

CLOSE TO HOME



DEALING WITH
dementia



Struggling with the symptoms

I met Roger while I was in college, working at the laboratory where he participated in research on memory. Roger could still understand and use very simple language, but he could only remember things that happened a long time ago. He had been diagnosed with probable Alzheimer's disease, and his dementia was progressing into the later stages.

Roger visited me daily for almost a year, but he never recognized my face or consciously recollected having met me before. However, his face lit up whenever he saw me. His eyes and smile seemed to acknowledge unconsciously our familiarity, on an emotional level, though he could not recall who I was. He was always accompanied by his wife, whom he relied on for all his activities of daily living, including dressing. He needed her constant assistance; otherwise he would get lost or become visibly distressed.

Roger's wife told me that he had been a Sunday school teacher for most of their lives. She recalled his fun-loving spirit and kind character. Roger's personality underwent changes in the course of his disease. When he became frustrated or confused, he lost his temper and used harsh language. Roger's wife winced whenever he was verbally aggressive toward others. She was very embarrassed by these outbursts; they were so out of character for him. I assured her that I knew these behaviors were not under his control; they were symptoms of his dementia.

In our study, Roger looked at pictures of various birds he hadn't seen before. Together, we intensively rehearsed the birds' names by matching them with pictures. Within seconds, Roger forgot having seen each bird, so when I asked him to tell me its

name, he grew frustrated and hurled profanities: "Why ask *me*? I've never seen that bird in my life! What do you take me for? A **** *birdman*?" But after weeks of repetition, he began muttering to himself about "ospreys," and "hoopoes" when presented with their respective pictures, without awareness that he knew their names. He had no explicit memory of them; he knew them implicitly.

Faith and community comforted both Roger and his wife amid hardship, although struggle remained.

Roger taught me that, while dementia may affect *explicit* memory (of facts, events, dates, names, and faces), *implicit* memory is preserved for a very long time. Implicit memory includes emotional memories, as well as memories of well-practiced activities like playing piano, singing favorite hymns, or reciting prayers or memorized Bible verses.

By spending time with Roger, I discovered how he was comforted and soothed whenever sincerely led in the Lord's Prayer, which he recited by heart (though he said he didn't know it). He once became fearful that I would leave him alone, and asked repetitively, "How long until you must go?" At first, I answered, "We only have one hour." While factually true, this was emotionally unsettling to him. I learned to offer a more empathic response: "We get to spend a whole hour *together*." Faith and community comforted both Roger and his wife amid hardship, although struggle remained.

The problem of dementia

What is dementia? It is an overall decline in intellectual and social abilities to the point that it interferes with daily functioning. It always includes memory problems and at least one, and maybe more, of the following:

- disorientation regarding time or place
- difficulty paying attention or concentrating
- difficulty with reasoning and problem solving
- a significant change in personality
- loss of initiative
- changes in overall mood
- poor judgment
- difficulty with spatial navigation
- perceptual problems
- difficulty understanding or using language
- loss of inhibition.

Dementia is not a disease itself. Rather it is a cluster of symptoms due to another underlying condition such as (to name a few)

- Alzheimer's disease
- Vascular dementia
- Lewy body disease
- Multiple sclerosis
- Parkinson's disease
- Huntington's disease.

Dementia is an overall decline in intellectual and social abilities to the point that it interferes with daily functioning.

Dementia isn't just a normal part of getting older, like going gray or having wrinkles or having mild, occasional forgetfulness. If you or a loved one show signs of dementia, see a doctor. Accurate diagnosis is extremely critical, especially since some conditions, like depression, have similar symptoms. Some conditions that cause dementia are reversible if detected and treated early, like alcoholism, infection, and drug reactions or interactions. Unfortunately, most dementias are currently progressive and irreversible.

Progression of dementia varies for each individual, depending on many factors, including the affected regions of the brain and the underlying condition. In cases of dementia that are degenerative (that is, the ones that keep getting worse), the late stages generally look similar: the patient becomes dependent on their caretakers for most, or all, of his or her activities of daily living.

Dependency presents a great challenge for both the patient and the caregiver. People with dementia don't want to give up their independence, such as living alone or driving. Their condition can make it difficult for them to make good judgments.

If you or someone you love has dementia, you are not alone. These days, we see many more people with dementia in our communities and churches. Life expectancy has increased over recent generations due to medical advancements and improved diet. However, longer life expectancy also tends to increase the prevalence of dementia, since dementia is more common for people over the age of 65. Roughly 24 to 28 million people in the world have dementia.

Dementia, the Bible, and the Christian story

Jesus spoke these words to Peter: “But when you grow old, you will stretch out your hands, and someone else will fasten a belt around you and take you where you do not wish to go” (John 21:18b). Reactions to these words can include both fear and resistance. It is difficult to lose independence. Love of personal freedom is natural.

However, obedience and discipleship are acquired only through faithful practice. Ultimate obedience requires yieldedness to God. It is easy to forget that this kind of self-yielding, which Jesus envisioned for Peter’s discipleship, brings glory to God (v. 19a).

In a sense, dementia takes some on a path of ultimate discipleship, however unwillingly. Jesus always leads, and he says, “Follow me” (v. 19b). Every day, not just when we are in the throes of illness, Jesus offers this invitation. There is a call for faith and trust as control is relinquished and care is given to another. Dementia can be another part of the path along the way of faith. God’s care and control is unchanging, even if the very consciousness of it undergoes change.

God is the keeper of lost memories, much in the same way that names are recorded in the book of life. And God is often engaged in the act of remembering. Acknowledging this can help people with dementia feel less fearful about letting memories go, should the path of discipleship go along that way.

The Bible uses the Hebrew word *zkhor* countless times to describe God remembering and being mindful of God’s children. Indeed, the man who died on a cross next to Jesus trusted the Lord to remember him in paradise. This defies the fear of oblivion or forgetfulness in the afterlife.

For the spouse or children of one with dementia, who have perhaps experienced the sting of non-recognition, Isaiah 49:15 offers comfort: “Can a woman forget her nursing-child, or show no compassion for the child of her womb? Even these may forget, yet I[God] will not forget you.”

As care is given, those who are caregivers literally enter into ministry. There is one New Testament word for both “ministry” and “service.” Caregivers are ministers through their presence, and through the executive decisions they make for their loved one. In a very real way, caregivers embody God’s unconditional love.

God’s care and control is unchanging, even if the very consciousness of it undergoes change.

It is possible that caretaking may require delegating care to professionals. While this, too, may not be “where you wanted to go,” it may become necessary. Know that God is ever mindful of your cares and concerns.

It is extremely important that the Christian community remember their members with dementia. Regular prayers for those suffering with dementia and their caregivers on Sunday morning can raise awareness of needs. When people with dementia are unable to go to church, the community can visit them. Even if they do not remember who you are, you remember who they are; you remember that you love them unconditionally. You embody God’s love as you visit. A Christian community would do well to learn about dementia to understand the symptoms and to know how to provide loving support.

Steps to take

A goal in the treatment of dementia is to control and slow down the symptoms. Sometimes the symptoms include a change in the abilities and behavior patterns of the patient. This provides challenges as daily routines and tasks can become more difficult and the patient struggles to remember basic skills. Patient safety is a concern if the patient forgets where he or she is, or believes that memories are reality.

Patients, families, and caregivers need to learn about the illness. They need to work together to prepare for the future, and it is best to do this in the early stages so that the one with dementia can participate in the preparation.

- 1.** If you suspect that you or a loved one may be showing signs of dementia, it is essential to get an accurate diagnosis. Meet with your primary physician so lab tests can be run to check for health concerns that mimic dementia. You may want to get a second opinion to verify the diagnoses and recommendations of your primary physician. Medication might be prescribed to address the symptoms of dementia, or to slow down the effects of dementia.
- 2.** It is good to be surrounded by a clinical team. A team will include your physician as well as possibly a neurologist, a neuropsychologist, a geriatrician, a pharmacist, a social worker, and others. They will provide useful recommendations and strategies for the best possible treatment.
- 3.** Consult with an attorney and a financial advisor to address current and future legal and financial concerns. Communicate your desires clearly now so that, if it becomes necessary, others will understand

your wishes and be able to follow-through accordingly. Family members or trusted individuals need to be involved in this step so that they are aware of your plans. Ask someone you trust to make decisions on your behalf in case you are no longer able to do so.

- 4.** Along with your family, consult with a social worker to find resources in your community. There may be services available such as adult day care, visiting nurses, or volunteers trained to work with dementia patients and their families. Some communities have support groups, and it is good to meet with others to share experiences and know that you are not alone in this situation. With your family and social worker, consider health care needs and living situations. How will these needs be met in the future should full-time care be necessary? Knowing options will help you and your family make well-informed decisions.



For further awareness:

Alzheimer's Association
www.alz.org

Alzheimer's Foundation of America
www.alzfdn.org

Alzheimer Society of Canada
www.alzheimer.ca

Bayley, John. *Elegy for Iris*. New York: St. Martin's Press, 1999.

Callone, Patricia, ed. *A Caregiver's Guide to Alzheimer's Disease: 300 Tips for Making Life Easier*. Demos Medical Publishing: New York, 2006.

Coste, Joanne Koenig, and Robert Butler. *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*. New York: Houghton Mifflin Co., 2004.

Dowling, James R. *Keeping Busy: A Handbook of Activities for Persons with Dementia*. Baltimore: John Hopkins UP, 1995.

Mace, Nancy L., and Peter V. Rabins. *The 36-Hour Day: A family guide to caring for people with Alzheimer Disease, other dementias, and memory loss in later life*. Baltimore: John Hopkins UP, 2011.

Warner, Mark, and Ellen Warner. *The Complete Guide to Alzheimer's Proofing Your Home*. Revised edition. West Lafayette, Ind.: Purdue University Press, 2000.

For the caregiver

Feelings of grief, anger, or guilt may be present as you experience the changes in your loved one. Exhaustion and fatigue are common in caregivers who are taking care of someone else's every need. Caregivers may be sandwiched between caring for someone with dementia and raising their own children. It can be a very awkward role reversal for adult sons and daughters to make judgments on behalf of their parent. Whenever caretaking occurs within the family, special emotional support and resources are very important.

It is suggested that caretakers resist constantly reorienting their loved one to reality as they understand it. For example, "You didn't just visit with Dad today. He died a year ago." Instead, try to enter into his or her reality. Otherwise, frustration grows. Remember that even in confusion and delirium there is often meaning. Finally, focus on whatever is preserved, be it singing, rote prayer, or even stories from long ago.

It is important to pursue self-care even as you care for another. The local congregation can be supportive by providing meals, respite care, emotional support and prayer. A minister or a counselor can be a resource as you experience loss due to your loved one's changes. Be proactive in naming how people can be helpful in this situation. People often want to help, but don't know how.

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**Local resources for help with
dementia:**

**For more information on other Close to Home
titles, go to:**

www.mennomedia.org/closetohome



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