Building a Person-Centered Culture for Dementia Care

Introduction

• Person-Centered Dementia Care is a way of providing care focused on knowing the UNIQUE person through respectful close relationships that foster normalcy, choice, purpose, belonging, security and strengths.

• 5.5 Million Americans are living with Alzheimer's Dementia.
• 1/10 people age 65 years or older have AD.
• 2/3 of Americans with AD are women.
• African Americans are 2 times as likely to have AD or other Dementias.
• Hispanics 1 ½ times as likely.
• 60% of older adults with Dementia reside in the community.
• 25% live alone.
• 42% of residents in Assisted Living have AD or other.
• 61% of Nursing Home residents have moderate or severe cognitive impairment;
• By age 80, 75% of people with AD are admitted to Nursing Homes.
Program Objectives

1. Core Values and Philosophy – Person-Centered Culture
2. Structural Elements to Support a Person-Centered Culture
3. Personalized Practices and Programs
4. Community Practice Recommendations
5. Video – “Person-Centered Matters”
6. Dementia Friendly Lehigh Valley (Promo)
7. Q&A

“Humanizing dementia care is a human rights issue.”
- Kim McRae, family caregiver

Core Values & Philosophy

- Foundation
- Set of Beliefs
- Examples of Person-Centered Culture:
  • Positive interactions are key
  • Direct involvement in decision making
  • Treating the person, not the disease
  • Understanding unique histories and preferences
  • Maintaining dignity and autonomy
  • An individualized approach recognizing uniqueness
    (Person-Centered Assessments and Care Planning)
Core Values & Philosophy

- Examples – continued
  - Understanding the world from the perspective of the individual living with dementia
  - Providing a supportive environment
  - Promote normalcy
  - Welcome families
  - Provide meaningful activities
  - Flexibility in routines
  - Focus on strengths and capabilities
  - Relationships over tasks

“Within all of us resides the need to be whole.”

- Oliver Sacks, M.D.

Structural Elements

Building Blocks

- Relationships and Community
- Leadership/Governance Support
- Care Partners/Workforce
- Services
- Meaningful Life and Engagement
- Environment
- Accountability
“Service is Compassion Made Visible.”
- Karen Love

Personalized Practices

“Music can lift us out of depression or move us to tears – it is a remedy, a tonic, orange juice for the ear. But for many of my neurological patients, music is even more – it can provide access, when no medication can, to movement, to speech, to life. For them, music is not a luxury, but a necessity.”
- Oliver Sacks, M.D.
Professor of Neurology,
New York University School of Medicine
“One of the blind spots people have is seeing the distress as the problem rather than a symptom of a larger need, so they treat the distress and never get to the heart of the matter.”

- Dr. G. Allen Power, author of “Dementia Beyond Drugs.”

Examples of Personalized Practices

- Patience, openness, authenticity in each interaction.
- Helping family/friends acknowledge changes.
- Developing policies and procedures to support person-centered outcomes in an organization.
- Commitment to fully train and build knowledge and skills for staff.
- Leaders coach and model effective practices.
- Leaders create and sustain meaningful relationships with residents and family members.
- Staff training and stability.
- Consistent staffing assignments.
- Holistic – Non-Pharmacologic interventions first.

Examples of Beneficial Personalized Practices

- Art – Worth, expression, calmness, self-confidence.
- Children/Teens
- Music – iPods
- Pets – Non-judgemental!
- Social Interaction
- Solitude
- Spiritual, Religions, End of Life
- Touch – Beneficial
- Bathing/Dressing/Grooming
Examples of Beneficial Personalized Practices

- Movement/Exercise – All Stages
- Therapeutic Smells
- Light and Lighting
- Noise/Sound
- Outdoors/Nature
- Sensory Stimulation
- Sustainability

“I want all my senses engaged.”

- Maya Angelou

Special Programs

- Montessori
- Music and Memory
- Brain Fitness – (Saido, Dakim, It's Never 2 Late)
- Art in the Moment
- Hand in Hand
- Bathing Without a Battle
- Compassionate Touch
- Spirit Alive
- Red Plate
- Timeslips
Community Practice Recommendations

• Make information about brain health and cognitive changes available to older adults and their families.
• Maintain routine procedures for detection and referrals for diagnostic evaluations and assessments.
• Provide education and support EARLY in the disease to prepare for the future.
• Provide education and information on the transitions associated with a progressive disease.
• Introduce technology that provides support.
• Connect with agencies in the community with expertise with Dementia.

Glossary

• Holistic – Refers to a bio-psycho-social-spiritual orientation to healthcare and well-being.
• Personalized Approach – Term preferred by experts rather than “non-pharmacologic” as the latter has a medical model of care connotation instead of a holistic one.
• Personalized Practices – This term defines specific person-centered practices. These practices are individualized and intended to support the personhood and authenticity of each person who is living with dementia.
• Person-Centered Core Values & Philosophy – There is a moral and ethical responsibility to support persons living with dementia as holistic, existential beings. Every person has his/her own meaning of life and authenticity (personality, spirit and character) that supersedes any physical condition. This forms the foundation for person-centered dementia care.
• Person-Centered Operational Practices – This term refers to the broad processes that anchor and operationalize person-centered dementia care.
• Person-Centered – Has its roots in humanistic psychology and the seminal work of Carl Rogers and Abraham Maslow based on the understanding that people are multi-dimensional beings and the psychosocial context of health and well-being is as important as the physical/medical aspects.
• Personhood – “Standing or status that is bestowed upon one human by others in the context of relationship and social being. Personhood implies recognition, respect and trust.”

(*Dementia Care: The Quality Chasm*—published by the Dementia Action Alliance)
Thank You

References for Presentations:

- Dementia Action Alliance
- “Dementia Care: The Quality Chasm” published by the Dementia Action Alliance
- CCAL Advancing Person Centered Living
- Alzheimer’s Association Dementia Care Practice Recommendations

Dementia-Friendly Lehigh Valley

• Who we are?
• Mission, Vision, Goals
• Initiatives
• Website: https://www.dfamerica.org/ Info@DementiaFriendlyLV.org
You can be part of building a dementia-friendly community!

We are actively seeking volunteers, members, and community partners to achieve our vision of the Greater Lehigh Valley being dementia friendly.

Please visit us online or contact us at the email provided to learn more about what you can do to contribute.

If you are interested in being involved, contact the Alzheimer’s Association, 800-272-3900, available in 200 languages.

WHO WE ARE

The Lehigh Valley Dementia Friendly Community Initiative is a collaborative and comprehensive approach to creating a dementia-friendly environment in the Greater Lehigh Valley. The goal is to create a community where people living with dementia, their families, and caregivers can remain in their community for as long as possible.

The Dementia Friendly Lehigh Valley (DFLV) Committee is committed to being throughout the dementia life for older adults and their caregivers.

We embrace dementia as a natural part of aging and seek to change attitudes and perceptions of those affected by dementia.

To become dementia-friendly, organizations and individuals will work to reduce stigma, increase awareness, and foster a community that is welcoming and supportive.

Q & A

1.

Someone in the U.S. develops Alzheimer’s disease every 3 minutes. Approximately 25,000 individuals are diagnosed annually in the Lehigh Valley.

2.

Approximately 56,000 people in the Greater Lehigh Valley are living with Alzheimer’s disease.

3.

Approximately 80,000 people are affected by dementia in the Greater Lehigh Valley, including family members and caregivers.

4.

Approximately $225 billion in costs are associated with Alzheimer’s disease and related dementias.

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