



Dementia Beyond Disease: *Enhancing Well-Being*

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Adapted from work of Dr G. Allen Power

The Biomedical Model of Dementia

- Described as a group 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 condition
- Quick to stigmatise (“The long goodbye”, “fading away”)
- Quick to disempower individuals
- Creates institutional, disease-based approaches to care
- Sees distress primarily as a manifestation of disease (“**BPSD**”)

Biggest Danger of Stigma → Self-Fulfilling Prophecies



Kate Swaffer

“Upon diagnosis I was Prescribed Disengagement™ from my pre-diagnosis life, which the health care system currently still supports. This sets up a chain reaction of hopelessness and fear, and is the beginning of learned helplessness, which negatively impacts a person’s ability to be positive, resilient and proactive, intimately affecting their perception of well-being and quality of life.”

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 interpretations of distress
- A challenge to many of our long-accepted care practices

Primary Goal: Enhance Well-being



Question:
*What does “well-being” mean to
you?*

The World Health Organisation (WHO) recently widened their definition of health to include psychological wellbeing which they define as:

‘ a state of mind in which an individual is able to realise his or her own abilities, cope with the normal stresses of life, can work productively and fruitful, and is able to make a contribution to his or her community’.

Benefits of Focusing on Well-Being

- Sees the illness in the context of the whole person
- Destigmatises personal expressions
- Understands the power of the relational, historical, and environmental context
- Focuses on achievable, life-affirming goals
- Brings important new insights
- Helps eliminate antipsychotic drug use
- Is proactive and strengths-based

Suggested Ordering of Well-Being Domains



Figure 2. The well-being pyramid illustrates the hierarchy of domains to be addressed for restoring well-being. (From *Dementia Beyond Disease: Enhancing Well-Being*, by G. Allen Power. Published by Health Professions Press. Copyright (c) 2014 by Health Professions Press, Inc. All rights reserved. Reprinted by permission.)

- *What if most of the hard-to-decipher distress that we see is actually related to the erosion of one or more aspects of the person's well-being??*
- *So... is it any surprise that people we care for have ongoing distress, even though we have "done everything we can think of" to solve it???*

For example...

- Addressing physical resistance during bathing becomes more than simply adjusting our bathing technique.
- It involves ongoing, 24/7 restoration of well-being, especially autonomy, security, and connectedness
- These domains of well-being must be not only be appreciated, but actively *operationalised* throughout daily life
- This requires a transformative approach to support and care in all living environments (i.e., “culture change”)

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 *operationalise* the philosophy—to ingrain it into the fabric of our daily processes, policies and procedures.
- That pathway is *culture change*.

The Key...



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

