Dementia as Living Death and Defeated Enemy

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In her essay, "Finitude and Death," Katherine Sonderegger writes that "the definition of creaturehood is finitude and death."[1] In some way, we all know this. "Change and decay in all around I see," wrote Henry Lyte in his well-known hymn, "Abide with Me," reminding us that this is the rule of life, not the exception. The peculiar thing is that while most persons in the United States would agree with the fact that change, decay, and death are guaranteed, many live as if these realities can be avoided. In particular, many of us live as if we are in charge of when we will die, as if we control our lives and therefore our deaths. In short, we live in a way that denies the basic human fact that we are creatures who are simultaneously living and dying.

The denial of this dual reality is almost certainly grounded in the human fear of death. No one minds discussing our living, but almost everyone avoids discussing our dying. When dying appears to us in various ways, the human instinct, perhaps particularly in the West, is to avoid it. But as Christians, we know that death is a conquered enemy; it does not have the last word. So what might it look like to approach manifestations of dying that we see around us not by looking for ways to overcome the force of death, but by recognizing that it has already been overcome in Christ? This essay will consider this question through one dreaded manifestation of death that we encounter: dementia. I will offer theological thinking and practices that help us look diseases like dementia square in the face, recognizing the horror of this living death and

[1] Katherine Sonderegger, "Finitude and Death," in *T & T Clark Companion to the Doctrine of Sin* (New York: Bloomsbury, 2016), 385.

claiming the victory over it that we have in Christ. If perfect love casts out fear, then Christ's love for us shown in his death and resurrection ought to offer us the opportunity to cast out our fear of death and allow us to minister well to God's people who suffer with diseases like dementia.

Dementia

Dementia is the umbrella term for various disorders that are the result of abnormal changes in the brain. According to the Alzheimer's Association, these changes "trigger a loss of memory and other thinking abilities severe enough to interfere with daily life."[2] This decline in mental ability that disrupts normal life skills is the single common denominator in all forms of dementia and is a primary diagnostic criterion for the disease.

Dementia and its accompanying symptoms come with unique cultural and societal challenges, not the least of which is convincing Western culture that persons with dementia have inherent worth. Persons with dementia do not tick any of the cultural boxes that would grant them power or even personhood. They are often old, they are weak, they are dependent. Western culture values productivity, independence, self-sufficiency, and power. By contrast, Samuel Wells writes that Western culture associates dementia with deficit, decline, and death.[3] Dementia, in other words, represents the loss of these key cultural values and therefore presents a fundamental threat to what is most important to us. Indeed, Christian physician and ethicist Dr. Lauris Kaldjian asserts that "it is not too strong to suggest that in our society, dementia stands as something of a cultural insult."[4] In part, this is because dementia raises the specter of death before us every time we encounter these persons. Wells writes, "Our society looks on dementia as a living death,"[5] and this presence of death among the living frightens us.

Scripture is familiar with a category of living death. In the world of the Old Testament, for example, death was an ever-present reality and a constant threat to the life God intended for his people. The life God intended was life in his presence as symbolized at the end of the book of Exodus when God's

[2] https://www.alz.org/downloads/facts_figures_2014.pdf.

[3] Samuel Wells, "Dementia and Resurrection," *Christian Century* (April 1, 2015): 33.

[4] Lauris Kaldjian, "Dementia, Decision Making, and the Image of God: Assessing the Impact of Foundational Beliefs on Goals of Care," unpublished paper.

[5] Wells, "Dementia and Resurrection," 33.

glory fills the tabernacle in the center of their camp. Indeed, God's presence with Israel was, according to Gordon Wenham, the "highest of all divine blessings."[6] The fullness of life for Israel was dependent on God's presence with them. God is the God of life, not death. Thus death, as understood in Israelite law, was an intruder that would render the Israelite camp "unclean" and jeopardize God's presence in Israel's midst.

Death came to Israel in various forms. As expected, animals and people die. When this happened, however, something had to be done to cleanse the camp of the impurity that had invaded. In the case of human death within the camp, whoever touched the dead body became unclean, as did the tent and the contents of the tent in which the body was found. The polluted person must go through a ritual of sprinkling himself or herself with the "water of cleansing" described in Numbers 19. In addition, the tent and all the people and furniture in it must also be sprinkled. Failure to cleanse oneself would defile the tabernacle and the offending person would be "cut off" from the community, essentially placed in the realm of death outside of the camp, rather than in the realm of life within.

Physical death was not the only form of death that could encroach on the camp or render persons unclean. Childbirth, bodily discharges including normal discharges of semen and menstrual blood, as well as various skin diseases would render a person unclean. Where the skin diseases are concerned, Jacob Milgrom suggests that the impurity associated with these conditions has to do with their association with death. He also notes the similarity in purification rites between the corpse-contaminated person and the person with the skin diseases listed in Leviticus 13.[7] The person with the skin disease was visually associated with death and thus treated like one who had come in contact with death and been infected by it. The person therefore straddled the boundary between life and death, both conditions being present in his body.[8] This person was associated with living death.

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[6] Gordon Wenham, *The Book of Leviticus* (Grand Rapids: Eerdmans, 1979), 18.

[7] Jacob Milgrom, *Leviticus 1–16: A New Translation with Introduction and Commentary,* The Anchor Bible, vol. 3a (New York: Doubleday, 1991), 819.

[8] For more on this see Mary L. Vanden Berg, *Christ's Atonement: The Hope of Creation* (Ph.D. diss., Calvin Theological Seminary, 2008), 83.

Unlike many people in our culture, Israel did not deny death. The rituals instituted by God forced Israel to recognize death for the horror that it is and the threat it poses to the community and to deal with it head on. Death is in fact associated with many of Israel's ritual regulations, and some form of cleansing from the impurity of death is the way to restore the person who has been defiled by death to life in community again. David Stubbs agrees with this assessment of cleansing, writing that the purpose of cleansing is "to move people and things from a deathlike state where corruption reigns to a renewed life, to a new creation."[9] The reality of the power of death was always with Israel. It could not, and should not, be denied. Recognizing and dealing with the reality of death allowed for the restoration of the camp as the place of life.

I do not think it is a stretch to see the connection between the persons with certain skin diseases in the Israelite community and persons with dementia today. Both in some ways represent the decay and corruption that could be associated with living death. The question for the church today is twofold: how do we theologically understand the living death of persons with dementia, and what might a pastoral response entail?

While it may be obvious, theologically we need to remind ourselves that death is an enemy as it was for Israel, but it is a conquered enemy. It is Holy Saturday as I write this, and although this was a dark day for Jesus' disciples, we know that the next day we celebrate God's ultimate victory over the threat of death through the resurrection of Jesus Christ. Indeed, even before his death and resurrection, Jesus demonstrated that death had no ultimate power. When Jesus touched those infected with death because of skin diseases, not only was he not infected by death, but the persons he touched were made immediately clean. Likewise, the living death of dementia still has sting both for the person experiencing it and for her caregivers. But it does not have the victory.

All of this talk about Christ's victory over death and death-like conditions is wonderful and full of hope, but what does it mean for how we care for people afflicted with dementia?[10] The first and likely most obvious implication for care

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[9] David L. Stubbs, *Numbers*, Brazos Theological Commentary on the Bible (Grand Rapids: Brazos, 2009), 156.

[10] While I am dealing here with dementia, this "living death" could include any number of other conditions and diseases characterized by ongoing decline. I think that it also has implications for how we care for our elderly.

is that, while it is normal to fear death, we must not let our fear put these people "outside of the camp," so to speak. Death's power has been obliterated by Christ. It can no longer infect a community, threatening life in the presence of God. Persons with dementia and their caregivers should be encouraged to participate in the visible church for as long as they are comfortable doing so. That might mean there are disruptions in our worship services or that we may need to accommodate certain practices to help them participate. For example, if your ecclesial community is used to going forward to participate in the Lord's Supper, perhaps you will need to designate someone who can bring the elements to persons with dementia who are unable, for any number of reasons, to move to the front. In a similar vein, a colleague shared with me a story of a husband in his church who gently led his wife with dementia forward for the Lord's Supper, helping her take the bread and dip it in the cup. This and other analogous practices could be encouraged for caregivers. Many churches are already learning to make accommodations for persons with disabilities, so encouraging persons with dementia to continue to participate in public worship with the community of Christ should not be a totally new concept. Having vulnerable persons in our midst reminds us of our own vulnerability and weakness, a reminder that helps us all recognize our need for Christ.

Inclusion of persons with dementia in public worship is also counter-cultural. Our culture worships power and ability. Weakness makes us uncomfortable. But God tells us that his power is made perfect in weakness (2 Cor 12:19). In Galatians 6, Paul writes that his only glory is in the cross, the ultimate sign of weakness. To eliminate the person with dementia from our worship diminishes the glory of weakness that God showed us in the cross, and is in some way also made present to us through these people. The cultural story of independence, self-sufficiency, and self-creation is a myth. We are neither independent nor self-sufficient. Our very lives are completely dependent on the mercy of God. Sitting next to someone with dementia reminds us of this and opens all of us to what John Swinton calls "the prophetic witness of weakness."[11]

Likewise, we do not create our own story. We receive our story as a gift. God's people are people whom God has called out from the chaos of the world into his story, into life with him. Our story is not ultimately the story of our

[11] John Swinton, *Dementia: Living in the Memories of God* (Grand Rapids: Eerdmans, 2012), 242.

achievements and failures. It is the story of what God has done and is doing with and through us, including those of us with dementia. Indeed, as the Christian community we recognize that, as the sixteenth-century Heidelberg Catechism (Q&A 1) asserts, "We are not our own but belong, body and soul to our faithful Savior Jesus Christ." Weekly worship reminds us of this basic truth. The person with dementia needs to hear this and experience it as much as the rest of us.

So what happens when persons with dementia can no longer worship with the community? Perhaps they can no longer move around easily or get into a car. Or maybe they have become combative and are difficult to be around. Or what about when they no longer recognize you or anyone else from the church? Bring the church to them.

By "bring the church to them," I am not suggesting that we occasionally bring them communion or visit them, although those are good things. Rather, I am proposing that we figure out ways to involve them in regular worship. During Covid-19, many churches began to livestream their worship services or provide songs and meditations on YouTube. Churches could remind caregivers that these resources are available and could be helpful for keeping their loved one connected to worship.

Another alternative for bringing the church to them could be to set up a rotation of groups of two to three people who would go to the person with dementia each week and worship with them using the livestream or other resources from the church. If the person is being cared for at home, this could have the side benefit of allowing the caregiver the opportunity to go to church. If the person is in a care facility, perhaps it would be possible to gather with several other church members in the same facility to worship together, if the rules of the facility allow for that. Don't be afraid to ask families to serve as volunteers for these services. Activities like this are a wonderful way to help children see how the church displays the love of Christ to the weak and powerless. If a full hour of worship is too much, the volunteers could just read a Scripture text, sing a few songs with the person or persons gathered, and pray together. The key is to do this regularly—not four times per year or once a month, but at least bi-weekly and preferably weekly. Remind the person often at these worship times that God will never forget them (even though they might

not remember God): "See, I have engraved you on the palms of my hands" (Isa 49:16).

In addition to involving these persons in worship, churches need to continue to help the congregation to be aware of persons with dementia, particularly once these people are no longer able to regularly attend worship. I have heard from some caregivers that, unlike people who have been hospitalized, or who have cancer, or have another illness, their loved ones with dementia rarely get prayed for by name in congregational prayer. It is almost as if, since the person with dementia no longer remembers the congregation, the congregation has permission to no longer acknowledge this person's needs in prayer. While there is no hope for improvement, let alone a cure, they need the prayers of God's people as much as anyone else. They should, with the family's permission, be included by name on prayer lists as well as in public intercessory prayer.

Churches could also encourage their members to find time to visit persons with dementia and their caregivers, praying with them, holding their hands, and reading the Bible to them. Often these people are quite isolated from others and are rarely visited. It can be intimidating to visit these people, but there are a number of guides that offer help. One of the best is Dr. Benjamin Mast's *Second Forgetting.*[12] He recognizes that it is not always easy to visit with persons whose memories are fading, but Mast offers some helpful suggestions for understanding the needs of persons with dementia so that these visits can be navigated well. Although these people may not remember your visit within moments of when you leave, the moments that you are with the person are meaningful to both the person with dementia and her caregiver.

Finally, we need to think more seriously about how to support caregivers. A pastor who is a friend of mine pointed out that there are entire industries set up to eject people from "the camp," to remove persons with dementia from view. Although there are certainly times when a caregiver, often elderly himself, simply cannot care for his loved one at home anymore, there are also times when caregivers are pushed to place the person in care before either party is ready. These cases are often accompanied with guilt and grief for the caregiver and increased confusion for the person with dementia. I know from personal

[12] Benjamin Mast, *Second Forgetting: Remembering the Power of the Gospel during Alzheimer's Disease* (Grand Rapids: Zondervan, 2014).

experience how complicated this is. Our family had to put my father into a nursing facility because my mother was no longer able to care for him. I can't help but wonder, however, if there were affordable alternatives that we overlooked that could have allowed him to remain at home and supported her better in her care of him.

Conclusion

In his book on dementia, Swinton writes, "It is easier to offer charity to people with dementia than it is to offer welcome." He explains, "Charity can mean giving alms to strangers—holding them at arm's length but convincing ourselves that we are acting compassionately. Welcome requires embrace, and rarely do we embrace strangers."[13] In the case of persons with dementia I would add that we fear fully embracing our parishioners with dementia because we fear the living death that they represent. In their weakness and finitude, we must encounter our own. As we learn to embrace these people, however, we will learn to better embrace our crucified Lord, whose life was characterized by weakness and suffering and whose final suffering on the cross culminated in his victory over death on Easter morning.

Every time we confess our faith—"Christ has died, Christ has risen, Christ will come again"—we declare this victory. As we come together to worship, and as we minister to those with dementia and other forms of living death, we must keep this victory at the forefront of our minds and the basis of our actions. Death has no power over us. It affects us, but it cannot contaminate us. It is a defeated enemy.

[13] Swinton, *Dementia*, 269.