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# Creating a Paradigm Shift: Culture Change Around Dementia

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## Introduction to Dementia

Dementia affects 5.8 million Americans. There are several different types of dementia. The typical definition of the effects of Dementia includes behavioral changes in a person. A diagnosis of this disease means more than being affected by the symptoms. When a person is diagnosed, their humanity is stripped away. Capacity of decision making is removed from each person and is replaced by expectations of symptoms of dementia.

Based on three qualitative interview-based studies, community members who have not interacted with people living with dementia, expressed fears regarding:

- Disruptive behavior,
- Resistance to staff trainings that are dementia-specific,
- Resistance to the costliness of creating accommodations, (Hebert & Scales. 2017).

Every 65 seconds someone develops the disease, (alz.org, 2019).

## The New Definition of Dementia

Dementia is a shift in the way a person experiences the world around her/ him. Defining it this way removes labels, stigma and disease.

Part of developing a paradigm is changing the way society thinks about dementia. Right now a biomedical approach is used to establish non-pharmacological methods for treating dementia.

Using different words creates a healthier mindset for creating a new way to look at living with dementia. Removing words such as intervention and treatment make living with dementia less clinical and thus make it more of a lifestyle change.

## Dementia Stigma

Stigma can be the product of good intentions.

Stigma contains three important elements:

1. Problems of knowledge (Ignorance)
2. Problems of attitude (prejudices)
3. Problems of behavior (discrimination)

Education Can be used to overcome stigma. Providing people with the right education can improve quality of life for people living with dementia.

Education should be available for:

- Providers
- Families
- Medical Professionals and Researchers
- Regulators
- Media
- Advocacy Organizations
- Lawyers, and legislators

## The Three Pillars

- 1. Experiential**  
Relating to a living model for people living with dementia
- 2. Well-being**  
Focusing on providing the person with a purposeful life
- 3. Transformation**
  - a. Personal: Both intra-personal (how we see people living with dementia) and inter-personal (how we interact with and support them).
  - b. Structural: Living environments that support the values of home and support the domains of well-being.
  - c. Operational: How decisions are made that affect people with dementia, fostering empowerment, how communication occurs and conflict is resolved, creation of care partnerships, job descriptions and performance measures, etc., etc.

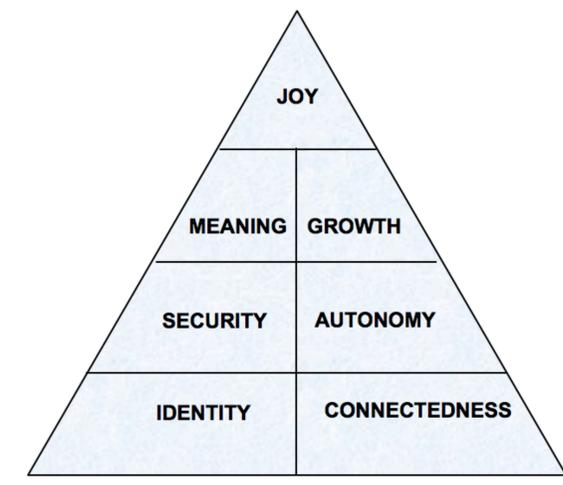
## Negotiating Autonomy and Risk: A Relational Approach

Keeping a person safe results in creating spaces that isolate the individual that is affected by dementia. This segregation removes the person from their community. **Risk creates purpose.** Situational risk has to be evaluated and the underlying cause of an action can be determined to decide whether an action can be adjusted or not.

## 7 Steps to Negotiating Risk

1. Discussion
2. Exploration of values, tie-in to well-being
3. Conditions of empowerment
4. Continuum of empowerment
5. Collaborative decision
6. Documentation and monitoring of results
7. Keeping other stakeholders abreast of the process

## Eden Alternative Domains of Well-Being



Based on this model, the number one necessity for a person is to feel connected to others while also holding onto their personal identity. If all of these categories are met, then a person maintains their well-being.

## Primary Goal: Enhance Well-Being

“The development of peer relationships with meaningful engagement in the greater community has been reported to promote well-being (Henwood & Downs, 2014; Hirst, 2016; Rahman, 2014; Woods, 2012)”, (Hebert & Scales, 2017).

## Creating Dementia Friendly Communities

Dementia friendly and age-friendly initiatives entail a similar approach, which is the creation of supportive, inclusive, and enabling environments that maximize independence through collaboration with diverse community stakeholders (Turner & Morken, 2016; DFA, 2017). Both dementia friendly and age-friendly initiatives also shift the narrative from deficit and burden to contribution and inclusion (Hebert & Scales, 2017).

Set up living space to care for the person rather than treat the person.

## Ideas for dementia-friendly neighborhoods

- Alternative identification processes if people forget their pin number.
- Training for police in helping people with dementia who are lost.
- Home adaptations including better lighting.
- Awareness training for shop and business employees.
- Wide and flat footpaths.

(Duffin, 16)

## Acknowledgements

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