



# Enhancing Well-Being in Older Adults Living with Dementia

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# Objective

*To change your minds about people  
whose minds have changed*

# *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*

# 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%!)  
Source: <http://www.cbc.ca/health/psychiatry/02-2003-03-01/02-2003-03-01.html>
- Similar data from other countries (2011 study of >4000 care home residents in 8 European countries → 26.4%)  
Source: <http://www.bmj.com/content/343/bmj.e6411>
- 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

*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.*

# 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

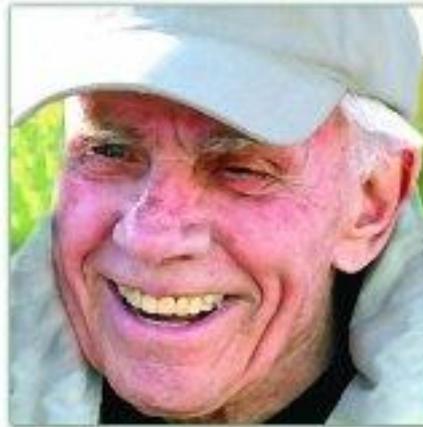
# Biomedical “Fallout”...

- 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 SHARAHANGI

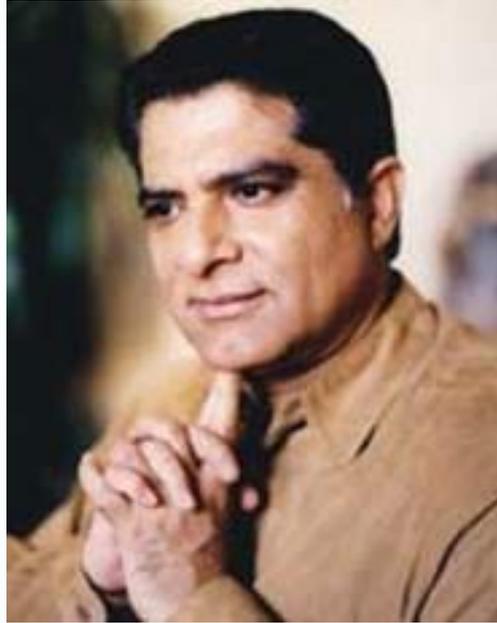
PATRICK FOX

IN COLLABORATION WITH SHARON MERCER

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

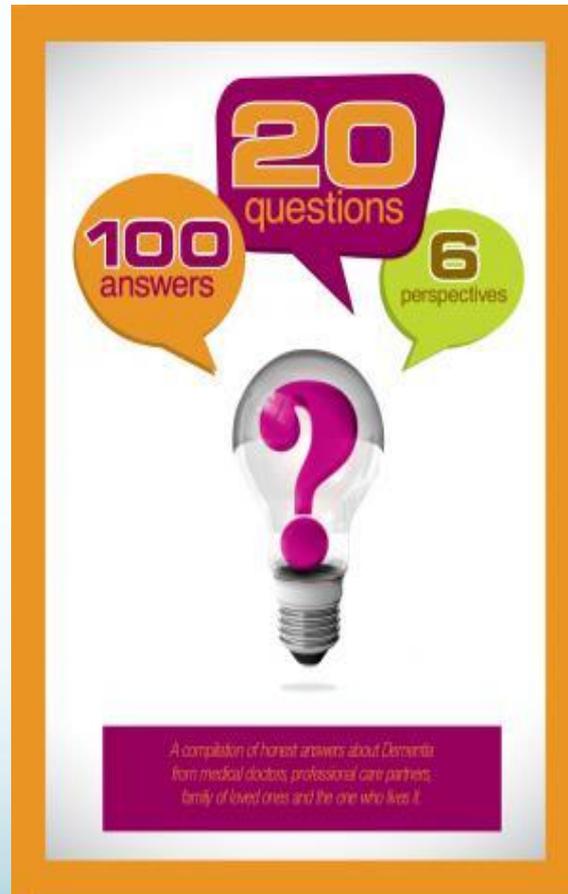
In Other Words;;;

**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...



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?*



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