

Dementia Beyond Disease: Enhancing Well-Being

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Enhancing the quality of life and care of older adults through partnerships in research, education and practice.



WHAT WE DO



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ACKNOWLEDGEMENT



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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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My Story...



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Big secret:
Antipsychotic overuse is not a
long-term care problem!

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Lessons from Culture Change

- See the whole person, not the disease(s)
- Put living first--ahead of clinical care; do not over-medicalise people's lives
- Honour individuality
- Honour people's rights and freedom to choose
- Break down rigid hierarchical systems, embrace flexibility
- Empower residents and team members
- Re-think attitudes, beliefs, and operational systems

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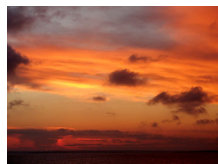
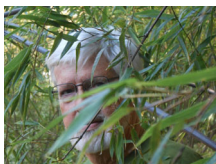
The Pill Paradigm



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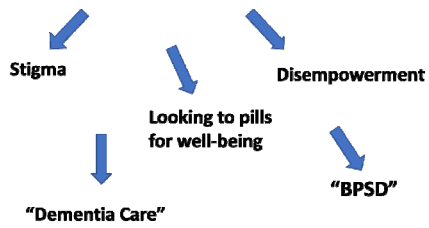
The Biomedical Model of Dementia



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Fallout from a Narrow Biomedical View



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Biggest Danger of Stigma

Self-Fulfilling Prophecies

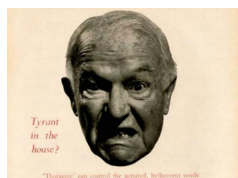


Kate Swaffer

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Old Thorazine Ad



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

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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"

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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



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Words and Actions Usually Represent...

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

(*NO medication will help these!)

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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.”

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A New Model

(Inspired by “True Experts” ...)



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A New Approach Rests Upon Three Pillars

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



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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...

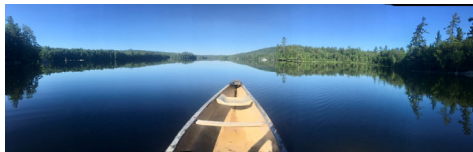
- From fatal disease to changing abilities
- From psychotropic medications to "ramps"
- A path to continued growth
- An acceptance of the "new normal"
- A directive to help fulfill universal human needs
- A challenge to our interpretations of distress
- A challenge to many of our long-accepted care practices



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A New Primary Goal: Enhance Well-being



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One Framework for Viewing Well-being

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

"The Eden Alternative Domains of Well-Being™",
Adapted by Power (2014)

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Advantages of Focusing on Well-Being

- Proactive vs. Reactive
- Strengths-based vs. Deficit-based
- Upstream vs. Downstream



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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 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*.

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Transformational Models of Care

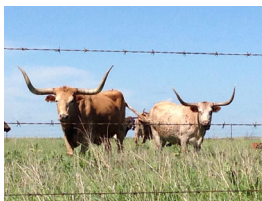


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Checking the Cows

Why “Nonpharmacological Interventions” Don’t Work!!



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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

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Poll Question #1

How important are these aspects of well-being in your own life?
Identity, Connectedness, Security, Autonomy, Meaning, Growth, Joy

- 1) Not at all important
- 2) Slightly important
- 3) Somewhat important
- 4) Quite important
- 5) Essential to a good life

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Poll Question #2

Does your community routinely address this or another well-being framework in your residents' care plans?

1. Yes
2. No

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A Well-Being Approach Can Be Used for Both:

- Ongoing support and care
- Decoding distress

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

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Filling the “Well-Being” Glasses



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The Key...



- Turn your backs on the “behavior”, and find the “ramps” to well-being!



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True Stories...



Angela Norman, DNP
Arkansas Health Care Foundation

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Arkansas Health Care Foundation

- Dr. Norman's team took the Well-Being Approach to the 25 highest-prescribing homes in the state.
- After six months, antipsychotics have been reduced by a relative rate of **49%** among these homes.
- Team is also supporting staff from ~100 homes across the state: Almost *NO* Geri-psych or hospital transfers in over 6 months
- Other states are asking Dr. Norman to come and teach the approach
- RIA/Power to formally study approach in 2019

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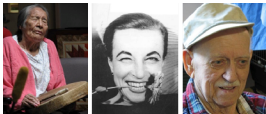


Dr. Richard Taylor

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

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Thank you!!
Questions??



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