



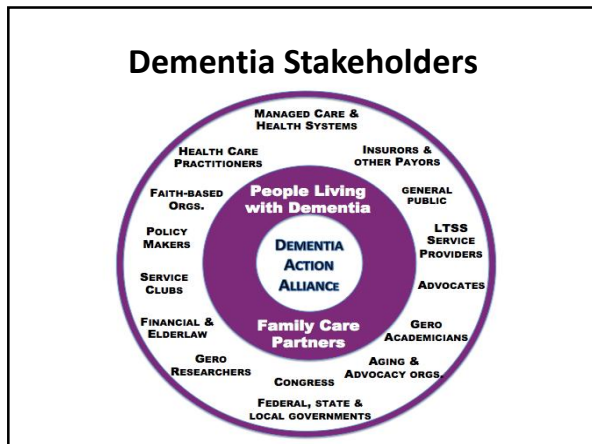
DEMENTIA ACTION ALLIANCE
2015 Pioneer Network Conference

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SEE deMENTia

The Dementia Action Alliance is a volunteer coalition committed to helping people live fully with dementia and supporting those who care about them. The Alliance is engaged in changing our nation's understanding of and attitudes about dementia.



DAA Leadership Team



Person-Centered Practices Focus on Bio-Pscho-Social-Spiritual Well-Being

Person-Centered Practices are deemed the gold standard by the World Health Organization and the Institute of Medicine.



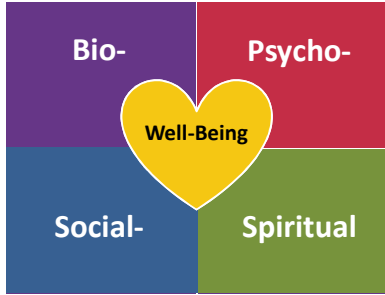
**1st Dementia Thought Leaders Summit
June 2012 ~ Washington, DC**

Objective –

Form consensus agreement on a definition and conceptual & operational framework for person-centered dementia care.

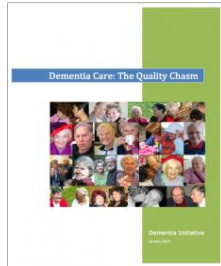


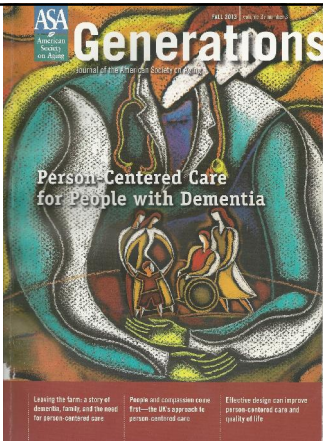
Person-Centered – The Whole Person



1st Summit Outcome White Paper

http://www.ccal.org/wp-content/uploads/DementiaCareTheQualityChasm_2-20-13-final.pdf



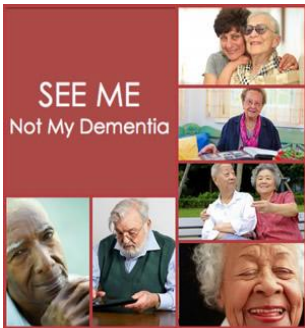


**2nd Dementia Thought Leaders Summit
June, 2014 ~ Washington, DC**

Objective –

Form consensus agreement on what is needed to improve dementia care in this country.





Dementia is saddled with societal stigmas and misperceptions. Prevailing mindset is of losses and diminishment.

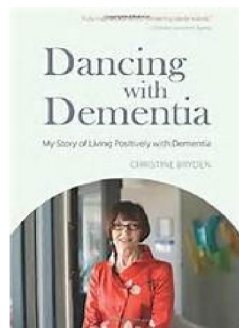
Our understanding of what an individual can do affects how they are treated. How they are treated impacts upon their overall well-being.

People can live full & meaningful lives with dementia.

“How you relate to us has a big impact on the course of the disease. You can restore our personhood and give us a sense of being needed and valued...”

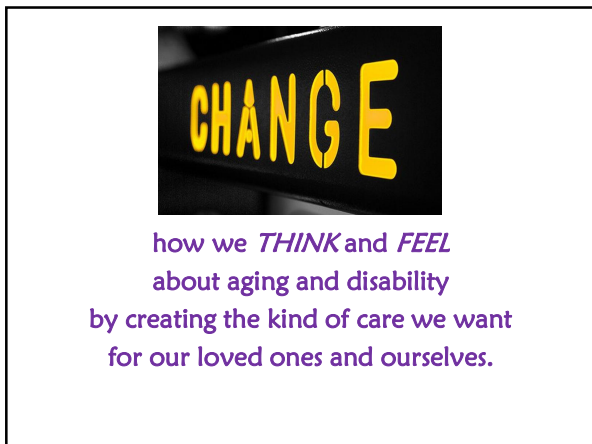
Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain our social networks”

- Christine Bryden









What is The Quality Chasm???

Sadly, people with dementia are so often treated as if they are "defective human beings" and "patients" rather than people.

BUT there are ways we can improve the experience for those living with dementia and the experience of the family care partners...

What is The Quality Chasm???

It is time to focus on the people who are living with dementia NOW, and those who are caring for them NOW.

UNTIL THERE IS A CURE, we must improve the quality of life for these people and those who care for them.

OLD Attitudes & Behaviors About Dementia...

- * "THEY" are not able to do anything.
- * They can't communicate.
- * They can't make any choices.
- * They will wake up when we say.
- * They will go to sleep when it's convenient to us...

**OLD Attitudes & Behaviors
About Dementia...**

- * They will bathe when it fits within our schedule.
- * They will eat what we say they will eat.
- * There is NOT a PERSON IN THERE.

They are DONE...

Source: Richard Taylor and Kim McRae, *Culture Change from the Inside Out and the Outside In: Humanizing Dementia Care*, 2008; *Changing the Culture of Dementia Care*, 2014.

There IS A Person In There!

People with dementia deserve person-centered care that respects their:

- Autonomy
- Choice
- Privacy
- Dignity

But they really need your help!

Nationally

“Overmedication of people with dementia is not simply a problem in nursing homes; It is a community-wide problem that reflects broad societal views.”



G. Allen Power, M.D.



What is The Quality Chasm???

“BEHAVIOR” is NOT BAD!!!

Behavior = COMMUNICATION

NOT an automatic Rx for DRUGS!

What is The Quality Chasm???

UNTIL THERE IS A CURE, we must improve the quality of life for these people and those who care for them.

What Is Person-Centered Dementia Care?

Changing how WE think and feel about people who are living with dementia...

Definition of Person-Centered Care

Person-centered dementia care is based on the fundamental premise that every individual has a unique background, human experience, and the right to determine how to live his/her own life.

Person-centered dementia care is relationship-based and focused on supporting the individual's emotional, social, physical, and spiritual well-being (e.g., belonging, experiencing a continuation of self and normality, purpose, meaning, enjoyment, comfort, and opportunities for growth).

What Is Person-Centered Dementia Care?

Changing OUR minds about people whose minds have changed.

“Dementia is a shift in the way a person experiences the world around her/him.”

~ G. Allen Power, MD, FACP

“People want to focus on what they CAN do, not what they can’t.

“The loss of some abilities may lead to social isolation, a decreased sense of purpose, and increasing dependence on loved ones for assistance in routine activities.”

Source: Morris et al., “Ubiquitous Computing for Cognitive Decline: Findings from Intel’s Proactive Health Research,” Intel Corporation, 2003.

The Eden Alternative...

Focuses on improving quality of life for Elders and their care partners by seeking to eliminate the three plagues of

- Loneliness,
- Helplessness,
- & Boredom



The Eden Alternative...




Built on 10 guiding Principles, grounded in ancient ideas, that emphasize how Human Habitats can transform how we care for each other.



“Meaningful care is that which nurtures the human spirit as well as the human body & recognizes, celebrates, & nurtures each person’s unique capacity for growth.”



Redefining Genuine Care...

-  Decisions belong in the hands of the Elder care partner or as close to him/her as possible
-  Care is not defined as treatment alone, but as helping another to grow
-  Meaningless activity withers the human spirit



Care Partnership

The needs of caregivers and care receivers alike are part of an interdependent system called CARE PARTNERSHIP.

~ The Eden Alternative

The Care Partner Team

- * Person typically described as the Care Receiver
- * Family Members * Friends
- * Neighbors * Volunteers
- * Medical Team
- * Home Health Professionals

~ The Eden Alternative

Care Partnership

A new approach to providing and receiving care that focuses on eliminating the three plagues of *LONELINESS*, *HELPLESSNESS*, and *BOREDOM* for all members of the Care Partner Team.

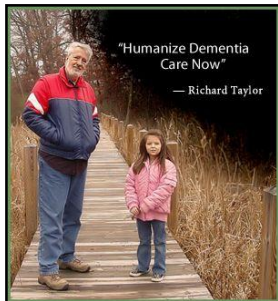
~ The Eden Alternative

Domains of Well-Being

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



Richard Taylor, PhD "Be With Me TODAY!"



In your role, what actions can you take to serve as a change agent?



**Dialogue with the Physicians
Q & A**

Chris Perna, Facilitator
– Jonathan Evans, MD
– G. Allen Power, MD



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