Unlocking the door:
Making Elder Care "Dementia-Friendly"

G. Allen Power, MD, FACP

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"By 2015, we want there to be a million people with the know-how to help people with dementia feel understood and included in their community."

Consider this…

If a *Dementia-Friendly Community* can be defined as a community that seeks to include and positively engage those who live with dementia, then long-term care and assisted living are on track to become the most *dementia-unfriendly* parts of our society.

History of Segregation in Dementia Care

- 1974: The Weiss Pavilion at the Philadelphia Geriatric Center (now part of the Abramson Center for Jewish Life), designed by Dr. Powell Lawton
- •Two goals: improve **wayfinding** and provide opportunities for spontaneous **interaction**
- •40 resident rooms around a large, open pavilion

History (cont.)

- 1976: Friendship House in West Bend, WI (now part of Cedar Community)
  - Very little documented about early model
  - Today, 60 cottage residences arranged into three 20-unit neighborhoods
  - "All-natural courtyard setting… with **no visible fencing** to encourage autonomy, promote physical activity and celebrate nature and life"

A series of brief arguments for integration

- Seeing the person, not the disease
- Clinical outcomes
- Programming and “aging out”
- The ubiquitous locked door
- Value of diversity
- Civil rights

Is This the Biggest Misconception in Elder Care??

- Over **100** forms of dementia
- Many variations and levels of ability
- Many histories, strengths, coping skills
- Many cultures
- Over 50 million people worldwide

but…

"One size fits all" housing and care???

Questions for You

- If you are diagnosed with dementia, do you want to live the rest of your life in a place that only has other people with dementia living there?
- Would you ever want to live in:
  - The Home for People with High Blood Pressure?
  - The Home for Former AL/LTC Executives?
  - The Home for____ (a Certain Race, Religion, Ethnicity)?
  - The Home for People Who Had the Same School GPA?
- Would such a place treat you like more, or less of a unique individual?
- Do you think that having segregated living makes other residents' and families' fear and stigma greater or less??

Clinical Outcomes

"There are no identified RCTs investigating the effects of SCUs on behavioral symptoms in dementia, and no strong evidence of benefit from the available non-RCTs. It is probably more important to implement best practice than to provide a specialized care environment."

- Cochrane Review 2009

(Lai, et al., http://www.cochrane.org/CD006470/)

Clinical Outcomes

- Gruneir, et al., 2017: Looked at all US homes via OSCAR reports from 1996-2004.
- Antipsychotics and restraints decreased across-the-board, no significant difference
- Some better results in homes that had an SCU, but they also had mixed living areas
- The authors concluded that any superiority of such providers was not due to the separate living areas themselves, but more likely reflected "other differences in overall facility operation and practice."

Clinical Outcomes

- Lachs, et al. 2016: Increased risk of elder-to-elder (verbal/physical) aggression or mistreatment
- Cadigan, Grabowski, Givens, & Mitchell, 2012: Increased antipsychotic use; less pain treatment
- Kok, Berg, & Scherder, 2013: Greater "deterioration in behavior," greater decline in ADLs
- Van Haitsma, Lawton, & Kleban, 2000: Overall poorer clinical outcomes, c/w non-segregated

Also, there is ***no*** standard definition or criteria as to what a "special care area" entails

Clinical Outcomes

- Namazi & Johnson, (1992!!!)

  - 22 residents observed 60 hours both with doors locked and unlocked (0915-1215, 1330-1630).

  - Recorded any "behaviors" seen within 30' of encountering a door

  - Locked doors: "1,417 active responses, 114 verbal responses, three aggressive responses… and four responses in the other category"

  - Unlocked doors: "393 active responses, 25 verbal responses, one aggressive response, and no other responses"

Namazi & Johnson (cont.)

- "Agitated behaviors" precipitated by encountering the door: 52 (locked) → 11 (unlocked)
- "Walking/wandering behaviors":

  1365 → 381
- Various "verbal behaviors": 79 → 23

Namazi & Johnson (cont.)

"An interesting aspect of this study was the observation of nonverbal behaviors displayed by residents after they found that the exit doors were open. Among those who were most eager to exit the unit, the experience usually ended when the resident was assured that the door was open and he or she could depart. Several residents held the door ajar with one hand, stepped outside, looked around, and then came back inside…Once a resident's sense of curiosity was satisfied, i.e., the resident recognized that he or she was not confined within the unit and was free to go in or out, he or she often chose to remain indoors. The element of choice also appeared to decrease negative exit door behaviors."

Keep in Mind…

- This is not about bad people, or bad care.
- It is about systemic and paradigmatic barriers to well-being, similar to what we have seen in institutional nursing homes.

"Programmed Units" and "Aging Out"

- The concept of activity programming driven by cognitive score, functional level, or diagnosis category is antithetical to individualized care

- Those who no longer "fit" the organization's programmatic approach often are moved out, which is antithetical to the primacy of relationship, and disruptive to the person's well-being

A Locked Door Is a Locked Door

- Staff-centered
- Often causes a *decreased* sense of security for the person and *increased* distress
- Erodes staff's critical thinking skills
- Erodes individualized approaches

Value of Diversity

- Sabat (2001): Being with healthy others creates "positive social personae"
- Caring roles for cognitively-able people
- Dangers of concentrating people with compromised stress thresholds, coping mechanisms and verbal skills
- Universal physical design preserves well-being through one's changing physical and cognitive abilities

Civil Rights

- Who else, besides convicted felons, is barred from living around others?
- Olmstead Supreme Court decision (1999)
- UN-CRPD and choice of housing

Antidotes to Fear

- Education of *all*
- De-stigmatization
- Relationship and deep knowing
- Well-communicated value-based organizational philosophy
- Enlightened practices that facilitate well-being for all

What is the definition of a restraint?

"A restraint is any device, attached to or adjacent to the person, which the person cannot easily remove, that prevents freedom of movement."

-US Centers for Medicare/Medicaid Services

So…

- These are restraints:

- And these *can* be restraints:

But…what about this???

Matt Perry (2013)

"Is it any wonder that my mother was **rattling her cage**, warehoused in a system that rarely meets the physical needs of residents while almost entirely neglecting their emotional and spiritual desires –not to mention their sensual ones? … We are on the precipice of disaster and can either follow the visionaries who seek to redefine aging, or continue to treat and **imprison our parents and grandparents**– in their bodies and our facilities…" (Perry, 2013)

https://www.calhealthreport.org/2013/01/21/seizing-the-chance-to-redefine-aging/

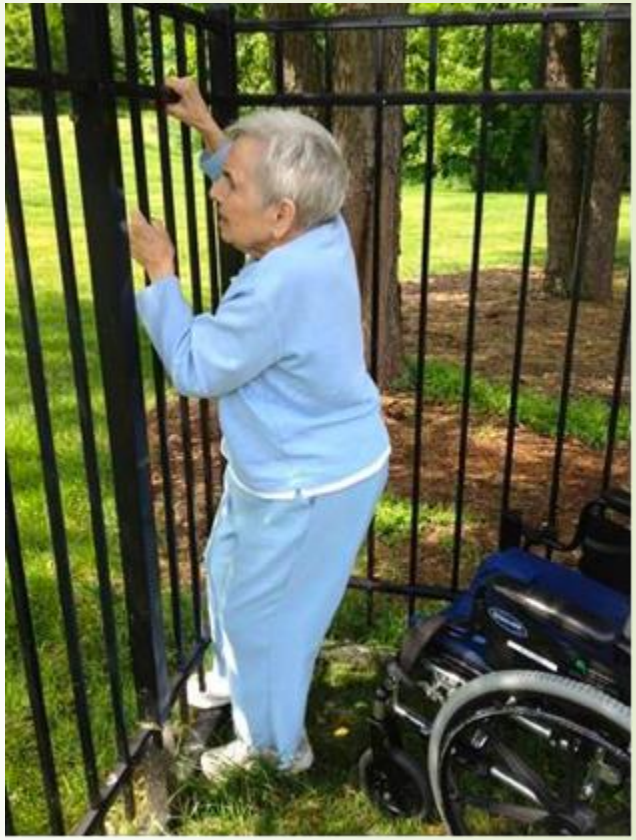


Photo credit, Matt Perry, 2013

Practical Pathways to Inclusion

- **Reframe dementia**
- **Focus on well-being**
- **Embrace complexity**
- **Reduce discomfort of environment**
- Foster relationships
- Open a space for regular and frequent communication, value diverse perspectives
- **Expand perimeter and individualize care**
- Negotiate upside and downside risk
- Leverage technology, respectfully

Reframing Dementia
First Step:

Changing Our Mindset

- Walking is a *normal, daily human activity*. "Wandering" and "elopement behavior" are labels that judge and pathologize the person's intent

- What do we do??
  - We go for a walk
  - We explore
  - We "stretch our legs"
  - We "get some exercise," do our "steps"
  - And.. sometimes we wander!

If you were in a locked living area and could not leave on your own, how would *you* feel?

- Could you relax at night?

- How long would you last before you started to "climb the walls"?

- Do *you* have a BPSD??

People may try to exit because…

- They are simply curious, exploring, or following the normal impulse to move

- They are not comfortable:
  - Trying to find something that is not there
  - Trying to get away from something that is there

(These "somethings" are usually not a tangible object!)

One Framework for Viewing Well-Being

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

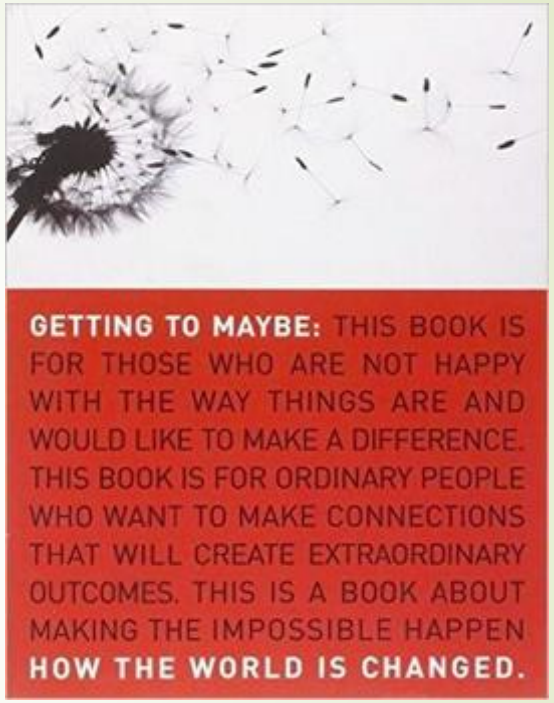
Adapted from Fox, et al. (2004 white paper),
now "The Eden Alternative Domains of Well-Being℠"

Benefits of Focusing on Well-Being

- Sees the illness in the context of the whole person
- Destigmatizes 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

Embracing Complexity

- "**Disasters** occur when complex issues are managed or measured as if they are merely complicated or even simple" (p. 10).
- In complex systems, **relationships** and **dialogue** are key.
- We need to learn to live and work with uncertainty.



(Westley, Zimmerman and Quinn, 2006)

Reduce Discomfort

- Decrease the pressure/frequency of people trying to leave because they are distressed

- Just as in transformational processes, stressors can be due to the *physical, relational, or operational environment*

A Few Physical Factors

- Is the layout confusing (long hallways, institutional trappings, large scale, double rooms, "hotel" appearance, poor wayfinding cues, etc.)?
- Does the living space provide comfort, familiarity, and meaning?
- Is the lighting inadequate or bothersome?
- Is the acoustic environment stressful?

A Few Relational/Operational Factors

- Do we rotate care partners?
- Are good communication techniques used?
- Do we listen and seek input at all times?
- How is our body language?
- Do we enter rooms unannounced?
- Do we wear uniforms?
- Do we respect people's own rhythms of rest/activity?
- Is it quiet at night?
- Do we provide generic activities that do not suit individual needs, alternating with long spells of non-engagement?

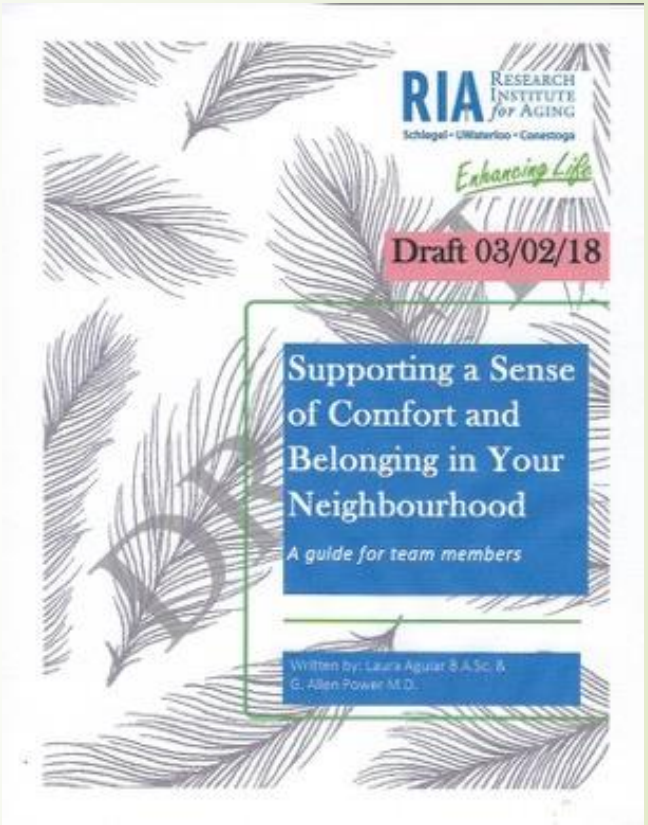
*Unless **all** of these and similar factors are explored and addressed, we **cannot** say that a person's dementia is the cause of her actions!!!*

Further Steps Toward Unlocked Doors

- Widen the perimeter, locking only outer doors
- Provide an accessible safe outdoor space

Steps (continued)

- Individualize alarms for those at risk
- Embrace development and use of new technology
- Individualize people's activity needs
- Dedicated staffing and attention to supporting well-being and a sense of comfort and belonging!!



True Stories
SentryCare – Dunbar Village
Bay St. Louis, Mississippi

Thank you! Questions?

DrAlPower@gmail.com
www.alpower.net