




DEMENTIA ACTION ALLIANCE
2016 Eden Alternative Conference

Walter Coffey
Chris Perna
www.daanow.org



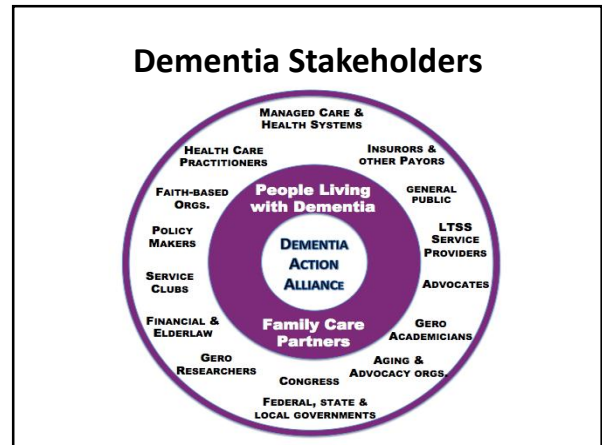
SEE deMentia

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



CCAL: Advancing Person-Centered Living
amda: The Society for Post-Acute and Long-Term Care Medicine
EDEN ALTERNATIVE
LeadingAge Georgia
TeepaSNOW: POSITIVE APPROACH TO BRAIN CHANGE



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

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

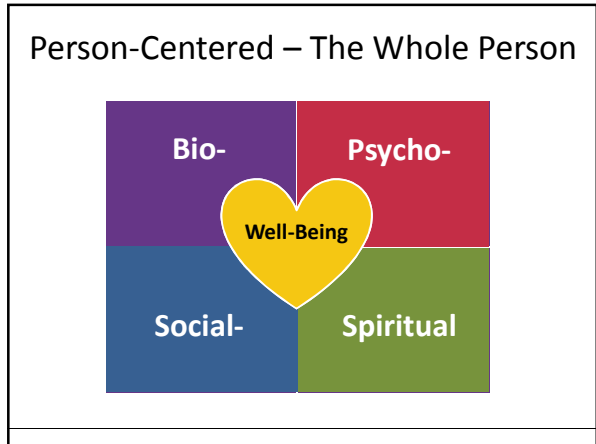


INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES
World Health Organization

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

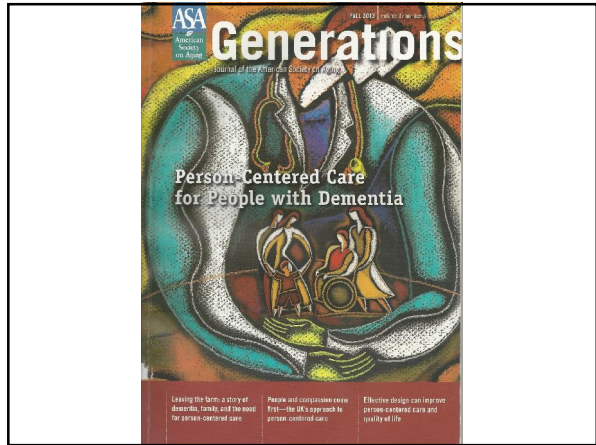
Objective –
Form consensus agreement on a definition and conceptual & operational framework for person-centered dementia care.





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.

SEE ME
 Not My Dementia

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

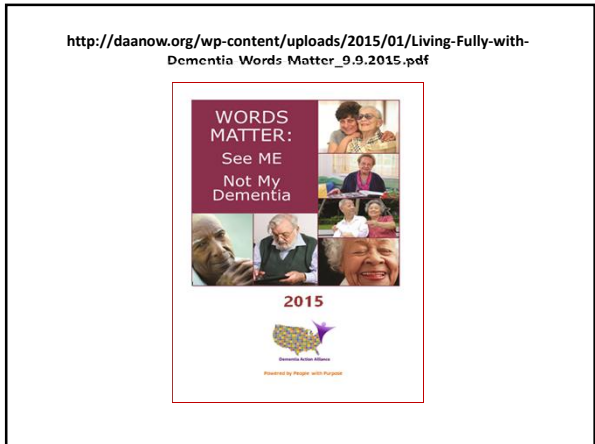
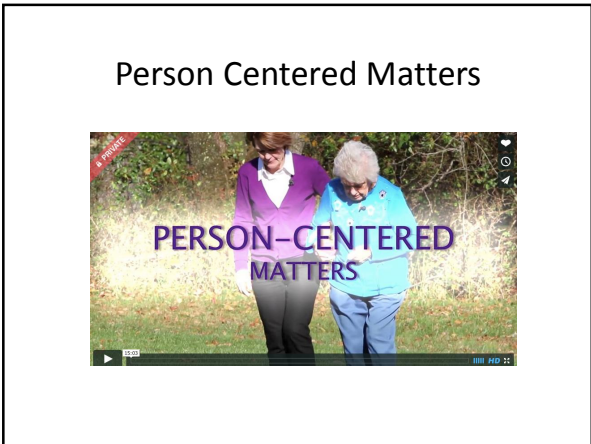
Our understanding of what an individual can do affects how they are treated. How they are treated impacts upon their overall well-being.

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



Living with Dementia: Changing the Status Quo

2016

White paper expressed consensus opinions of **32 co-authors**

- 3 people living with dementia
- 4 geriatricians
- 4 dementia service providers
- 1 occupational therapist
- 1 physical therapist
- 2 social workers
- 1 state provider assn exec
- 4 gero researchers
- 3 nurse practitioners
- 2 care partners
- 2 gero academicians
- 2 dementia advocates
- 3 dementia educators

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how we *THINK* and *FEEL* about aging and disability by creating the kind of care we want for our loved ones and ourselves.

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!

Help people live fully with dementia – what is possible?



Know Each Person.

~ Pioneer Network

We have to start with one person at a time...

The Words & Language We Use Matter

Language can have tremendous impact on how people living with dementia feel about themselves, and how they are treated and considered by others.

People with dementia say that words like “demented” make them want to “curl up and die!”

“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.

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.”

~ F. Allen Power, MD, FACP

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

“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being.”

~ Atul Gawande

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.



“BEHAVIOR” is NOT BAD!!!

Behavior = COMMUNICATION

NOT an automatic Rx for DRUGS!

Decoding Distress NOT “Managing Behaviors”

Distress is more likely due to a person’s attempt to cope, problem-solve, or communicate needs.

Two Different Views

Biomedical or Traditional

“vs”

Experiential or Person-Directed
or Person-Centered
“CULTURE CHANGE”

Definition of Person-Centered Care

Person-centered dementia care is based on the fundamental belief 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).

Person-Centered Dementia Support

This is achieved through reciprocal, respectful relationships by:

- Valuing personal autonomy, choice, comfort and dignity;
- Enabling opportunities for continuation of normalcy and growth of self; and
- Enhancing individual purpose, meaning, enjoyment and belonging.

~ Dementia Action Alliance

“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.”



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.



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

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

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

The Eden Alternative's Domains of Well-Being™



- Identity
- Connectedness
- Security
- Autonomy
- Meaning
- Growth
- JOY

The Eden Alternative Domains of Well-being™