



Expanding the Possibilities of Living Well with Dementia

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Objectives

- **Learn** about an approach to supporting people living with dementia that centers on the concept of enhancing well-being.
- **Experience** the power of 'authentic partnerships' and 'dialogue education' through an active exploration of their respective principles and practices.
- **Compare** the *Dialogue Project* to more traditional training initiatives and educational programs in terms of learning outcomes and potential for cultural transformation.
- **Consider** how something like the *Dialogue Project* can be integrated into your organization.



Opening Small Group Exercise

What does **well-being** mean to you?



Please make a list with your tablemates.



One View of Well-Being

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

Adapted from Fox, et al. (2005 white paper); now "The Eden Alternative Domains of Well-Being™"

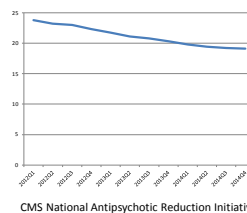


Problems with Focusing on Illness

- Does not see the whole person
- Reductionistic (e.g., cognitive assessments, stages) and deficit-based
- Stigma, stigma, stigma
- Medicalizes and pathologizes people's words and actions ("BPSD")
- Encourages drug use and other reactive, "intervention"-based approaches



Biomedical Approach to Reducing Antipsychotics...



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 contexts
- Focuses on achievable, life-affirming goals
- Brings important new insights
- Helps eliminate antipsychotic drug use
- Is proactive and strengths-based



A Question (or Two) for You:

- 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?
- Well-being is a need that transcends all ages and cultures, and yet...
- There is no professional training program that teaches about well-being and how to operationalize it...
- So... is it any surprise that people we care for have ongoing distress, even though we have "done everything we can think of" to resolve 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 not only be appreciated, but actively operationalized throughout daily life.
- This requires a transformative approach to support and care in all living environments (i.e., "culture change").



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



Why "Nonpharmacological Interventions" Don't Work!

The typical "nonpharmacological intervention" is an attempt to provide person-centered care with a biomedical mindset:

- Reactive, not proactive
- Discrete activities, often without underlying meaning for the individual
- Not person-directed
- Not tied into domains of well-being
- Treated like doses of pills
- *Superimposed upon the usual care environment*

Checking the Cows



Transformational Models of Care



Transformation

- **Personal:** Both intra-personal (how we see people living with dementia) and inter-personal (how we interact with and support them)
- **Physical:** Living environments that support the values of home and the domains of well-being
- **Operational:** How decisions are made that affect the elders; fostering empowerment; how communication occurs and conflict is resolved; creation of care partnerships; job descriptions and performance measures; etc.



*MAREP's
Living and
Celebrating
Life
through
Leisure
Team*

(Dupuis, Whyte, Carson, et al., 2012)

Leisure – Well-Being Alignment

Being Me	↔	Identity
Being With	↔	Connectedness
Seeking Freedom	↔	Autonomy
Finding Balance	↔	Security
Making a Difference	↔	Meaning
Growing and Developing	↔	Growth
Having Fun	↔	Joy



A Suggested Well-Being Hierarchy



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.)

A Well-Being Approach Can Be Used For:



- Ongoing support and care, and
- Decoding distress



Culture Change is for Everyone!

- Nursing homes
- Assisted living
- Federal and State regulators
- Reimbursement mechanisms
- Medical community
- Families and community
- Liability insurers
- **Educational approaches**

(Example from the Resource Center)



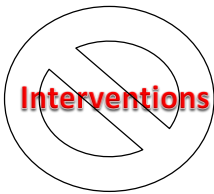
Collaborative Reflection

- We asked, “What is the culture of residential dementia care: 1) across the nation; and 2) at the Resource Center?”
- Broadly speaking, the current culture of residential dementia care is neither adequate nor acceptable for ensuring the well-being of persons living with dementia, or their care partners.



Current Challenges

- Interventionist, medical model oversimplifies the human experience
- ‘Expert’-dominated culture privileges scientific knowledge over lived experiences, focuses on the efficient fulfillment of functional goals, and creates recipes for care and silos of service delivery
- Disempowering hierarchies limit opportunities for participation in decision-making
- Misunderstandings and stigma make persons living with dementia invisible and limit their contributions to their own care and services



Well-Being ✓



With ✓



Call for Care Partnerships

“...We need to move away from labeling ourselves as care-giver and sufferer, towards becoming a care-partnership, in which we accept, collaborate, and adapt to new roles within the journey of dementia ... In this care-partnership, the person with dementia is at the center of the relationship, not alone as an object to be looked at, as merely a care recipient. Instead, we become an **active partner** in a circle of care.”



Christine Bryden
Dancing with Dementia: My Story of Living Positively with Dementia (2005)



Authentic Partnerships

Actively incorporate and value diverse perspectives and include **all** stakeholders (care partners) directly in decision making, including persons living with dementia



Dupuis, S.L., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loisel, L., & Sadler, L. (2011). Moving beyond patient and client approaches: Mobilizing authentic partnerships in dementia care. *Dementia*.



Problem with Dementia/Culture Change Education

- Efforts to improve dementia care tend to reproduce current challenges and perpetuate a dehumanizing paradigm.
- How often are training initiatives or educational programs are designed by so-called ‘experts’ and implemented from the top-down, transferring knowledge in a one-size-fits-all manner?

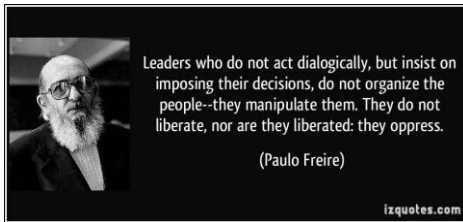


Critique and Inspiration

- “Any situation in which some [people] prevent others from engaging in the process of inquiry [or change] is one of violence; ...to alienate humans from their own decision making is to change them into objects.” (Freire, 2007, p. 85)
- Leaders should not be “proprietor[s] of revolutionary wisdom,” but should instead practice “co-intentional education.” (Freire, 2007, p. 69)
- “Whatever the problem, **community is the answer.**” (Wheatley, 2010, p. 157)



Critique and Inspiration



Problem → Opportunity!

- In order to change the culture of dementia care, we must **change the culture of education** about dementia care.
- We need training initiatives and educational programs that include and offer meaningful roles to persons living with dementia – the true experts – and their care partners as people work together to expand the possibilities of living well with dementia.



How Adults Learn – Six Factors

Malcolm Knowles:

1. Respect
2. Immediacy
3. Relevance

Jane Vella:

4. Safety
5. Engagement
6. Inclusion

Adults retain:

- 20% of what we hear;
- 40% of what we see and hear; and
- 80% of what we hear, see and DO.



Traditional Training	Dialogue Education
Lectures, PowerPoint presentations, sometimes Q&A afterwards	Learning activities : draw on own experiences, engage with new content, apply it, and consider its application to context
Monologue and sometimes Q&A afterwards	Dialogue throughout
Primarily auditory (passive listening); some visual (watching PowerPoint)	Visual, auditory, and kinesthetic – mentally, physically and verbally engaged
Teacher is accountable	Mutual accountability
Teacher's knowledge counts	Everyone's knowledge counts
Favors deductive knowledge	Supports both deductive/inductive knowledge
Focus on delivering content	Focus on developing content through process
Low sense of ownership and learning	High sense of ownership and learning
Requires little preparation (for some)	Takes time to prepare well

Think-Pair-Share

- Please **reflect** on some of the differences between traditional training and dialogue education (Vella, 2002 & 2008), and **consider** the following questions:
 - How do these approaches align with or reflect the qualities of **your** best learning experience?
 - How do these approaches align with culture change values?
- Then, please **find** a partner and **share** your answers.



Our Journey (October 2014 – July 2015)



The Dialogue Project

A Process for Transformative Education, Community Conversations and Collaborative Action

Through our shared participation, we aim to:

- Expand the possibilities for living well with dementia
- Nurture relationships, collaboration and teamwork on each neighborhood to strengthen connection, communication and mutual trust
- Identify, co-create and work toward future organizational improvements

Five Cyclical Components



Presentations on Well-Being



Neighborhood Retreats



Critical Reflection on Retreat #1*

Need to:

- involve more people in planning process
- strengthen trust on leadership team (i.e., safe space guidelines are just a beginning)
- clarify and align leadership values and practices
- strengthen willingness to share power
- Deepen our compassion – growth opportunities for everyone!



Leadership Retreat*



Advisory Team*

- Elders
- Family care partners
- Direct support care partners
- Neighborhood coordinators
- Leadership team



Daily Neighborhood Shift Huddles



Neighborhood Gatherings and Goals

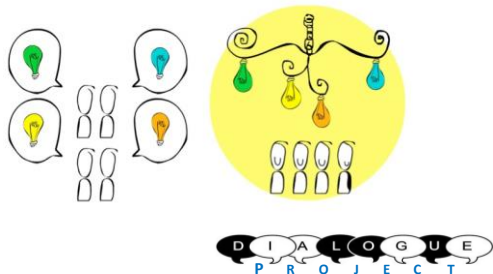


Example of Neighborhood Goals

Neighborhood	Goal for Identity and Connectedness
1A	Potluck gatherings
2A	Dedicated neighborhood staff
1B	Honoring the elders' wishes regarding daily schedules
2B	Dedicated care partners
AL / ADP	Re-creating personal and outdoor spaces



Innovation Celebration



Concluding Large Group Discussion

How can you envision doing something like the *Dialogue Project* in your organization?

- or -

How would transformative education, community conversations and collaborative action benefit your organization?



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Authentic Partnerships

What is the Authentic Partnership Approach?

- This approach actively incorporates and values diverse perspectives and includes all key stakeholders in decision-making, including persons with dementia, their family, partners in care, and professionals.
- The Authentic Partnership approach includes three guiding principles and five enablers.
- It harnesses the collective capacity within all partners, promoting empowerment, equality and social change.

3 Guiding Principles of Authentic Partnerships

Genuine Regard for Self and Others	Synergistic Relationships	Focus on the Process
<ul style="list-style-type: none"> • Value and know each other • Honour individual uniqueness/ abilities • Believe that everyone can learn and grow 	<ul style="list-style-type: none"> • Value interdependence • Include diverse stakeholders • Hear/include all voices • Build on the group's diversity • Promote shared learning 	<ul style="list-style-type: none"> • Stay flexible & responsive to change • Learn from mistakes • Embrace creativity • Remain open to new possibilities

5 Enablers of Authentic Partnerships

Connect and Commit	Create a Safe Space	Value Diverse Perspectives	Establish and Maintain Open Communication	Conduct Regular Reflection and Dialogue
<ul style="list-style-type: none"> • Bring together a diverse group of partners • Collectively determine goals and expectations • Identify strengths and resources • Develop mutually agreed upon guidelines for supporting the partnership 	<ul style="list-style-type: none"> • Create a space that is emotionally and physically comfortable • Build trust so members can openly express their views • Discuss how to foster strong relationships • Be attuned to indicators of discomfort or frustration • Provide a familiar environment, free of distractions 	<ul style="list-style-type: none"> • Appreciate the contribution of all partners • Value different types of engagement • Act on partners' insights • View differences as opportunities 	<ul style="list-style-type: none"> • Provide a range of ways for communicating • Provide time for people to process information • Use accessible language • Keep all partners 'in the loop' • Clarify meanings 	<ul style="list-style-type: none"> • Provide opportunities for self and group reflections and dialogue • Regularly ask: <ul style="list-style-type: none"> ⇒ How is the approach contributing towards building authentic partnerships and incorporating all voices? ⇒ What is working well? ⇒ What could we be doing differently?

"[This approach] values me as a person and the contributions that I can make to dementia care, to my own care. This approach stops the exclusion of persons with dementia by actively including us and our family members in our own care and in the process of developing our care plans" - Partner with dementia

Created in partnership with:

marep

Murray Alzheimer Research and Education Program



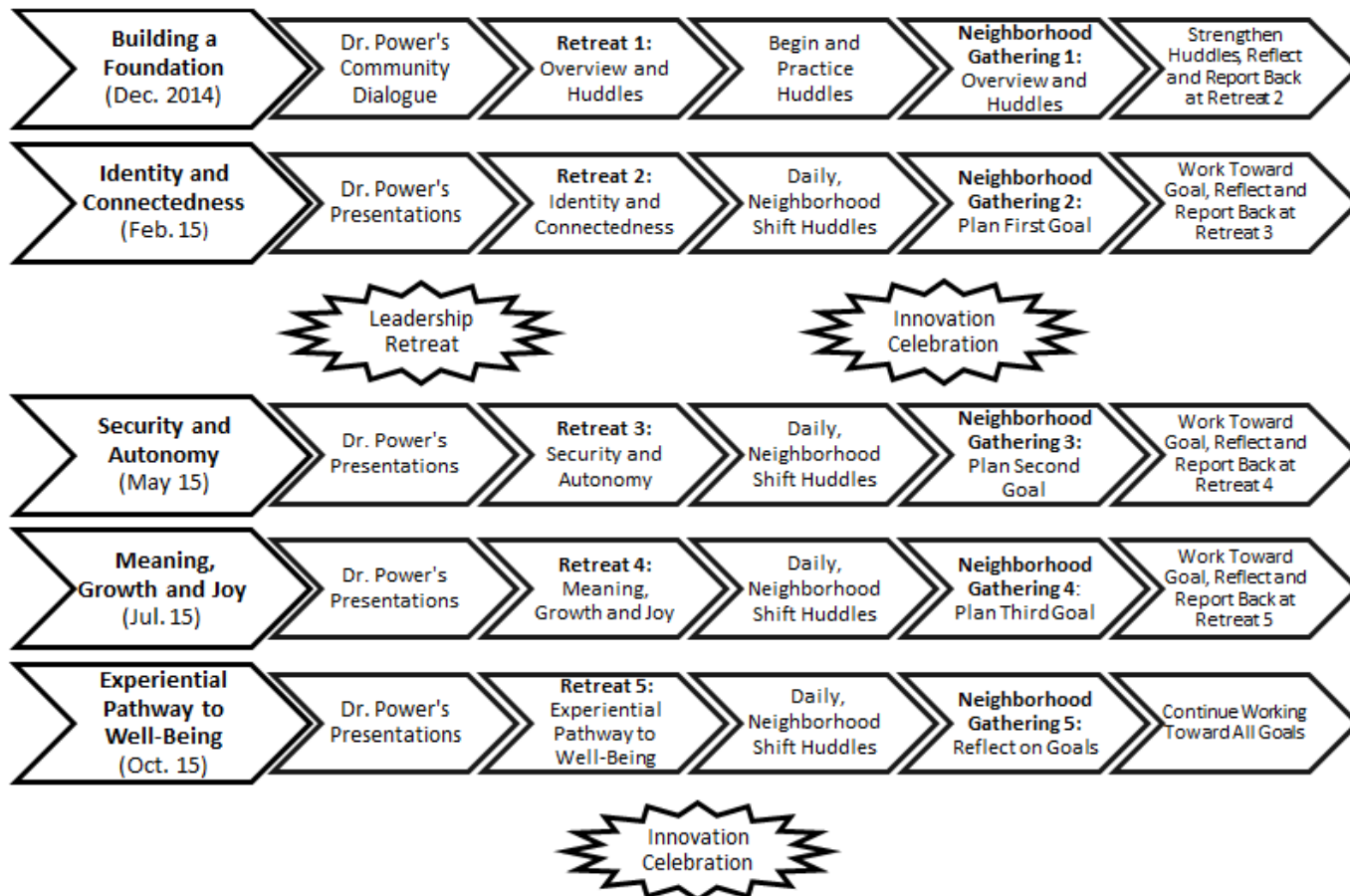
Developed by: Alzheimer's Resource Center

What is the Dialogue Project?

At the Resource Center, we have a deep desire to continually reflect on and improve the experiences of visiting, working in and living at our community. While it may be expedient and efficient for handful of leaders to design improvements and then roll them out, a top-down approach limits the valuable contributions all community members could make to shaping a better future, given the time and space to reflect, listen, learn, and act together. Plus, any improvements or changes we make together are destined to be more effective and sustainable. Embracing this belief, the Resource Center has embarked on an initiative to provide opportunities for transformative education, community conversations and collaborative action, bringing employee and family care partners together to learn *with* and *from* the Elders who live at or visit the Resource Center. We call these opportunities the **Dialogue Project**, and through our shared participation, we aim to:

- Expand the possibilities for living well with dementia;
- Nurture relationships, collaboration and teamwork on each neighborhood to strengthen connection, communication and mutual trust; and
- Identify, co-create and work toward future organizational improvements.

Overview of the Dialogue Project Process (December 2014 – December 2015):



Description of the Dialogue Project Components:

Well-Being: At the Resource Center, we believe well-being is the path to a life worth living. As a part of the Dialogue Project, we explore ideas for how to promote the well-being of all community members as it relates to seven domains, as described in Dr. Power's book: identity, connectedness, security, autonomy, meaning, growth, and joy.

Dr. Power's Presentations: Prior to each set of neighborhood retreats, Dr. Al Power provides a 90-minute presentation (offered at two different times) about the domains of well-being that will be explored at the upcoming set of retreats. His presentations, based on his book, *Dementia Beyond Disease*, are open to all interested community members.

Neighborhood Retreats: Guided by Dialogue Education and Appreciative Inquiry, each interactive neighborhood retreat, lasting for 4 ½ hours, engages neighborhood members in dialogue and reflection regarding the domains of well-being: Identity and Connectedness (Retreat #2 in February); Security and Autonomy (Retreat #3 in May); Meaning, Growth and Joy (Retreat #4 in July); and all domains (Retreat #5 in October).

Daily, Neighborhood Shift Huddles: Organizations are most effective when they use systems to foster timely, accurate, problem-solving communication that provides equal voice, shared knowledge and shared goals. When neighborhood members communicate and solve problems together every day, they have the structures and skills in place to problem-solve on a larger scale, as needed, for effective quality improvements. A 'huddle' is a process we can use to create such a system of communication. A huddle is basically a 10-minute, stand-up, learning circle with a small group of people. It can be thought of as *Having Useful Dialogue Daily Linking Everyone* (H.U.D.D.L.E.). At the Resource Center, huddles provide neighborhood teams, including residents and family members, with a regular opportunity to reflect and share ideas related to the most recent retreat topics and/or possible neighborhood goals. They are also a great vehicle for daily communication and team-building. Huddles can help balance teams as they communicate and work together toward a more ideal future; ensuring all neighborhood members have a voice and a choice in the decisions that affect their lives.

Neighborhood Gatherings: Each Neighborhood Coordinator hosts a neighborhood gathering that corresponds with each retreat. The date and time of each neighborhood gathering is determined based on what works best for each neighborhood. Participation is voluntary and open to all neighborhood members. The first neighborhood gathering was an information meeting. Subsequent neighborhood gatherings are used to collaboratively plan **one** neighborhood goal related to **one** of the topics or possible goals explored during the most recent retreat. After planning and communicating the goal and action plan to the entire neighborhood, the neighborhood team is encouraged to: 1) take action; 2) observe and study what happens; 3) reflect on the impacts or outcomes of the goal as a basis for future planning and action; and 4) report on the goal and its impacts at the beginning of the next retreat (i.e., PDSA or PAR cycles).

Leadership Retreat: In March 2015, a group of 22 organizational leaders, including senior leaders, departmental leaders and neighborhood coordinators, spent 3 days together in a beautiful setting with the following goals: 1) to examine the inner dimensions of our own leadership; 2) to explore mindful, serving and collaborative leadership philosophies and practices; and 3) to develop a shared set of leadership principles and values to guide us individually and collectively.

Innovation Celebrations: Twice a year, each neighborhood team has an opportunity to create and share a success story or new learning related to one goal they have worked toward during a community-wide Innovation Celebration. Each neighborhood is invited to find a creative and fun way to visually share their success story or new learning, which is presented at the Innovation Celebration and then displayed on each neighborhood for one week. This is a great way to celebrate each neighborhood's accomplishments and spark ideas for future action.

For more information, please contact:
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