

Holding a lamp

Ministry as memory fades

Ingrid Loepp Thiessen

God lights a lamp

Songs we love become part of our life story and our memory, ready for retrieval when we need them most. They can stay with us forever. There is a new song in *Voices Together* with a melody that rises to celebrate the enormous joy of angels and softens as love is found. The song has won my heart with its comforting, expansive text, a short, simple melody, and such joy. I repeat it again and again because it speaks to my soul.

*God lights a lamp,
And she searches ev'rywhere
For the hidden, lonely heart.
God lights a lamp,
And she searches ev'rywhere.
When she finds you, oh, she sings:
"I have found my treasure, my precious silver coin.
I have found my love!"
Even angels will hear the news,
What once was lost, is found.¹*

The song retells Jesus's parable about a woman who loses a coin and searches until she finds it. It is a picture of God, who is searching for us. We are precious, lost treasure. In this story, we are joyfully and lovingly found, safe again at home, and celebrated.

This parable—and the song that retells it—speaks to me as a chaplain in a long-term care setting for a couple of reasons. First, personally, I can identify with being lost sometimes, far from who I am meant and called to be. As a chaplain, I know the desperate feeling of being lost, not knowing

1 "God lights a lamp," lyrics by Katie Graber; composed by Anneli Loepp Thiessen, *Voices Together* (Harrisonburg, VA: MennoMedia, 2020), 299. Text reprinted here by permission of the authors. For a recording of the song, see <https://www.commonword.ca/ResourceView/82/22687>.

what to say, when to show up, when to leave, or how to be present in a difficult situation.

Second, I identify with the woman holding the lamp, sweeping, searching, finding, and celebrating. In this story is a calling. As a chaplain, it is my task to light a lamp and continuously search for a way to connect to the human treasure, the precious silver coin, the hidden lonely heart, the loved one who has dementia. Everything I do as a chaplain is about communicating God's peace in the midst of fear, finding hidden treasure in a vessel that is changing, and celebrating moments of grace and love on a difficult journey. It is about shining a light into ancient memories to find a lost spark, a hidden glimmer, a deep hope, the seeds of faith, the eternal beauty of a soul—and then to have a party. Yes, *I have found my treasure, my precious silver coin. I have found my love! And even angels will hear the news!* This is my calling as a chaplain among people with dementia, and perhaps it is the task of all who seek to provide spiritual care.

Journeying alongside those with dementia

Dementia is a disease of the brain. The brain increasingly fails to do what it has always done, and over time this affects every aspect of life for the person with dementia and for those who share life with them. The most common type of dementia is Alzheimer's disease; some other types include Vascular Dementia, Lewy Body Dementia, and Frontotemporal Dementia. There are also other diseases, like Parkinson's disease, which can impact a person's cognitive functioning. Each disease has different expressions. Dementia is progressive, getting worse over time as the failure of the brain intensifies. At the very end of the disease, a person may no longer walk or sit up. They may barely move, their muscles becoming increasingly rigid. The person may or may not be able to eat or use the washroom independently. They may need assistance with all the activities of daily life. Attempts to speak may not be understood by listeners. Swallowing might become difficult. The immune system may fail to send warning signals.

The journey to this later stage can take a long time and will begin with more subtle but equally frightening changes. In the earlier stages, dementia may result in a reduced ability to solve problems and understand directions. There may be forgetfulness, personality and behavior changes, memory loss, and frustration that increasingly affects all areas of life. A seemingly simple thing like going for a walk may become increasingly challenging as the disease progresses.

Amid all these difficulties, there are many kindnesses and gifts to be found: the support of friends in the midst of grief, a beautiful smile indicating recognition or understanding, a playful laugh between new friends, an old friend who comes alongside, moments of insight amid memory loss, and the meaningful management of a difficult diagnosis are among them. The zeal of everyone involved to make it work and the expanded

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circle of people showing their love, music that draws out the best in us, prayers, Scripture verses that offer faith and comfort, and the joy that children bring are all mercies along the way.

The journey with dementia and the journey alongside someone who has dementia can leave us feeling bereft, grieving, and lost, and this can go on for years. As spiritual care providers, we can feel lost. We do not know how to begin,

where to shine the light, how to interpret the responses, and sometimes even what we are looking for. Family and friends who support people with dementia might also use the language of lost-ness. Grieving, they may say things like *I just can't anymore* or *She is lost to us* or *He is a shell of who he used to be*. This is such a painful place to be.

For those people who have dementia, the pain and the losses are compounded. Dementia can lead to intense anxiety that rises when thoughts are jumbled, repeated, or forgotten. There is the panic of not knowing how to get home or find a wallet or purse. There is the deep, long grief of knowing what is coming and that everything is only going to get worse. There is a painful awareness that control is being lost.

Lost-ness is seldom, if ever, a good thing. It's painful for all involved, and it can make us frantic and afraid. Yet, Christine Bryden, who writes about her own journey with dementia, reminds us that all is not lost. The human soul, the human treasure is always still there. "As we [persons with dementia] become more emotional and less cognitive," she writes, "it's the way you talk to us, not what you say, that we will remember. We know the feeling, but don't know the plot. Your smile, your laugh and your

touch are what we will connect with. Empathy heals. Just take us as we are. We're still in here, in emotion and spirit, if only you could find us."²

Lighting a lamp

The spiritual care task is to keep lighting a lamp and to illuminate the space around us, until we find what we are looking for: a spiritual and emotional connection to the person who is still in there. This connection, no matter how fleeting, communicates the message, *You are treasured and valued, loved and honored, and I'm celebrating that with you.*

There are some basic things to consider before and during a visit with someone who has dementia or their support people.


Know the person and the situation. It is important to know what kind of dementia the person has and how advanced it is. Determine whether there is a preferred time to visit. For some people with dementia, the hours before supper are the most difficult and may not be the best time to visit. In the early and middle stages of dementia, a person may have regular activities or routines that shouldn't be disrupted. Conversely there may be activities that the spiritual care provider can join in on. If visiting a long-term care home, call ahead so the staff can help the person be ready for the visit. Talk to family and friends about the person's accomplishments, career, joys, and hobbies; use this information in conversation with the person with dementia. It is also critical to find out about the family and caregivers to determine if they are receiving adequate support themselves and are not isolated.

Create success. Dementia is a failing of the brain; this means that words, instructions, memory, logic, and script are increasingly problematic. In supporting a person with dementia, it is important to make repeated adjustments, over time, so that the visit leads to good feelings rather than failure. As the disease progresses, avoid phrases like *You remember me, don't you?* Avoid testing a person's memory by asking them to provide details about their children or career. If the person with dementia cannot answer your questions, it can be embarrassing and discouraging. Instead, considering the stage of dementia, try weaving details that may trigger a memory into your own words. For example: *Marcie, it is so good to see you. I was just*

2 Christine Bryden, *Dancing with Dementia: My Story of Living Positively with Dementia* (Philadelphia: Jessica Kingsley, 2005), 138.

talking to your son Paul and thought I would just drive over from Yatton Mennonite Church to see you. I wanted to tell you about our church service on Sunday.

Connect through emotions and senses. The language of dementia is feelings and emotions. A person with dementia increasingly cannot access words, but their feelings and emotions are there. Spiritual care for persons with dementia needs to rely less on words and more on creating an experience. The presence, grace, kindness, and gentleness of the spiritual care-

 **The presence, grace, kindness, and gentleness of the spiritual caregiver will be felt even if the words cannot be comprehended.**

giver will be felt even if the words cannot be comprehended. So it is important to find ways to connect on an emotional level. Bring along some things that may produce a smile, such as a picture of a baby or puppy, a nice photo, or a fresh flower to celebrate the beauty of creation. Show joy at seeing the person. Delight in their surroundings. Walk together.

Be silent together. Laugh together with funny pictures or even toys. (I have a battery-operated cat that giggles while it rolls on the floor; it always gets a smile or a laugh.) Sing and repeat the first verse of well-known heart songs. Use familiar scriptures. Provide something to hold like a large print bulletin with a few short Bible verses, the first verse of a song, a picture, and a short prayer or blessing and go through it together. Play familiar music on your phone and just listen together.

Kathy, a resident experiencing end-stage dementia, celebrated her wedding anniversary one weekend. Days later, I ran into her. I sat down directly in front of her and said, “Kathy, I’m so happy to see you.” Kathy looked at me, and I said, “You had a great big wedding anniversary this weekend. How wonderful! Congratulations!” She smiled. “The girls were here and the grandchildren.” She kept smiling—no words. “And they all wanted to be here because they love you so much.” Kathy smiled and nodded. “It’s wonderful how your family loves you so much.” Kathy smiled, lifted her hand, and patted her heart. In this case there were no words that Kathy could speak, but there was so much that she could feel. She could remember love. This is an emotional and spiritual connection that is good for the heart and soul.

Consider sensory abilities. Many people experience changes in their eyesight and hearing as they get older. For a person with dementia, making eye contact is critical and requires you to sit at eye level, directly in front

of the person. Teepa Snow, a dementia educator, describes the vision challenges this way: In early dementia, a person loses their peripheral vision; they are seeing things as if through a scuba diving mask. In mid-stage dementia, it is as if everything is seen through binoculars. In late-stage dementia, it is as if you are looking through a monocle.³ Spiritual caregivers need to bear this in mind, get close, and sit in the line of vision of the person with dementia. There may also be hearing loss, which may require the use of a simple voice amplification system and a headset so that you can avoid raising your voice at the person. Having a pastoral visit in the nursing home living room may work sometimes; at other times, though, it is important to find a quiet place, like the chapel, so the person can more easily focus on the visit.

Celebrate. Emotional and spiritual connection with someone is always a gift. We can celebrate the courage and resiliency of people who are living with dementia—people who, despite the failure of the brain, smile brightly, hold a hand gently, participate in life, and love their family and the people around them. One can also celebrate and affirm family caregivers: partners, children, friends who faithfully visit and inspire us with their commitment, flexibility, and love. This is a beautiful thing; what an honor it is to be in the presence of such beauty. Prayers spoken during a visit can celebrate a lifetime of work, faith, and resilience. As lamplighters, we celebrate the human treasure in a person with dementia and thank God for them. This gratitude can be spoken at the end of any visit.

Conclusion

None of us knows how our years will unfold, and rarely do we know ahead of time that dementia will be part of our journey. I hope, though, that if I am ever living in long-term care and have dementia, someone like my pastor or an elder or a spiritual friend will come looking for me again and again. They will light a lamp and gently remind me of my faith and my hope, repeating words lodged in my distant memory. If I cannot chime in, they will speak the words for me, gently holding my hand. My spiritual care provider will express hope in the simplest of words and in so many different ways. If I cannot pray, they will pray for me. They will know about my life, my accomplishments, my gifts, and my struggles, and they will honor me. They will love my family and support them as they

³ See Teepa Snow, “Dementia Video: Changes in Vision,” <https://youtu.be/iaUsRa5kNyw>.

support me. If I do something unexpected or awkward, there will be so much grace. My pastor will remind me of how God sees me, in case I have forgotten. My spiritual caregiver will search for music that speaks to my soul, music I have always loved, music like the new song from *Voices Together*, and they will sing it with me:

*God lights a lamp,
And she searches ev'rywhere
For the hidden, lonely heart.
God lights a lamp,
And she searches ev'rywhere.
When she finds you, oh, she sings:
"I have found my treasure, my precious silver coin.
I have found my love!"
Even angels will hear the news,
What once was lost, is found.*

And I will draw on all my strength—perhaps managing just one raspy note—and we will sing together. We will have a connection. My whole being will be singing, and for one brief, wonderful moment, we won't be lost at all. We will hold the lamp together. And, as with that parable of the woman finding her lost coin, all of heaven will rejoice with us.

About the author

Ingrid Loepf Thiessen lives in Kitchener, Ontario. She graduated with an MDiv from Anabaptist Mennonite Biblical Seminary and previously graduated from Canadian Mennonite Bible College. She has worked as a pastor and has spent the last fifteen years working as a chaplain in long-term care homes. As a child she enjoyed simply being in the presence of her Great Aunt Maria (her Tante Michi). This may have paved the way for her life's work. She counts it an honor to spend time with people in the final years of their lives. She is married to Jim, a pastor, and they are parents of three adult children. Ingrid enjoys singing and all kinds of music-making, cooking, and a not-too-hard Sudoku. Recently she has found great joy in witnessing the many miracles that a garden provides every day.