): \$5.4 billion→\$18.2 billion (#1 drug sold in the US in 2013 was Abilify: \$1.6 billion)
- Prescriptions, (2000→2011): 29.9 million→54 million (~2.2 million Americans have schizophrenia)
- 29% of prescriptions dispensed by LTC pharmacies in 2011
- Overall, ~20% of **all** people in US nursing homes are taking antipsychotics (~30% with a diagnosis of dementia)
- Medicaid spends more money on antipsychotics than it does on (1) antibiotics or (2) heart medications

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## Big Secret #1:

Antipsychotic overuse is not an American problem!

- Denmark (2003) – 28%
- Australia (2003) – 28%
- Eastern Austria (2012) – 46%
- Canada (1993-2002) – 35% increase (with a cost increase of 749%!)
- Similar data from other countries (2011 study of >4000 care home residents in 8 European countries→26.4%)
- Worldwide, in most industrialized nations, with a diagnosis of dementia: ~35-40%

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**Behavioral Expressions in Dementia  
Do Drugs Work?**

- Studies show that, at best, fewer than 1 in 5 people show improvement  
Karlawish, J (2006). *NEJM* 355(15), 1604-1606.
- Virtually all positive studies have been sponsored by the companies making the pills
- Many flaws in published studies
- Two recent independent studies showed little or no benefit  
Sink et al. (2005), *JAMA* 293(5): 596-608; Schneider et al. (2006), *NEJM* 355(15): 1525-1538.

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**Risks of antipsychotic drugs**

- Sedation, lethargy
- Gait disturbance, falls
- Rigidity and other movement disorders
- Constipation, poor intake
- Weight gain
- Elevated blood sugar
- Increased risk of pneumonia
- Increased risk of stroke
- **Ballard et al. (2009): Double mortality rate. At least 18 studies now show increased mortality, (avg. increase ~60-70%)** *Lancet Neurology* 8(2): 152-157

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**Big Secret #2:**  
Antipsychotic overuse is not a nursing home problem!

- Nursing home data can be tracked, so they get all the attention
- Limited data suggests the magnitude of the problem may be even greater in the community
  - Rhee, et al. (New England, 2011): 17%
  - Kolanowski, et al. (Southeast US, 2006): 27%
- 2007 St. John's audit
- If 4 out of 5 adults living with dementia are outside of nursing homes, there are probably *over 1 million Americans with dementia* taking antipsychotics in the community (vs. ~250,000 – 300,000 in nursing homes)
- Our approach to dementia reflects more universal societal attitudes

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A Question for You...

*What is*  
**Dementia** ?

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The Biomedical Model of Dementia

- Described as a constellation of degenerative diseases of the brain
- Viewed as mostly progressive, incurable
- Focused on loss, deficit-based
- Policy heavily focused on the costs and burdens of care
- Most funds directed at drug research

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Biomedical "Fallout" ...

- Looks almost exclusively to drug therapy to provide well-being
- Research largely ignores the subjective experience of the person living with the disease
- Quick to stigmatize ("The long goodbye", "fading away")
- Quick to disempower individuals
- Creates institutional, disease-based approaches to care
- Sees distress primarily as a manifestation of disease

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### Illustrative Example:

CONVERSATIONS WITH ED  
Waiting for Forgetfulness: Why Are We So Afraid of Alzheimer's Disease?



ED YONG  
NARRATED BY ED YONG  
WITH ILLUSTRATIONS BY SEANAN MURPHY

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So...

### Why Do We Follow this Model??

- Are we bad people?? *No!*
- Are we lazy? *No!*
- Are we stupid? *No!*
- Are we uncaring? *No!*
  
- Do we have a paradigm for viewing dementia? *Yes!!*

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“Instead of thinking outside the box, get rid of the box.”

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**A New Model**  
(Inspired by the True Experts...)



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**A NEW DEFINITION**

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



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**Where This “Road” Leads...**

- From fatal disease to changing abilities
- The subjective experience is critical!
- From psychotropic medications to “ramps”
- A path to continued growth
- An acceptance of the “new normal”
- The end of trying to change a person back to who he/she was
- A directive to help fulfill universal human needs
- A challenge to our biomedical interpretations of distress
- A challenge to many of our long-accepted care practices

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In Other Words:

# EVERYTHING CHANGES!

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## Three Views

- "Dad has totally lost it. He thought I was his father instead of his son. He is gone beyond recognition."
- "If I call you 'Mom' or 'Dad', I am probably not confusing you with my mom or dad. I know that they are dead. I may be thinking about the feelings and behaviors I associate with mom and dad. I miss those feelings; I need them...I just so closely associate those feelings with my mom and dad that the words I use become interchangeable when I talk about them." (Richard Taylor)
- "Old people often use an object like a wedding ring to symbolize something from the past. A person in present time, like yourself, can represent a mother or sister. When old people combine one thought with another, they are often poetic." (Nader Shabahangi)

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## Perspectives...



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Does cough syrup cure pneumonia?

Behavioral expressions are the *symptom, not the problem!*

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Big Secrets # 3 & 4:

- Our primary goal is *not* to reduce antipsychotic drugs!
- Our primary goal is *not even* to reduce distress!!

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Primary Goal:  
Create Well-being

- Identity
- Connectedness
- Security
- Autonomy
- Meaning
- Growth
- Joy

(“Wandering “ Example...)

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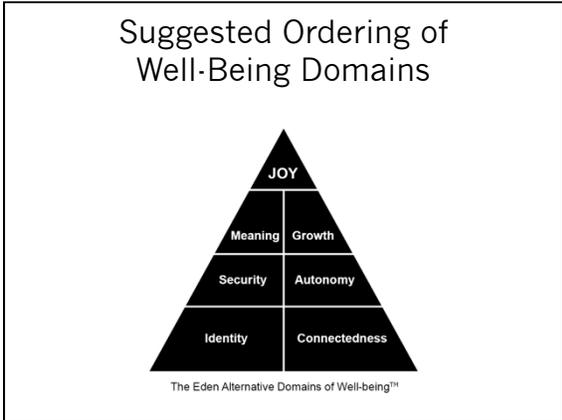
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- MAREP (Ontario, Canada)**  
Living Life through Leisure Team
- Being Me
  - Being With
  - Seeking Freedom
  - Finding Balance
  - Making a Difference
  - Growing and Developing
  - Having Fun

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- Leisure – Well-Being Alignment**
- Being Me                    ← →    Identity
  - Being With                ← →    Connectedness
  - Seeking Freedom        ← →    Autonomy
  - Finding Balance         ← →    Security
  - Making a Difference     ← →    Meaning
  - Growing and Developing ← →    Growth
  - Having Fun                ← →    Joy

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So what does this have to do with culture change??

Everything!!

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### Why it matters

- No matter what new philosophy of care we embrace, if you bring it into an institution, the institution will kill it, every time!
- We need a pathway to *operationalize* the philosophy —to ingrain it into the fabric of our daily processes, policies and procedures.
- That pathway is *culture change*.

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### Big Secret #5: *Checking the Cows* Why “Nonpharmacological Interventions” Don’t Work!



- The typical “nonpharmacological intervention” is an attempt to provide person-centered care with a biomedical mindset
- Reactive, not proactive
- Discrete activities, often without underlying meaning for the individual
- Not person-directed
- Not tied into domains of well-being
- Treated like doses of pills
- *Superimposed upon the usual care environment*

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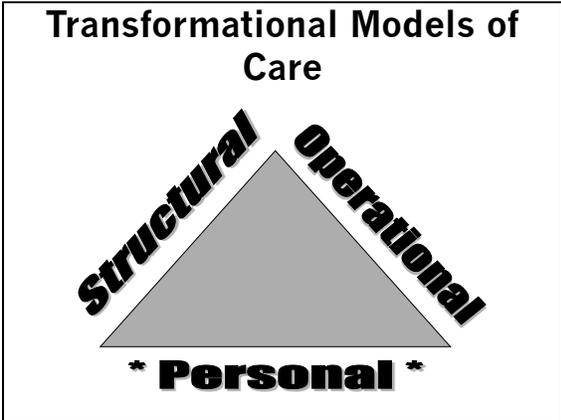
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**Transformation**

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

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**One's own home can be an institution...**

- Stigma
- Lack of education
- Lack of community / financial support
- "Caregiver" stress and burnout
- Inability to flex rhythms to meet individual needs
- Social isolation
- Overmedication in the home

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### Big Secret #6: Culture change is for *everyone*!!

- Nursing homes
- Assisted living
- Federal and State regulators
- Reimbursement mechanisms
- Medical community
- Families and community
- Liability insurers
- Etc., etc.

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### True Stories



Looking beyond the words...

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### Questions so far??



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