

## Activity Guide and Discussion Questions

Lesson One: Understanding Mid-Stage or Moderate Alzheimer's  
pages 113–116, *Dementia and the Church: Memory, Care, and Inclusion*  
Supplementary Activity

### “Bert and Willa”

Excerpt from *Alzheimer's a Crash Course for Friends and Relatives*, by Mary Cail  
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#### **Materials:**

- A large dry erase board or chalkboard
- “Bert & Willa” PDF
- Handout: “Stages of Alzheimer’s Disease” fact sheet produced by the Alzheimer’s Association: <https://www.bu.edu/alzresearch/files/pdf/StagesofADAlzAssoc3.pdf>. (attached)

**Time Required:** about 30 minutes

#### **Process:**

1–3 (See pages 113-114, *Dementia and the Church: Memory, Care, and Inclusion*)

4. Introduce the reading selection, “Bert and Willa,” which is the story of a couple living with mid- or moderate-stage dementia. You can either distribute copies and allow time for reading, or have a reader for the story. Ask participants to imagine, as they read or listen, what Bert and Willa’s lives are like; to try to think of themselves as Bert or Willa. Which person would they rather be? Discuss the story using the following questions:

- (Bullet point 1) How do you think Bert gets through his life from day to day, when the days are all essentially the same, barring an emergency or the presence of a caregiver for a few hours? What brings him joy or eases his isolation? Did you feel greater empathy for Bert or Willa? If you had to take the place of either one, which one would it be, and why?

*Note:* The second and third bullet points (pages 114-116) can be adapted almost “as is” by substituting the names “Bert” and “Willa” within the discussion points.

- (Bullet point 4) At what cognitive level is Willa functioning? If you had to guess a chronological age according to her apparent functional skills, what would it be? Does she seem capable of doing anything on her own safely? What modifications has Bert made to the house, and do these restrictions seem to bother her?
- (Bullet point 5) Imagine Bert and Willa joining our congregation. How could we support them? How could we make their lives easier? What would they bring to us?

## Willa and Bert

*What is dementia caregiving like when friends vanish? Here is one couple's story—compelling in love and devotion, disturbing as an example of the isolation that can too easily happen.*



WHEN I FIRST SAW Willa and Bert together, they were strolling up a narrow street in a neighborhood where each lot has a well-kept clapboard house and a few shade trees. Leaves swirled in late autumn wind. Cars parked bumper to bumper made a tight chain along the sidewalk. From the back, the two had the look of accepted intimacy—the way they leaned toward each other, the way his hand guided her arm. They were talking, laughing occasionally.

They heard me approach and turned, and I was surprised by Bert. He was striking, with eyes like shallow ocean waters, vivid blue against the November sky. I had seen him before only in a conference room with the ceiling panels of fluorescent light that make most people appear wan and haggard, as though they may be recovering from the flu. He was there week after week for a couple of hours, his tall frame cramped in a folding metal chair, commiserating with other caregivers. Some days he seemed tired and quiet; others, he raked his hands through silver

hair and talked about Willa. He had invited me over to meet her, and she gazed at me with expectation, smiling, uncertain of what to say.

She was a broad-shouldered woman then, with long red hair streaked in gray. Had she not been wearing eyeglasses pieced together with loops of cellophane tape, she could have walked straight from an Andrew Wyeth portrait of Helga. In her mid-sixties, Willa was the age a veteran of medicine's highest ranks might think of stepping away from the mandates and pressures to the calmer work of consulting. Considered during



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the Clinton administration for the post of Surgeon General, she should have had much to offer. But she couldn't remember anything about infectious disease or public health problems. She no longer knew her face in a mirror. Bert tended to her

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during those years as he would have a small child. "Willa is the love of my life," he still says.

Back at the house, a width of nubby carpet, soiled and damp, ran over the porch, down the stairs, and across a strip of lawn to make a safe walkway on days slick with rain. Bert led Willa through the door and into the kitchen, where a box of disposable latex gloves, hand sanitizer, and rubbing alcohol seemed out of place alongside a rack of drying dishes. He hung his trench coat on the back of a chair, then unbuttoned Willa's jacket and slipped it off her shoulders. "Now, my dear, let's go back in here," he said and opened a thick Styrofoam partition placed against the door to the hallway. A handmade lock barred Willa from the stove, the chairs she could easily stumble over with her shuffling gait, and the door leading outside. She wandered into one of the two rooms where she lived during the middle phase of her dementia, restricted by gates and barriers.

Bert settled in a chair at the kitchen table, evidently relieved to have a visitor. Our conversation shifted quickly from books to Shakespeare, to nuclear energy, to his unabashed opinions about sex. "I miss

having real conversations,” he said. “Let me show you why.” He stood up and walked to the gate. “Willa? Come here, Willa, and hand me your glass.” He paused, waiting for a response. “The glass, honey, I’ll put some milk in it.”

Willa approached from her side and looked at him blankly. “My glass?”

“Yes, see that glass?” He could have reached the glass on a shelf beside a plate flecked with sandwich crumbs, but he spoke again to Willa. “Hand me your glass, dear.”

Willa turned to a mirror on the opposite wall and looked at herself. “Well,” she began patiently, “I’ve told you many times about it. What? How can I do everything? I can’t, you know.” Her tone was what it might have been less than a decade earlier when speaking to one of several hundred subordinates.

“The glass, Willa. The glass. Do you want some milk?”

Willa picked up an empty plastic tray. “I don’t know. It looks like something spilled in there.” She flipped the tray over and inspected the back.

Bert raised his voice. “The glass! Do you want some milk? Hand me the glass, Willa!”

Willa stepped forward and stared deliberately into his face for a few seconds. “I’m trying,” she said quietly, as though addressing someone she considered slightly irrational.

“Just hand me the glass, honey. I can’t reach it.”

“I don’t think it happened like that. That isn’t what I told you.”

Bert turned to me. “She’ll never hand me the glass. She can’t do it. She doesn’t understand.”

Willa picked up a child’s alphabet puzzle and sang, “A-B-C-D-E-F-G-H-H-I-G-K-M-N.” She set the puzzle down and gazed through a window. “What do you do with the man who said he had to go there, he says. Oh, that was very, very bad. That was very bad. Are you going to the end?” She raised her eyebrows in question. A framed

photograph captioned *Queens University School of Medicine* hung on the wall beside her. One of only a few women, Willa had stood in the second row, shoulders held back proudly, in the white coat of a newly minted physician. “Well, I am, too,” she concluded, walking into the other room. “I don’t know where I’m going to go, if I ever get here. That’s the ditty, ditty, ditty, ditty, ditty, ditty.”

Bert met Willa thirty years ago through his mother, a psychiatrist who hoped to lure her son from his solitary life as a West Coast journalist to the altogether different role of business manager for her medical practice on the opposite side of the country. Persuading him to make a three thousand mile relocation and career change, she realized, would require a more substantial enticement than maternal need. For this purpose, she put forward the strikingly beautiful and recently separated Willa, who asked only regarding Bert’s suitability as a blind date, “Is he tall, and does he dance?”

Shortly after meeting the “gorgeous, brilliant, and interesting” Willa, the tall-man-who-danced packed a van and headed for Florida, where a romance blossomed. A while later Willa changed positions, and the couple, inseparable by then, moved together to the District of Columbia.

“Almost every day was good,” Bert said, reminiscing about that idyllic period. “We’d read to each other or just talk for hours. Saturday morning was the best. I’d go down and make us breakfast and bring it up to her, and we’d eat it in bed. And then we would make love.” He talked about walking along the shores of the Potomac on weekend afternoons to watch Willa sailing a boat on the river. She was an avid sailor; he was not. Evenings, she went with him to a nightclub where he sang. “We were known as sweethearts,” he said. “I’d always sing love songs to her.”


Their lives went along tranquilly for many years, until Willa began to show signs of confusion and lack of initiative at work. Finally she was fired from her position as the director of a network of health services.

In the stress of losing the career and lifestyle she loved, her dementia intensified. She was desperately aware, then, of her condition. Bert recalls having dinner with friends one evening. Willa abruptly left the table in frustration. She stood a few steps away and said, to no one in particular, “Please, please help me. Can someone please help me?”

As her mind faded, Bert simplified the love songs he sang to her, until at last they were only “ta-da-da” marching rhythms to keep time as they bounced a plastic beach ball back and forth in a simple game. While she could still play, Willa would bat at the ball with clumsy jerks, her body crouched forward in anticipation. She used to be a great table tennis player. When a psychological evaluation, required in response to her slipping job performance, first raised the question of Alzheimer’s disease, Bert wrote an indignant rebuttal to her supervisor, concluding with the tongue-in-cheek claim that Willa could, furthermore, beat the psychologist or anyone else at Ping-Pong. He never mailed the letter.

EVEN AFTER WILLA HAD PASSED WELL INTO DEMENTIA, weekend mornings were a time of easy companionship, as they had always been before. One Saturday in winter, I watched the two of them resting on the bed after a walk. Willa lay with her arms stiffly at her sides and her chin tucked to her chest. A book review was being broadcast on television. Subtitles flashed across the bottom of the screen. She read sentence fragments and inserted them into her

talk. “Gary Nash. Will we be able to get out of here? The unknown American. The unknown American? G, C ... C-Span! C-Span. We hope we can grow with it,” she said, laughing.

 *Even after Willa had passed well into dementia, weekend mornings were a time of easy companionship.*

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Bert’s arm curved around the back of her pillow. Light from the window caught his eyes as he looked down gently at her face. “That’s good, my dear.”

When we were alone in the kitchen, he told me their sexual relations had ended four years earlier. “I had to work at it then because she was having some trouble. It was baffling to her, so I only tried again a time or two. She wasn’t interested, and she didn’t understand. There wasn’t anything more to do. I lie next to her and hug her, but I wouldn’t do anything sexual. She seems to enjoy being close to me. She’s smiling and happy, but the relationship we had is gone. A diagnosis of Alzheimer’s means you are going to lose the person you knew. She was my sweetheart, best friend, partner, entertainer, and helpmate.” Other than affectionate touching, the only physical contact he has with Willa is in changing her incontinence pads, a task which was complicated by her resistant thrashing until her strength finally ebbed. “I’m glad she hasn’t thought of spitting at me yet,” he said ruefully. He takes these behaviors in stride, realizing they are a part of dementia but not of the Willa he loves. “Willa is so important to me,” he added, “that to take care of her is to take care of myself.”

A few months later, on a blustery March afternoon, he showed me the changes he had noted on a chart pinned to the kitchen wall. “Here, she could put on her own shoes,” he said, turning back a page or two, “Now, she can’t.” He has used the chart from the beginning to keep track of her medications, daily schedule, and regressing abilities. Willa had been puttering in one of the back rooms with her hired caregiver, Becky, and we heard her cry out in distress. Bert glanced briefly in her direction and continued to read his notations. “You see, in the morning she’s usually only wet, but the bed is flooded. “I’ve found that by using five absorbent pads in the Depends, urine doesn’t get all the way up to the pillows, but I always have to do a load of laundry.”

“Oh, stop it! STOP!” shouted Willa.

“Becky is probably trying to brush her hair,” he said dismissively, as though outbursts of temper were an unremarkable part of daily life. After a few minutes Becky opened the kitchen gate. Willa was dressed in an overcoat and bright red gloves, with a scarf tied under



her chin. “Hi, my dear!” he said. “You’re going for a walk. How nice.” He straightened her coat and turned to Becky. “I think this is a good idea. It’s windy today.” He took a tube of lip balm from his pocket and rubbed it on Willa’s lips. They gave each other kisses, wiping their lips together in a ritual of affection. “That’s the best way to put on ChapStick,” he told me, in mock seriousness.

FOR AS LONG AS SHE COULD, Willa walked twice a day with either Bert or Becky, unable to go alone without getting lost. She ambled along, barely lifting her feet enough to clear the pavement. Bert had planed the soles of her tennis shoes to make tripping less likely. She kicked feebly at pine cones and rocks. She read license numbers from cars and words from street signs and seemed pleased with herself. She paused in front of a political sign in someone’s yard one afternoon. “Stand...up...for...peace,” she read slowly and turned to Bert with an eager smile. Encountering a stretch of rough road, she cried in the voice of a child, “Money, money...money, money, mon-eeee!” her voice stressing the end of the word in anxiety.

“That’s mommy,” he translated. “She’s calling for her mother.” He coached Willa constantly: *This way, my dear. Willa, let’s turn here. Come with me. Good, that’s good.*

Willa and Becky returned, and we sat around the kitchen table to share a favorite treat, butter pecan ice cream. Bert got paper bowls and plastic spoons out of the cupboard and took a tub of ice cream from the freezer. He opened the refrigerator door to show me labeled packages of cooked meat he had bought from a restaurant and saucepans of boiled peas and oatmeal—his method of squeezing the preparation of meals into the busy schedule of caregiving.

Becky scrutinized Willa from across the table. “Her hair has natural curl in it, but it’s getting too long.”

“I started cutting her hair when we were in St. Petersburg before we lived together,” Bert said. “She was the only woman in the world


whose hair I would cut. I had to be in love with her, and I had to have her naked.” He laughed lightly at the memory. “I don’t cut it anymore, but she got compliments when I did.”

Impatient for her snack, Willa picked up the ice cream and took a bite straight out of the carton. “Very good, honey,” he said with undaunted cheerfulness. “Now that’s going to be your piece.” He ladled around the tooth marks and flicked the scoopful into her bowl. Willa ignored it and took another bite from the carton. “Here, I’ll give you this piece, too, my dear. Willa’s very persistent when she wants something.”

Becky offered her a spoon. “There, honey. You have a spoon for it. You don’t have to eat it out of the carton. You have a spoon.” Willa looked at her like she was speaking in Greek.

Becky cared for Willa several times a week during the middle phase of her dementia, so Bert could do the shopping and run errands. Otherwise he seldom went out. His efforts at holiday celebrations—a small Christmas tree stood in a window; a dozen dry Valentine roses drooped in a vase by the sink—were lost on Willa.

“Before she had this trouble, we were very much in love,” he said once, as evening fell and darkness made the kitchen seem smaller. “I miss the way she was. She’s very different, and I’m going through a grieving process. I know I’ve lost her; those times will never be back. But what hurts the most is for her to be brought so low that she has

 *“The love I’ve felt for her continues, but with a changed circumstance. I guess what I’m trying to say is, in a way, love does conquer all.”*

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to be incontinent and live in this strange world. She used to be brilliant. I miss her companionship, and I suffer from the lack of that meaningful engagement in my life. I’m engaging with her, but it’s very much in the caregiving role. The love I’ve felt for her continues, I’m

finding, but with a changed circumstance. I guess what I’m trying to say is, in a way, love does conquer all.”

I DIDN'T SEE BERT AND WILLA again for more than two years. I was finishing the first draft of this book then, and I stopped by with a question for Bert. The same dingy carpet stretched from the sidewalk to the back door, but the barrier to the kitchen had been removed. Willa could no longer walk. She lay almost motionless in a reclining chair with her mouth gaping open and her eyes vacant. "Look, Willa," Bert said, shaking her foot and jostling her a little. "It's Mary. Can you look Willa? Look."

"Ma, ma, ma, ma, ma, ma," Willa mumbled, and the trace of a smile crossed her lips.

"That's it! There's a smile," said Bert and patted her shoulder. His voice had the same good-humored lilt, and his eyes had the same tenderness. He had pulled thick white socks over her hands, which were curled into tight fists. Without the socks, her fingernails, he said, would dig into her palms.

The whole scene was bleak: Willa wasting away in a room smelling of alcohol and soap, with packages of Depends stacked along the walls. The pages of Bert's chart were curled from use and filled with his notations about her. I wondered how she could be so thin and frail and be alive; how Bert could have carried on day after day, apparently without losing any of his affection for her. I imagined how different it would have been had friends been around regularly, bringing the outside world in and allowing him a break from the tedium.

Bert has lost touch with the friends he had before Willa's illness. Except for the Alzheimer's Association support group on Tuesdays and the company of paid caregivers, he has virtually no opportunity for significant social contact. "I tend to be in denial about how isolated I am, because I'm so self-sufficient," he said. "We're human beings, and we need to be in relationships with each other. You can't be great at tennis and keep playing against the backboard. You have to go out and hit back and forth with somebody. We do need each other. I understand that about myself."<sup>27</sup>

## Stages of Alzheimer's Disease

Experts have documented common patterns of symptom progression that occur in many individuals with Alzheimer's disease and developed several methods of "staging" based on these patterns. Progression of symptoms corresponds in a general way to the underlying nerve cell degeneration that takes place in Alzheimer's disease.

Nerve cell damage typically begins with cells involved in learning and memory and gradually spreads to cells that control other aspects of thinking, judgment and behavior. The damage eventually affects cells that control and coordinate movement.

Staging systems provide useful frames of reference for understanding how the disease may unfold and for making future plans. But it is important to note that all stages are artificial benchmarks in a continuous process that can vary greatly from one person to another. Not everyone will experience every symptom and symptoms may occur at different times in different individuals. People with Alzheimer's die an average of four to six years after diagnosis, but the duration of the disease can vary from three to 20 years.

The framework for this fact sheet is a system that outlines key symptoms characterizing seven stages ranging from unimpaired function to very severe cognitive decline. This framework is based on a system developed by Barry Reisberg, M.D., Clinical Director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center.

Within this framework, we have noted which stages correspond to the widely used concepts of mild, moderate, moderately severe and severe Alzheimer's disease. We have also noted which stages fall within the more general divisions of early-stage, mid-stage and late-stage categories.

### **Stage 1: No cognitive impairment**

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

### **Stage 2: Very mild decline**

Individuals at this stage feel as if they have memory lapses, forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

### **Stage 3: Mild cognitive decline**

Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people

- Performance issues in social and work settings noticeable to others
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organize

**Stage 4: Moderate cognitive decline**  
(Mild or early-stage Alzheimer's disease)

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent events
- Impaired ability to perform challenging mental arithmetic. For example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as marketing, planning dinner for guests, or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations

**Stage 5: Moderately severe cognitive decline**  
(Moderate or mid-stage Alzheimer's disease)

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number, or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet

**Stage 6: Severe cognitive decline**  
(Moderately severe or mid-stage Alzheimer's disease)

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pajamas over daytime clothes or shoes on wrong feet

- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or fecal incontinence
- Experience significant personality changes and behavioral symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviors such as hand-wringing or tissue shredding
- Tend to wander and become lost

### **Stage 7: Very severe cognitive decline**

(Severe or late-stage Alzheimer's disease)

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer care, support and research.

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