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#### Inherent worth

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*Living Lutheran, August 2021*

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## Study guide

# Inherent worth

By Robert C. Blezard

Those suffering from dementia can feel isolated, excluded and dismissed by the rest of society, and their caregivers can feel overwhelmed and unsupported. Jesus calls Christians to love all our neighbors as ourselves and to care for those who are suffering. As God's people, we can assist those with dementia and their loved ones to live with dignity, community and peace.

### EXERCISE 1: WHAT IS DEMENTIA?

"Dementia is not a specific disease but is rather a general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities," according to the U.S. Centers for Disease Control and Prevention. "Though dementia mostly affects older adults, it is not a part of normal aging" ([cdc.gov/aging/dementia](https://cdc.gov/aging/dementia)).

In normal aging, a person may exhibit mild memory loss, such as occasionally misplacing car keys, forgetting a word (only to remember it later) or not remembering the name of an acquaintance, but dementia is more serious. People suffering dementia may forget deep memories, have problems with attention, communication, reasoning, judgment and problem-solving, and a visual perception beyond typical age-related changes in vision. "Normally, knowledge and experiences built over years, old memories, and language would stay intact," the CDC says.

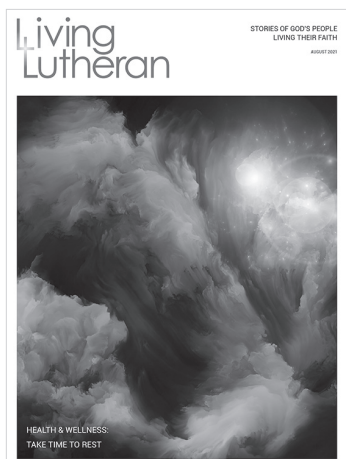
- What do you know about dementia? Where did you learn about it?
- Can you describe the difference between dementia and a normal "slowing down" of aging?
- Are the symptoms and "warning signs" of dementia generally understood?
- What myths or misconceptions about dementia are you aware of? Why and how can misinformation about dementia be harmful?

**For action:** As a study group, research the symptoms, causes and treatments for dementia and help educate members of your congregation. You might also invite an expert to speak or lead a discussion on dementia.

### EXERCISE 2: EXPERIENCE WITH DEMENTIA

Most people have some personal experience with dementia—a loved one, a friend or an acquaintance who is affected by, or whose family is affected by, dementia. Similarly, most congregations have members and families who have or are dealing with dementia. If we talk about it and share our stories, maybe we can come to a better understanding of dementia and be of greater help to those affected by it.

For the discussion that follows, please caution group members to be respectful of those who are sharing and to keep sensitive disclosures confidential.



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## Study guide: **Inherent worth** *continued*

- What has been your or your congregation's experience with dementia? Have there been members or are there members and families who have been affected by dementia?
- How has and how is the congregation responding to members who are living with dementia and with members who have loved ones living with dementia?
- How has your congregation used its experience with dementia among your membership to further understanding about dementia, and to invite others to learn about the condition, and to care and support families living with dementia?
- What has your congregation learned as a result of its interactions with members and families who are living with dementia?
- Invite members of the study group, if they are comfortable, to share stories of dementia among loved ones or within their families or circle of friends. (Please be sure to stress confidentiality among the group.)
- What responses to dementia have you seen that have been helpful and constructive? Less-than-helpful?
- What are the needs of people who live with dementia or who care for them? How can we better meet them?

### EXERCISE 3: STIGMA OF DEMENTIA

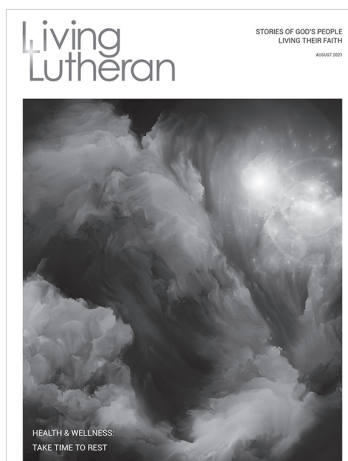
Because of the negative associations and perceptions associated with dementia, people who experience it, as well as their loved ones, may be fearful, ashamed or embarrassed to talk about it with others. And the stigma surrounding dementia may cause others to treat someone with the condition differently—viewing them with suspicion or anxiety, excluding them from conversation or activities, withdrawing support or friendship. These stigma-driven responses aren't helpful either to those with dementia or their caregivers, families and communities. How can we, as God's people, reduce stigma and encourage a better understanding of dementia?

Invite your study group to call out the first words that come to mind when they hear "dementia." (Not necessarily what they themselves think of dementia, but what words and associations are common.) As participants call them out, have someone write them on a whiteboard or newsprint. (Alternatively, ask participants to write them on paper and collect them for discussion.) When done, discuss:

- What do these words reveal about our culture's reaction or response to dementia and those who are experiencing dementia?
- What words may be the result of myths or misconceptions about dementia?
- What words tend to reinforce a false and negative understanding of dementia? How might these words contribute to the stigma surrounding dementia?

Stigma discussion questions:

- From your experience, what kind of stigma is associated with dementia? Where does it come from? How is it harmful to those with dementia and their loved ones?



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## Study guide: **Inherent worth** *continued*

- How would you respond if you or a loved one was diagnosed with dementia? Would you be embarrassed or ashamed? Would you try to conceal it from others, not talking about the diagnosis or its impact on you? How would you feel, and how would you cope?
- If you found out that a friend or acquaintance was living with dementia, how would you respond? How would it change your perceptions of the person? How might you treat that person differently? How would the diagnosis affect your relationship?
- How can you, your congregation and your community work to change the stigma surrounding dementia?

**Next steps:** Type “stigma and dementia” into an internet search engine to learn more about how myths, misinformation, fear, shame and embarrassment contribute to a harmful stigma surrounding dementia. Find resources to help educate others about dementia.

### EXERCISE 4: A GROWING PROBLEM

Dementia is expected to increase in the United States as our population ages. The U.S. Centers for Disease Control and Prevention estimates that the number of Americans over 65 years old will increase from 12.4% in 2020 to 19.6% by 2030. The CDC predicts a corresponding increase in the number of those experiencing dementia. Those affected include members of our families, our communities and, of course, our churches.

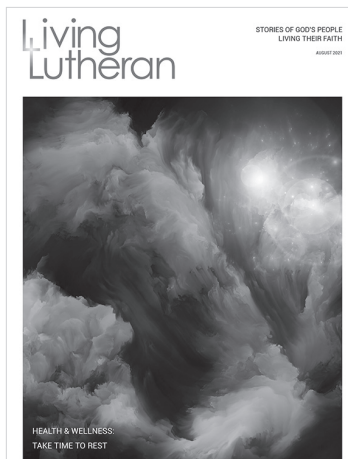
Like those of other mainline denominations, members of ELCA congregations tend to be older (median age 52) than the general U.S. population (median age 38). Since dementia predominantly affects older people, this means our churches will most certainly be witnessing more dementia in our membership. Are we prepared?

- What has been your congregation’s experience with members facing dementia?
- Has your church seen an increase in the number of congregants with dementia?
- How does your congregation work to support, care for and assist its members who are experiencing dementia? How is it helping others to understand dementia? Are those efforts enough? What more could or should be done?
- How might your congregation prepare for a future with more members facing dementia? Why is it important that your congregation do so?

**For action:** Research dementia and its implications for patients and loved ones, as well as how communities can support those living with dementia. Find or create educational materials to help others better understand dementia. Put it all together to form a congregational action plan for helping others with dementia.

### EXERCISE 5: THE “GOLDEN RULE”

Jesus taught, “In everything do to others as you would have them do to you; for this is the law and the prophets” (Matthew 7:12). The phrase “law and the prophets” refers



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## Study guide: **Inherent worth** *continued*

to the main bodies of Jewish thought as expressed in the Old Testament: The law of Moses and the teachings of all the prophets. So Jesus was saying that the “Golden Rule” was a distillation of everything the Bible teaches.

- How do you understand the Golden Rule? Is it complicated? How would you explain it to a second-grade Sunday school class? To confirmands? To an adult study group?
- Is the Golden Rule easy to live by? What has been your experience?
- Why does Jesus say that the Golden Rule encompasses the law and the prophets?
- If you or your loved ones were experiencing dementia, how would you want to be treated? What kind of help and support would be helpful?
- When it comes to your and your congregation's relationships with people experiencing dementia and their families, how would the Golden Rule guide your interactions?

# Inherent Worth

WHAT THE CHURCH CAN LEARN FROM PEOPLE WITH DEMENTIA

By Megan Brandsrud



After completing the “Dementia Through a Pastoral Theological Lens” course at Lutheran Theological Southern Seminary, Columbia, S.C., students participate in a commissioning service and receive stoles. The stoles are handmade by Lynda Everman, an advocate on behalf of people with dementia.

When Ken Carder’s wife, Linda, was diagnosed with frontotemporal dementia, he began to consider the high value society places on intellect, and how capacity relates to identity.

He quickly learned that viewing his wife’s dementia solely through a medical lens gave too narrow a focus.

“When she was aware of what was happening to her, she

would say, ‘I’m just worthless,’” Carder recalled. “Her self-image began to decline, and I thought, how do I help her and help myself know that the real Linda is still there—the Linda who is

known in God's own grace—that she is made in the image of God as a gift and dementia doesn't destroy that gift?"

A retired bishop in the United Methodist Church, Carder leaned on his theological and pastoral perspective for guidance. He found solace in having a faith perspective that offers the practice of lament.

Carder did extensive research on Linda's disease and learned that when people with dementia are isolated from their community, their condition worsens. He recognized that people with dementia weren't at the center of his own pastoral care efforts.

Seeking to change the status quo and demonstrate how congregations can join in ministry with people who have dementia, Carder created a class at Lutheran Theological Southern Seminary in Columbia, S.C., where he serves as guest professor, called "Dementia Through a Pastoral Theological Lens."

Following Linda's diagnosis, the couple moved into the Heritage at Lowman, a Lutheran retirement community in Chapin, S.C., that provides memory support. It gave him an idea for crafting his course. "Here I am living in a Lutheran ELCA community and teaching in an ELCA seminary," he said. "These two institutions agreed to partner, so the classes are held on the campus of the retirement community."

Students spend the first part of each class learning about dementia and discussing theological concepts. The class then joins residents of Lowman's Bethany building, site of its memory care program, to lead a hymn sing and devotion time before interacting with residents individually.

"I try to emphasize that the people at Bethany are our teachers," Carder said. "We find God in them. We don't take God to them."

Visiting the residents can be an anxious experience for some, Carder said, adding that about half his students in the course had no prior experience with people who have dementia. This can be an asset, he explained, because those students don't interact with residents expecting to provide answers or solve problems. They focus on just being present with them, which Carder said is crucial.

### Ministry of presence

Mandy Achterberg, pastor of St. Stephen Lutheran Church in Northglenn, Colo., said the ministry of presence was one of her main takeaways from Carder's class. "Knowing that the people I was spending time with likely wouldn't remember anything I said but would experience in their body a memory of feeling loved and cared for that would last long beyond my visit, I learned that having the right words weren't necessary, but my presence and care most certainly were," she said.

Throughout the course, students develop a plan for a congregational ministry with people who have dementia. They discuss how memories are held in community and how people can be disciples of Jesus even when they no longer remember him.

This is a point that has stuck with Achterberg. "If we are to take the incarnation seriously, then a mental capacity to remember or know God is not as central as God remembering and knowing us," she said. "Dementia doesn't separate us from God."



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**“If we are to take the incarnation seriously, then a mental capacity to remember or know God is not as central as God remembering and knowing us.”**

Rebekah Swygert Boatwright said her experience in Carder’s course shaped not only her view of dementia within the church but also how she sees herself as a beloved child of God.

“Human worth and dignity are inherent and lie in God’s promises and God’s story,” she said. “When we allow ourselves to let go of how the world sees human value and worth, we are free to be the hands and feet of Christ like never before.”

Now she is applying what she learned in the course by leading a study on Carder’s book *Ministry With the Forgotten: Dementia Through a Spiritual Lens* while on internship at Trinity Ecumenical Parish, Moneta, Va. “I plan to have this conversation in any congregation I go to where it seems appropriate,” she said. “Beyond this study, I find myself incorporating

the conversations we had in Bishop Carder’s class into sermons, conversations and Bible studies often.”

Carder said congregations need to be intentional about including people with dementia and those who care for them rather than treating them simply as objects of outreach ministry. He noted that the median age of members in mainline churches, including the ELCA, is 52, whereas the median age in the United States is 38.

“We are 20 years older than society, and 10% of people 65 or older is going to have some form of cognitive impairment,” he said. “That means we’ve got a disproportionate number of people in our churches [who will be affected]. These folks can transform us and transform the church if we welcome them at the center of our life and mission.”

Carder believes the church is uniquely positioned to address how people with

dementia are treated and to erase the stigma. “As Apostle Paul says in 1 Corinthians 13, knowledge passes away, language ceases, but what remains is love,” he said. “And it’s the church that is in the business of being a community in which love is real, practical, lived out in relationships.”

He said his understanding of love was expanded by his experience with his wife, who could no longer remember him when she died, shortly before their 58th wedding anniversary.

“She taught me that I loved her without expecting anything in return from her,” he said. “And is not that the essence of agape—seeking the well-being of the other simply because of who they are as a child of God? And in so doing, we are participating in the triune God’s dance of love.” †

Download a study guide at **[livinglutheran.org](http://livinglutheran.org)** by clicking on the “Spiritual practices & resources” tab.

## Service of commissioning

Students who complete the “Dementia Through a Pastoral Theological Lens” course participate in a commissioning service. Below is a portion of the liturgy.

*Through this class, you have focused attention on the special needs, gifts, challenges and opportunities of relationship and ministry with people affected by neurocognitive diseases. At Bethany, you have experienced God’s special presence and ministry with people whom society and the church tend to diminish and neglect. You*

*have loved them and been loved by them. You have received their gifts and offered the gift of your presence and ministry. They have helped us to become a community of grace and mutual support. They have taught us what the church can be when love dominates relationships.*

*We ask you now if you will commit to continue what has begun in this class and lead congregations to experience the joy, love and renewal through ministry among people who live with dementia diseases.*