



Re-thinking Dementia: A Well-Being Approach

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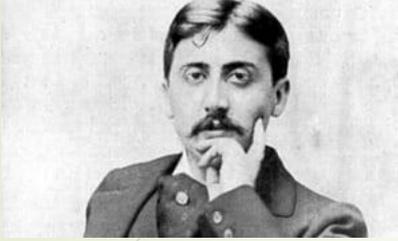


Disclosure

The presenter has no affiliations that would constitute a conflict of interest for this presentation.



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

My Story...



THE 'BIG SECRET':

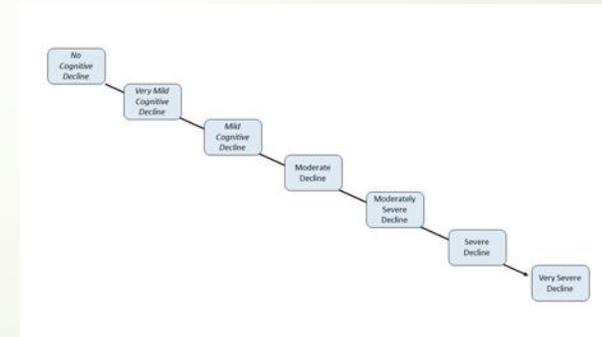
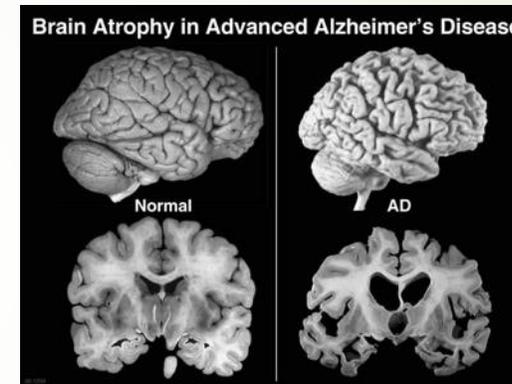


Antipsychotic overuse is not a
long-term care problem!

The Pill Paradigm



The Biomedical Model of Dementia





Fallout from a Narrow Biomedical View



Stigma



Disempowerment



**Looking to pills
for well-being**



“Dementia Care”



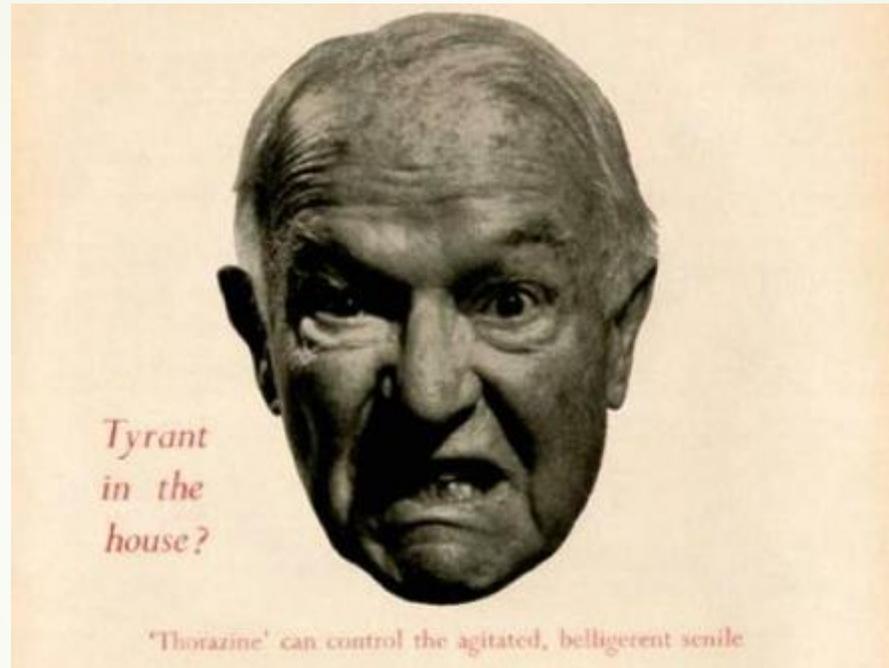
‘BPSD’

Biggest Danger of Stigma → Self-Fulfilling Prophecies



Kate Swaffer

Old Thorazine Ad



How much have things **really** changed since then??



Do We Hold People Living with Dementia to a Higher Emotional Standard than Ourselves??

You and I	People with Dementia
Walk, explore, do our 'steps', get bored and leave	'Wander', 'elope', 'exit-seek'
Get restless when forced into others' rhythms	'Sundown'
Shop in bulk	'Hoard'
Get angry, sad, anxious or frustrated	Exhibit 'challenging behaviours'
Don't like being locked up, bossed around or touched by strangers	Are 'resistive', 'agitated', or 'aggressive'

The Problem with BPSD

- Relegates people's expressions to brain disease
- Ignores relational, environmental, and historical factors
- Pathologises normal expressions
- Uses flawed systems of categorisation
- Creates a slippery slope to drug use
- Does not explain how drug use has been successfully eliminated in many care homes
- Misapplies psychiatric labels, such as psychosis, delusions and hallucinations
- Has led to inappropriate drug approvals in some countries



Words and Actions May Represent...

- Unmet needs / Challenges to well-being*
- Sensory Challenges*
- New communication pathways*
- New methods of interpreting and problem solving*
- Expressions of agency*
- Response to physical or relational aspects of environment*
- May be perfectly normal reactions, considering the circumstances!*

(*NO medication will help these!)

Shifting Paradigms

How would *you* respond if you were told:

- ▶ 'Over 90% of people living with dementia will experience a BPSD during the course of their illness.'

VS

- ▶ 'Over 90% of people living with dementia will find themselves in a situation in which their well-being is not adequately supported.'

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



Oversight Hearing
WATCHING THE COUNCIL OF THE DISTRICT C
COMMITTEE ON HOUSING AND NEIGHBORHOODS

A New Approach Rests upon Three Pillars



- 'Experiential model of dementia'
- Well-being as a primary outcome
- Transformation of the living/care environment



A New Definition

‘Dementia is a shift in the way a person experiences the world around her/him.’



Where This 'Road' Leads...



In Other Words:



Everything changes!



A New Primary Goal: Enhance **Well-being**





One Framework for Viewing Well-being

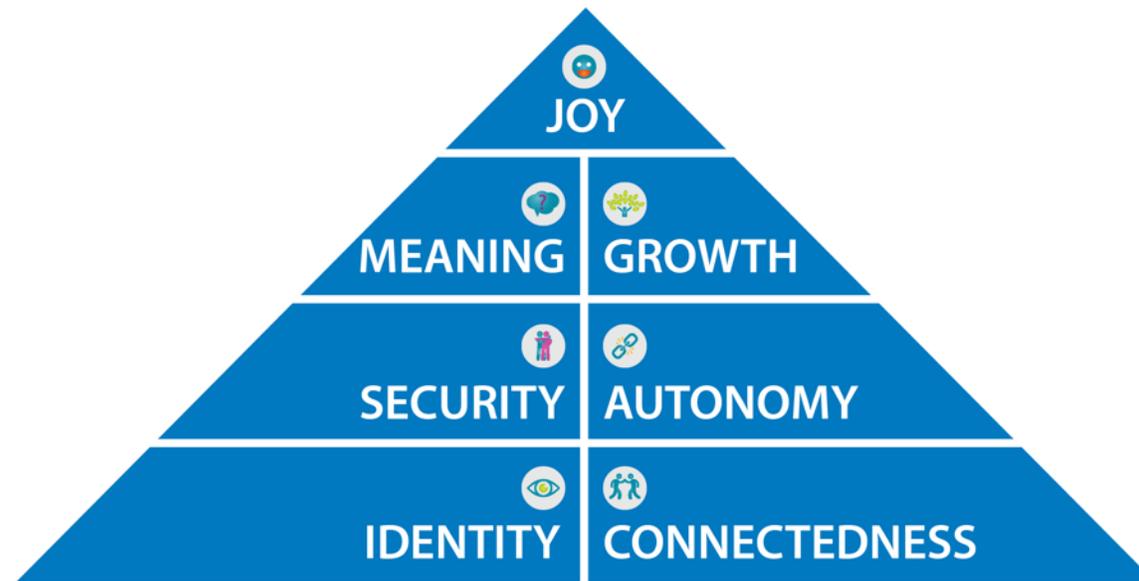
- **Identity**
- **Connectedness**
- **Security**
- **Autonomy**
- **Meaning**
- **Growth**
- **Joy**

‘The Eden Alternative Domains of Well-BeingSM’
adapted by Power (2014)

Advantages of Focusing on Well-Being



Helping Restore Well-Being for People Living with Dementia





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 institutional system, the system will kill it, every time!
- We need a pathway to *operationalise* the philosophy—to ingrain it into the fabric of our daily processes, policies and procedures.
- That pathway is *culture change*.

Transformational Models of Care



Checking the Cows

Why 'Nonpharmacological Interventions'
Don't Work!!



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

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



A well-being approach
can be used for both:

➤ **Ongoing support and care**

➤ **Decoding distress**





**People who
wonder whether
the glass is half
empty or half full
miss the point.
The glass is
refillable.**

Filling the 'Well-Being' Glasses



The Key...



*Turn your backs on the 'behaviour,'
and find the 'ramps' to well-being!*



True Stories...



Angela Norman, NP
UAMS

Arkansas Health Care Foundation

- ▶ Pilot: Dr. Norman approached one provider and asked for 4 homes struggling with antipsychotic use
- ▶ Began to work with staff on enhancing well-being domains for all elders proactively and then shifting systems to support.
- ▶ In 6 months, 3 out of 4 homes had a relative reduction of their antipsychotic rate of **>60%**, and increased staff satisfaction. All continue to improve, one now >90% relative reduction.
- ▶ Angela: 'I believe this proactive approach is the key. It has changed my practice!'

Arkansas (cont.)

- Dr. Norman's team took the Well-Being Approach to the *25 highest-prescribing homes* in the state.
- In six months, antipsychotics were reduced by a relative rate of **49%** among these homes.
- Team is supporting staff from ~100 homes across the state: Almost **NO** Geri-psych transfers in over 6 months
- Other states are asking Dr. Norman to come and teach the approach
- RIA/Power to formally study approach in 2020



'People talk about person-centred care. But if the view of the person doesn't change, then centering on them actually makes it worse.'

*Thank you!!
Questions??*



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