

Dementia through the Lens of Grace
Mt. Hebron United Methodist Church 4/3/2022
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Introduction

- A. What Feelings Emerge When You Think of Dementia?
- B. Why Is Dementia Most Feared Disease?
- C. Goal of Session: Widen Lens by Viewing People with Dementia through GRACE

WHAT IS DEMENTIA

- A. Umbrella Term of Which Alzheimer's Is the Major Disease
 - a. Constellation of symptoms: memory loss, word-finding difficulties, impaired judgment and problems with day-to-day activities, caused by injury or loss of brain cells (neurons).
 - b. Major forms of dementia: Alzheimer's Disease, Frontotemporal Dementia, Vascular Disease, Lewy Body, Parkinson's, Huntington's, Mixed Dementia, etc.
- B. While Dementia Is Primarily a Disease of the Brain, It Has Multiple Psycho/Social/Spiritual Manifestations: Stigma, Isolation, Diminished Self-image
- C. Most Spiritually Challenging of All Diseases

WHAT IS GRACE AND WHAT DIFFERENCE DOES GRACE MAKE?

- A. **Grace: The gift of God's presence and power to create, liberate, restore, forgive, reconcile, and transform human beings, communities, nations, and the entire cosmos.**
 - 1. Grace is universally present
 - 2. Grace is God and supremely manifested in Jesus the Christ
- B. **Grace Broadens the Lens through Which We View All Life**
 - 1. Bible is story of unfolding of God's transforming Grace: Creation; Exodus; Exile; Jesus' Birth, Life, Teachings, Death, Resurrection, Ascension; Holy Spirit and Birth of Church. These are both historical events and metaphors of God's manifestation of Grace.
 - 2. Story of God's mighty acts of salvation
- C. **Dementia Seen Primarily Through Medical Lens: symptoms and persistent losses.**

BROADENING THE LENS

- A. **From Symptoms to Stories**
 - 1. Personal stories and part of THE STORY OF TRIUNE GOD
 - 2. Dementia may destroy ability to recall part so our story, but we ARE our stories.
 - 3. Stories are held in community: Only lose our memories if we lose our community
- B. **From Capacities to Beloved Child of God, Bearing the Divine Image**
 - 1. We are more than our cognitive abilities
 - 2. Worth lies in One to whom we belong
 - 3. "Wayfarers on the way to God"—from God, with God, to God (1John 3:1-2)
- C. **From Burdens to Participants in Triune God's Dance of Love**
 - 1. "Bear one another's burdens, and in this way you fulfill the law of Christ" (Gal. 6:2)

2. Love as a dance of giving and receiving
 3. Grow in capacity to love
- D. From Individualism and Isolation to Beloved Community**
1. Identity is held in community: “I am because we are.”
 2. Baptized into Christ
 3. We are stewards of one another’s identity and worth

CHURCH AS COMMUNITY OF GRACE

- A. Extension of the Incarnation of God in Jesus Christ**
1. God comes in weakness and vulnerability
 2. God chooses the powerless and “foolish” (1 Cor. 1:27—30))
 3. Jesus no less the Savior as a babe in Mary’s arms than man hanging on Cross
- B. Becoming a Dementia Friendly Community/Church**
1. Remove hiddenness and stigma of dementia
 2. Educate and advocate
 3. Provide simple acts of love and support to persons with dementia and those who care for them
- C. Receive the Gifts of Those with Dementia**
1. Gift of *being*
 2. Growth in fruits of the Spirit: love, joy, peace, patience, kindness, generosity, faithfulness, gentleness, and self-control (Gal. 5:22—23)

GRACE AND ENTERING THE WORLD OF PEOPLE WITH DEMENTIA

- A. Ministry of Presence:**
1. Ministry *with* rather than ministry *to*
 2. Presence as extension of God’s Incarnation
- B. Introduction to Validation Therapy and Video: Gladys Wilson and Naomi Feil**
- What feelings do you have as you watch?
Who was most blessed, Gladys or Naomi?
- <https://www.youtube.com/watch?v=CrZXz10FcVM>
- C. Principles and Tips for communicating (handout)**

CONCLUSION

- A. Concluding Remarks
- B. Scripture Reading: 1 Corinthians 13:4-13; Romans 8:35-38

Basic Concepts of Person-centered Care
Don Wendorf, Psy.D. and Lynda Everman (June 2021)

1. Keep in mind you are relating to a PERSON, not a diagnosis or set of symptoms or limitations. All persons have value, no matter their status or condition.
2. These are persons “living with” dementia, who still have the needs, feelings, thoughts, issues, etc. as other persons, including the need to be known, loved, loving, productive, competent, giving and spiritually involved.
3. The core, personhood, essence, soul of the person is still there and can be accessed, supported, and connected with if we learn how and are reasonable in our expectations. It may be helpful to hold in mind an idea of who that person has always been and why you have loved them, especially during difficult times.
4. Relate through empathy: the ability to identify and understand another person’s feelings, thoughts, actions, etc. from their perspective, whether you feel the same or agree with them or not.
5. Empathy opens up a range of possible responses, based on what you know about what they seem to be experiencing, through your own similar experiences with frustration, anxiety, anger, grief, joy, sadness, etc. How would you want to be treated if you were experiencing the same thing?
6. Meet this person in the moment, in their reality. Don’t try to re-orient, argue, test their memory, etc. This is about their needs, not yours, and not your ego. Being kind is usually more important than being right.
7. You know your loved one and their needs better than anyone, but you must be open to others’ help and feedback for your blind spots or when your own personal reactions get involved. Forgive yourself when you fail or flounder.
8. Empathy may help you see their “resistance” or “oppositional” behavior or seemingly delusional views differently, perhaps as anxiety or fear or misperception or confusion. Try to see the situation through their eyes. Keep in mind the phrase: “The person with dementia isn’t giving you a hard time; they’re having a hard time.”
9. Despite limitations in cognition or communication abilities, there may be a kind of emotional memory such that the person knows you are someone they can trust, who loves them and they love you. The heart remembers what the mind forgets.
10. Change or constantly review your expectations. Look for new ways to communicate and connect, like through music or art, through touch and smiles, through actions, etc., if words aren’t working well. Don’t expect it to be as it’s always been or to remain as it is now.
11. Support lives of dignity, meaning and purpose and as much self-determination as possible, including life and treatment choices and shared decision-making with care “partners” for as long as possible.

TIPS FOR COMMUNICATING WITH A PERSON LIVING WITH DEMENTIA

Be aware of the stage of the disease

- Capacities to communicate vary with each person and each stage
- Know important components of the person's story that enable you to connect

Set a positive mood for interaction.

- Be aware of your attitude and body language.
- Be pleasant, warm, affirming, and respectful.

Get the person's attention.

- Limit distractions and noise.
- Address the person by name.
- Identify yourself by name and relation.
- Use nonverbal cues and touch to help keep the person focused.
- If the person is seated, get down to his or her level and maintain eye contact.

Focus on feelings more than thoughts, aim at the heart more than the brain.

- Be alert to sensory means of communication: sight, smell, taste, touch,
- Avoid abstract concepts as much as possible

State your message clearly.

- Use simple words and sentences.
- Speak slowly, distinctly, and in a reassuring tone.
- Refrain from raising your voice higher or louder; instead, pitch your voice lower.

If you ask questions, use simple, answerable ones.

- Ask one question at a time.
- Refrain from asking open-ended questions or giving too many choices. Use visual prompts and cues to help clarify.
- *Avoid asking questions that rely on short-term memory.*

Listen with your ears, eyes, and heart.

- Be patient in waiting for a reply.
- If the person struggles, it's okay to gently suggest words.
- Watch for nonverbal cues and body language and respond appropriately.
- *Always strive to listen for the meaning and the feelings that underlie the words.*

Respond with affection and reassurance.

- People with dementia often feel confused, anxious, and unsure of themselves.
- Stay focused on feelings and respond with verbal and physical expressions of comfort, support, and reassurance.

Maintain your sense of humor, but never at the person's expense.

- People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

Be yourself and simply treat the person as another human being with dignity and worth. Their difficult behaviors are *not* meant to give you a hard time; they mean that the person is having a hard time.