Changing the Culture of Home and Community-Based Care

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, and Boredom

Founders, Dr. Bill and Judy Thomas

The Eden Alternative is...
Based on the belief that aging is about continued growth and development, not simply a period of decline.

Founders, Dr. Bill and Judy Thomas
The Eden Alternative is…

Committed to reclaiming the term “Elder.”

An Elder is someone who, by virtue of life experience, is here to teach us how to live.

Eden at Home…

♦ Applies the Eden principles to home and community-based care.

♦ Enhances quality of life for Elders living at home and their care partners.

Culture Change…

“Lasting changes to the shared ways of thinking, beliefs, values, procedures and relationships of the stakeholders.”

In Long-Term Care…

Institutional Model of Care ➔ Person-Directed Model of Care
Traditional Model…

♦ Perceives those with dementia as primarily impaired
♦ Perceives behavioral symptoms as confused and/or neurochemically mediated
♦ Attempts to ‘normalize’ behavior through medication
♦ Viewpoint: “He’s confused, because he has dementia.”

Source: Allen Power, M.D.

Person-Centered Model…

♦ Perceives those with dementia through their own eyes as much as possible
♦ Focuses care around existing strengths and abilities
♦ Perceives behavioral symptoms as an attempt to problem-solve, cope with stressors, achieve control, or communicate needs
♦ Conforms environment to Elder’s perception of the world, not vice versa
♦ Viewpoint: “I’m confused, because I don’t understand what he is trying to tell me.”

Source: Allen Power, M.D.

Changing the Culture of Care in Our Communities…

Why Pursue It?
Statistically speaking…

♦ < 10% of older people requiring care live in a nursing home.

♦ Family caregivers provide the overwhelming majority of homecare services in the U.S., approximately 80%.

♦ Value of the services family caregivers provide for “free” is estimated to be $257 billion a year.

♦ By the year 2030, the Elder population will more than double to about 70 million.

Statistically speaking…

♦ Every 71 seconds, someone in America develops Alzheimer’s disease. By mid-century, someone will develop Alzheimer’s every 33 seconds.

♦ Roughly 7 out of 10 people with Alzheimer’s disease are living at home and receiving 75% of their care informally.

♦ The stress of family care giving for people with dementia has been shown to impact a person’s immune system for up to three years after their care giving ends.

♦ Caregivers of people with Alzheimer’s and other dementias provide more hours of help, on average, than caregivers of other older people.

Even a home can feel like an institution if…
The Continuum of Care…

- True culture change cannot occur only in the vacuum of LTC organizations
- Empowered community members raise the bar and inspire high involvement

Changing the Culture of Care in Our Communities…

*What are some of the barriers?*

- Cultural perceptions of aging
- Cultural perceptions of ideal care
Changing the Culture of Care in Our Communities…

What are some of the barriers?

♦ Cultural perceptions of aging

♦ Cultural perceptions of ideal care

Ageism is…

♦ Stereotyping of or discrimination against people because of their age.

♦ Values, beliefs, and behaviors that imply that someone’s value and capability is based on his/her age group.

Ageism Creates Loneliness…

Because of negative societal messages about aging...

We may not seek out the company of Elders as much, because we don’t fully appreciate what they have to offer us.

Our Elders may isolate themselves due to ill feelings about their own self worth.
Ageism Creates Helplessness…

**Because of negative societal messages about aging…**

We may assume that our Elders have little to contribute to our communities.

We may not recognize the unique abilities and gifts that individual Elders can bring to our daily lives.

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Ageism Creates Boredom…

**Because of negative societal messages about aging**

Elders who may feel isolated and devalued by their communities may fall victim to boredom.

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Changing the Culture of Care in Our Communities…

*What are some of the barriers?*

♦ Cultural perceptions of aging

♦ Cultural perceptions of ideal care
The Zero Sum Game…

**Dependence**
- Failure
- Institutional
- Burdensome

**Independence**
- Success
- Aging in Place
- Worthy

A Contradiction…

**Aging in Community**

**Dependence**
- Failure
- Institutional
- Burdensome

**Independence**
- Success
- Aging in Place
- Worthy

A Non-Zero Sum Game…

**Aging in Community**

- Builds on Strengths
- Embraces Interdependence
- Focuses on Giving & Receiving

- Acknowledges & benefits from the contributions of all
A Non-Zero Sum Game...

Aging in Community

Builds on Strengths

Embraces Interdependence

Focuses on Giving & Receiving

Acknowledges & benefits from the contributions of all

A Human Habitat is...

Where different species live and interact in a supportive, empowering way -- eager and able to thrive, not just survive!
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 needs of caregivers and care receivers alike are part of an interdependent system called **Care Partnership**…

Culture change at the grassroots level should introduce the new paradigm through a variety of means and to various stakeholders…
Eden at Home

Focuses on the creation of collaborative and supportive care partner teams that include the participation of the Elder herself...

How Does It Work?

Eden Alternative trains Certified Eden at Home (EAH) Trainers...

Who might want to be a trainer?

Representatives of:

- Non-profit organizations
- State agencies,
- Case management,
- Home-health organizations,
- Faith-based organizations,
- Area Agencies on Aging,
- Senior centers, Adult day centers,
- Hospitals, Hospices, or
- Long-term care organizations with assisted living and/or independent living options, home health outreach, or an interest in supporting the needs of short-term rehabilitation patients who are going back home.
How Does It Work?

Who should attend Care Partner Workshops?

- Family members
- Friends
- Neighbors
- Elders
- Home health professionals
- Staff, or
- Anyone interested in promoting person-directed care at the grassroots level.

Invite different stakeholders to the table so that they can learn from each other!

#1- Planting Seeds: Growing Awareness

- Owning our fears and attitudes about aging, disability and dementia
- Reframing our perspectives about aging, disability, and dementia
- Clearing the way to seeing care in a new light

The Care Partner Team:

- The Elder
- Family members
- Friends
- Neighbors
- Volunteers
- Medical Team
- Home Health Professionals
Giving and Receiving: A Two-Way Street

It is often easy to get trapped in a one-dimensional experience of the caring relationship.

Discovering Balance

Opportunities to Give and Receive = Empowered Care Partners

#2 - Tending the Garden: Using the Tools

How do the three plagues impact different care partners on our team?

How do we apply the Ten Principles to fight them?
The Antidotes

Companionship is the antidote to Loneliness

The opportunity to Give as well as Receive is the antidote to Helplessness

Spontaneity & variety is the antidote to Boredom

The Importance of Close & Continuing Contact

- Builds trust, easing ADLs
- Creates sense of safety and familiarity
- Reveals important non-verbal information
- Enhances social interaction
- Allows us to be deeply known

For other care partners on the team:

- Creates support via connectedness
- Keeps the team “in the know” regarding the elder care partner’s changing needs
- Helps team tune in to signs of burn-out in each other
- Allows us to be deeply known
Creating Opportunities to Give as Well as Receive

♦ Building on strengths, identify interests
♦ Promote independence by using cues and breaking down tasks into smaller steps
♦ Staying responsive as strengths change and remaining flexible
♦ Simply ask... explore possibilities

“It is a failure of the imagination when we can’t appreciate what even our frailest of Elders has to offer us. This is our challenge -- to find ways for ALL to give as well as receive -- no matter how subtle, no matter what their cognitive challenges may be.”

- William Thomas,
Co-founder of the Eden Alternative

Inviting Spontaneity & Variety

♦ Elders can teach us the gift of being truly in the moment
♦ Honoring the value of a daily rhythm while leaving space for unscheduled time and unexpected joys
♦ Tuning into individual rhythm and natural tendencies -- be responsive and be willing to try something new
Robert's Story…

#3 - Gathering the Harvest: A Supportive Team Process

♦ Self-care
♦ Shared communication skill set
♦ Shared leadership

Home Health & the Team

♦ Home visits/services scheduled to fit needs & preferences of the provider or the client?
♦ What efforts are made to know the client deeply & how is this knowledge incorporated into care plan?
♦ Does business model emphasize efficiency & productivity quotas or person-centered care?
♦ Are those staff members on the front line of care actively consulted on design of the care plan?
♦ Are all members of the staff empowered to be leaders?
Human Habitats…

♦ Help care partners work together supportively
♦ Help Elders maintain function & independence
♦ Promote gentleness between care partners

“In our culture, it is easy to dismiss the oldest of the old as having nothing to contribute to our understanding of life. It is our duty to open ourselves to the distinct forms in which their wisdom comes to us.”

- William Thomas,
  Co-founder of the Eden Alternative

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