

Negotiating Autonomy and Risk for People Living with Dementia

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



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Opening (Half-) Story: 'Frank and the Locked Door'



Heather Luth
Dementia Program Coordinator,
Schlegel Villages, Ontario, Canada



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Poll Question #1

What would you do now??

- 1) Change the door code and remove Frank's privileges
- 2) Only allow supervised trips outside
- 3) Continue the plan as before
- 4) Something else?

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Poll Question #2

What you do think *your organization* would choose?

- 1) Change the door code and remove Frank's privileges
- 2) Only allow supervised trips outside
- 3) Continue the plan as before
- 4) Something else?

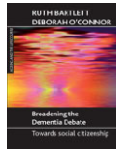
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Remarkable Quote #1

'Oppressive and discriminatory practices often have their foothold in the well-meaning, well-intentioned ideas of those least intending to do harm.'

Bartlett & O'Connor (2010)



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Remarkable Quote #2

'Much of what we call "person-centred care" is simply bossing people around in a very individualised way.'

Daniella Greenwood
Aged Care Consultant
Melbourne, Australia

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'AI 101'



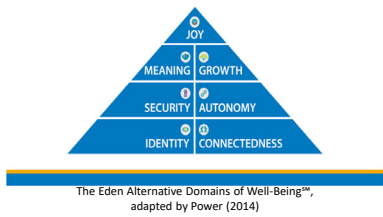
My Approach Rests upon Three Pillars

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

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Helping Restore Well-Being for People Living with Dementia



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Points of Contact (and Conflict)

Autonomy ↔ Identity and Connectedness

Autonomy ↔ Security

Autonomy ↔ Meaning and Growth

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How well-meaning people can erode autonomy (I/C):

- Stigma and low expectations
- Exclusion from discussion / decisions
- Communication and care practices
- Care systems and staffing patterns
- Staging systems, assessments and categorizations (esp. 'BPSD')
- Segregated living environments

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How Segregation Erodes Autonomy

- Locked doors
- Lack of choice in determining where to live
- Lack of individualization
- Lack of contact with more able 'social personae' (Sabat)
- Stigma and low expectations → Self-fulfilling prophecies

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Security and Autonomy

- Fragile dynamic (can enhance or inhibit)
- Two common practices that erode autonomy:
 - All-or-none thinking
 - Surplus safety



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All-or-None Thinking

- Stems from:
 - Stigma
 - Inability to see nuances of ability
 - Misunderstanding of carer role
 - Misunderstanding of empowerment
 - Inflexible care systems

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Surplus Safety (Thomas & Ronch)



Excessive concern with *downside risk*, relative to *upside risk*

- *Downside risk*: The chance that something will turn out **worse** than expected
- *Upside risk*: The chance that something will turn out **better** than expected
- With dementia, nearly all of the focus is on **downside risk**

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Remarkable Quote #3

“We want autonomy for ourselves and safety for those we love. That remains the main problem and paradox for the frail. Many of the things that we want for those we care about are things that we would adamantly oppose for ourselves because they would infringe upon our sense of self.”

- Atul Gawande

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Surplus Safety Policies also Erode Critical Thinking!



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Remarkable Quote #4



*"The only risk-free human environment is a coffin."
-Bill Thomas, MD*

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Supporting Autonomy

- Optimize communication and facilitation skills
- Consider a spectrum of ability
- Look at upside as well as downside
- *Negotiate* risk

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Optimizing Our Interpersonal Skills

Strong communication and facilitation skills constitute the most basic level of empowerment!

- Understand communication barriers
- Understand shifts to emotion-based expression
- Understand 'embodiment' as a form of choice (Kontos & Naglie, 2009)
- Work together through tasks
- Solicit frequent consent and input

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7 Steps to Negotiating Risk (Power, 2014)

- Discussion
- Exploration of values, tie-in to well-being
- Conditions of empowerment
- Continuum of empowerment
- Collaborative decision
- Documentation and monitoring of results
- Keeping other stakeholders abreast of the process

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The Rest of the Story: 'Frank and the Locked Door'



Heather Luth
 Dementia Program Coordinator,
 Schlegel Villages, Ontario, Canada



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Autonomy and Meaning/Growth: A Story from Tennessee



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And... What about Downside Risk??

- Downside risk is real
- Start with relationships
- Use incremental steps to minimise downside, achieve early victories, and enable cumulative organizational shifts
- *Never ask about the risk of doing something without also asking, "What is the risk of not doing it??"*

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"An injury or death after leaving a building is a serious event, and would likely be reported all over the news. The gravity of such outcomes is not to be minimized.

"But for every person who actually suffers such a fate, how many people on a daily basis are forced to live with anxiety, fear, and life-giving needs that remain unmet? Or withdraw and give up on life, as many prisoners of war have done? Or become overmedicated with dangerous and sedating drugs as a result of their distress? Hundreds? Thousands?

"These are also very newsworthy negative outcomes that will start to be more widely publicized as consumer awareness grows...

"We must always negotiate risk, balancing it against the ability to live life to the fullest extent possible."

<http://changingaging.org/dementia/the-hidden-restraint-part-4/>

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One last quote to consider:

The most dangerous situation for people living with dementia may well be the self-fulfilling prophecy!

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Thank you! Questions?



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