Enhancing Well-Being in Older Adults Living with Dementia

G. Allen Power, MD, FACP
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Objective

To change your minds about people whose minds have changed
“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
U.S. Antipsychotic Prescriptions Since 2000

- U.S. sales, (2000→2012): $5.4 billion → ~$14 billion

- Prescriptions, (2000→2011): 29.9 million → >55 million (,2.5 million Americans have schizophrenia)

- 29% of prescriptions dispensed by LTC pharmacies in 2011

- Overall, ~23% of people in US nursing homes are taking antipsychotics (>1/3 with a diagnosis of dementia)

- Medicaid spends more money on antipsychotics than it does on (1) antibiotics or (2) heart medications
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%
Behavioral Expressions in Dementia
Do Drugs Work?

- Studies show that, at best, fewer than 1 in 5 people show improvement
  

- 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.*
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
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. ~400,000 in nursing homes)
- Our approach to dementia reflects more universal societal attitudes
A Question for You…

What is Dementia?
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
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
Illustrative Example:

Conversations with Ed
Waiting for Forgetfulness: Why Are We So Afraid of Alzheimer's Disease?

Ed Voris
Nader Shabahangi
Patrick Fox

In collaboration with Sharon Merger
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!!**
“Instead of thinking outside the box, get rid of the box.”
A New Model
(Inspired by the True Experts…)
A New Definition

“Dementia is a shift in the way a person experiences the world around her/him.”
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
In Other Words;

Everything changes!
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)
Perspectives…

A compilation of honest answers about dementia from medical doctors, professional care partners, family of loved ones and the one who lives it.
Does cough syrup cure pneumonia?

Behavioral expressions are the **symptom**, *not the problem*!
Big Secrets # 3 & 4:

• Our primary goal is *not* to reduce antipsychotic drugs!

• Our primary goal is *not even* to reduce distress!!
Primary Goal: Create Well-being

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

(“Wandering “ Example…” )
MAREP (Ontario, Canada)
Living Life through Leisure Team

- Being Me
- Being With
- Seeking Freedom
- Finding Balance
- Making a Difference
- Growing and Developing
- Having Fun
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
So what does this have to do with culture change??

Everything!!
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.
Big Secret #5: Why “Non-Pharmacologic Interventions” Don’t Work!

- The typical “non-pharmacologic 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*
Transformational Models of Care
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).
Big Secret #6:
Culture change is for everyone!!

- Nursing homes
- Medical community
- Federal and State regulators
- Reimbursement mechanisms
- Families and community
Creating the *Context* for an Experiential Approach

- Positive view of aging
- Seeing the whole person
- Looking through the person’s eyes
- Being centered and present in the moment
- Communication and facilitation skills
- Looking beyond the words
- *Turning our backs on the “behavior”, and finding the “ramps” to well-being*
“When we care for an elder, we care for that part of ourselves that will someday grow old.”

- Dr. Nader Shabahangi
Thank you!
Questions?

apower@stjohnsliving.org
www.alpower.net