

Dementia and Faith

Lumina is committed to loving like Jesus and partnering with the Spirit in affirming the meaning and purpose of lives touched by dementia. We tell a powerful counter story of God's creation in which cognitive changes do not separate us from God's love, nor dismiss our ongoing vocation as human beings.

At the cross section of dementia and spirituality basic questions of faith and life arise. What happens if I forget who I am? What if I forget who God is? Theological quandaries can threaten the spiritual well-being not only of those living with dementia but also their care partners. When the flotsam and jetsam of life and faith crowd the narrowing experience of dementia, we may experience theological logjams we've never thought of before. A practical theology of dementia respects the real emotion out of which these questions are born, while holding out hope firmly based in God's story and Jesus' example of love.



Being and belonging are core to our experience as human beings. How we understand personhood and belonging forms a sense of self and impacts well-being. Narratives of personhood played out in society, in subcultures and communities, in families and even within oneself form our worldview in ways we don't realize. Ask yourself what and who are valued by western culture in general and you can begin to see why the impact of dementia is felt not only medically, but socially, emotionally and spiritually. If the metanarrative of society insists on productivity, intellect and independence, we are tasked with telling and living out the powerful counter story of God's creation.

Jacob was sitting in the chapel waiting for the Good Friday service to begin, his focus fixed intently on the region around the right wheel of his chair. This is not unusual for Jacob and one might wonder how much meaning he will gain from the liturgy and music of the service. Is there a possibility of spiritual connection? How we see the Jacob's of our world can make all the difference.

As spiritual beings, the sum of our being lies much deeper than our capacity to do or think. Theologian John Swinton leans into the implications of Psalm 139 to form a counter narrative about our identity and value. "If God knew us when we were still in the womb, and if God does have plans for us to prosper, then neurological decline cannot separate us from the love of God and our ongoing vocation as human beings. The powerful counter story out of which we form our practice begins with assumption since we are made in God's image¹, all of humanity is invested with a nonnegotiable dignity deeply rooted in God's endless love.¹

A practical live-out theology of compassionate care for those living with dementia include the communities in which they live. Together we lean into God's love. We confront fears, lament what is lost and focus on what remains. Fear is a common and understandable response to the realities of dementia. How we deal with fear as individuals and as a community directly impacts the quality of care and community provided. Fear negatively impacts our capacity for intimacy – the safe loving relationships which all of us need to thrive despite our losses². Fear blocks our responsiveness to others and depletes energy available for loving

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others.³ It is God's first love for us that empowers us to move beyond fear⁵ to ourselves dwell in and invite others into safe places of love and acceptance.⁴

A care partner sat beside Jacob, bringing the bulletin for the service down to his visual field, his focus shifted and his bodies rose along with the paper until they could connect with a smile and a greeting. Handing him his own bulletin, the care partner signaled to Jacob that he was a welcome participant in the worship service.

The language we use can help to create the counter story of nonnegotiable dignity we need to tell. This language includes both celebration and lament. Lament helps us to name the difficult realities of brain changes in a way that “draws the sting of bitterness and opens up the possibility of reconciliation with God, with one another, and with oneself.”⁵ From lament we turn to the celebration. We are beloved not because of what we do, or know, or remember but because we are created by God.

Our vocation as human beings assumes the possibility for spiritual connection even when we can't see it and even when it looks different than before. These changes can be most keenly felt by care partners, family and faith communities. Adapting attitude and actions rest on the supporting communities. Theologian and author John Swinton writes, “each encounter between human beings is an encounter with the Holy” and it is as we “remember the holiness of the person with dementia that we act in sanctified ways.”⁶ The work of creating a supportive and spiritual stimulating community requires attentiveness and intention.

Throughout the service, the care partner pointed to the liturgy or hymn and began to notice that Jacob was tracking with the service, following the words of the liturgy and lifting his gaze to the pulpit. Now and then a word or phrase came a half step behind but in tune with the flow of worship.

Understanding the person helps us to better facilitate spiritual connections that honor their own faith journey. In focusing on what is still available to them, we endeavor to provide meaningful and accessible spiritual connections that incorporate the personal and corporate practices of their faith tradition. We also acknowledge that what connects with one person can change from day to day or person to person. Providing spiritual care for those living with brain changes seeks to be present rather than seeking specific results. We assume that the Holy Spirit is active even when it isn't humanly evident.

At the close of the service, the care partner knelt at Jacob's side. With alert eyes and a small smile, Jacob said a simple, “Thank you”, as a tear slid down his cheek. He might not have sung the hymns or understood the words of the speakers, but spiritual connection happened in that service and in the moment of deep gratitude.

1. *Genesis* 1:27

2. Swinton, John. *Dementia: Living in the Memories of God*. pp. 20

3. Nouwen, Henri J. M. *Lifesigns: Intimacy, Fecundity and Ecstasy in Christian Perspective*. Doubleday, New York, NY, 1990. pp. 30

4. Benner, David G. *Surrender to Love: Discovering the Heart of Christian Spirituality*. Intervarsity Press, Downers Grove, IL, 2003. pp. 40

5. *I John* 4:7-18

6. Nouwen, Henri J. M. *Lifesigns: Intimacy, Fecundity and Ecstasy in Christian Perspective*. The Crossroad Publishing Company, New York, NY, 1992. pp. 39

7. Swinton, John. *Racing with Compassion: Pastoral Responses to the Problem of Evil*. Wm. B. Eerdmans Publishing Co. Grand Rapids, MI, 2007. pp. 118

8. Swinton, John. *Dementia: Living in the Memories of God*. Wm. B. Eerdmans Publishing Co. Grand Rapids, MI, 2012. pp. 222

