



# Dealing Faithfully with Dementia: Scriptural Themes to Guide Us on the Journey

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It is estimated that around 50 million people worldwide have been diagnosed with Alzheimer's disease, with approximately 5.5 million of them in the United States. Once we take into account spouses and other close family caregivers, we can at least double the number of people whose lives are profoundly affected by the disease. Alzheimer's is only one of several kinds of dementia, and the number of people with all kinds of dementias is likely to increase exponentially in coming decades. This is because of an approaching population bulge in many parts of the world in the years when dementias become more prevalent, that is, sixty-five and older.

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Dementia tests the faith, hope, and love of all of us. The thought of having to deal with it bewilders and frightens many of us. Dementia challenges our usual ways of thinking about what it means to be human, how God relates to us, and how we relate to God. As dementia progresses, it also places huge demands on family caregivers and wider family structures.

One way to help us as we seek to walk well with those who have dementia is to remind ourselves of some key scriptural themes, including what it means to be in the image of God and the value of our physical selves for our identity before God and in relation to others. These themes are important, not just for how we *think* about dementia, but especially for how we *care for* people with dementia. From these themes we can reflect on good practices that honor the personhood and dignity of those with dementia. As we will see, we can become “guardians” of someone’s personhood on their behalf when they can no longer keep hold of their identity for themselves.

## OUR LIVES ARE HIDDEN WITH CHRIST IN GOD

But before we explore such themes, let’s acknowledge that dementia puts a question mark beside some of our most usual and most beloved ways of expressing our faith. A significant part of the beauty and wonder of what it means to be a Christian

is that our faith is so deeply relational. The eternal Son comes to us in the person of Jesus. Throughout scripture God relates to his people in ways that are deeply personal, summoning his people to respond to him in kind. To be a Christian means the awesome reality that the Triune God is in intimate relationship with us, and we with God.

How can we speak of knowing God and loving Jesus when someone no longer recognizes their spouse of fifty years? If they once professed Jesus as Lord, it seems that they can’t do that anymore, or not in a way that we can recognize. And what does the good news of our identity in Christ mean when advanced dementia seems to have robbed someone of any sense of their own unique identity? Add to this, if we have had an overly cognitive

understanding of what it means to be in the image of God, does the apparent disintegration of someone’s mind and memory call into question whether or not they are in the image of God, and so whether they are truly human?

As we seek a scriptural framework for understanding what it means to be human, especially in the situation of dementia, here are some verses to keep in mind.

First, consider Colossians 3:3-4: “For you have died, and your life is hidden with Christ in God. When Christ who is your life appears, then you also will appear with him in glory” (English Standard Version). *Your life* – who you are, your true personhood and identity – *is hidden with Christ in God*. To know that Christ holds our identity for us is crucial, not only to our perspective on dementia, but also as we think of the many ways that our culture seeks to define our identities, be that in debates around gender and sexuality, perceptions of race, or other pressures. God’s concern in the face of the many ways that our society seeks to determine our identity

is that we know and value the identity he defines and keeps for us as his permanently adopted children.

Also consider 1 John 3:2: “Beloved, *we are God’s children now*; it does not yet appear what we shall be, but we know that when he appears we shall be like him, for we shall see him as he is” (italics added). Especially in the situation of severe dementia, we must hold on to this assertion – those who have dementia continue to be God’s children *now*, even in dementia, even when what makes them who they are seems to have disappeared.

Both of these texts also remind us of something else that is very significant as we reflect on the situation of dementia: that while who we are now is extremely important, it is also penultimate. *All of us* are awaiting the fullness of who we will be.



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So, while we lament the apparent disintegration of personhood in someone with severe dementia, we all need to ask a rather peculiar-seeming question: Do you really know who you are?

The Christian answer to that for all of us is, only partly. Obviously, it is a truism that some people are more self-aware than others, but that is not what is meant here. None of us knows who we truly are because that cannot be known yet. Only God knows who we truly are now, far better than we can ever know ourselves, let alone anyone else. What's more, we will not be who we fully and truly are until we are with God in glory. Only then will all that is incomplete and broken about us be made whole. We are indeed God's children now, even in dementia, and our lives are hidden with Christ in God. Our personhood is kept safe with him, to be fully and finally revealed when we see him face to face and know him as we are known.

## **GOD IS THE GUARANTOR OF OUR PERSONHOOD**

This means many things as we think about someone with dementia. Above all, it means that we are not the guarantors of our own personhood. God alone is the guarantor of our personhood. If the time comes when I no longer know myself as "me" anymore, then this is wonderfully good news for me and for the people who love me. My perception of who I am can completely disintegrate, but it does not mean that who I truly am is lost. It is kept safe for me in Christ. We cannot ultimately lose our personhood, because it is not actually ours to lose.

But this also means – and this can be profoundly challenging for the rest of us – that the situation of someone with dementia is not so radically different from ours. It is simply the most extreme form of what is true for all of us. We do not fully know who we are, and in fact, we are not yet who we truly are. In our own walk of faith, we constantly forget our true identity as children of God. We do not always act in ways that are fitting for our personhood as brothers and sisters of Christ. We fail to recognize the Spirit of God when he calls us. Lacking trust, we live as if we have forgotten the history of God's prior goodness to us – his faithfulness in our lives and in our family's story, and in all that he has done for his whole family as we see this in the scriptures. One of the most unnerving things is not how different the person with dementia is from us. It is how many similarities there are between the person with dementia and us!

None of this is meant to take away the horror and pain of the situation of dementia, but it is to say that there are difficult truths for us all to face, and dementia confronts us with those in particular ways. Dementia also shows us very powerfully the sheer grace of the gospel.

The grace that is there for us when, day by day we forget God, and do not live fully into our identity as children of God, is there for the person with dementia too. While we forget God, God never, ever, ever will forget us, and he will come through on all his promises to us. This is because God's faithfulness is not grounded in or dependent upon us. Especially, it does not depend on what the person with dementia can no longer be and do. Just like his faithfulness to all of us, God's faithfulness to the person with dementia is grounded in his very self. This connects with attachment theory, and its significance in the field of psychology. God has put his people in Christ, thus his attachment to us is sufficient and permanent even though our subjective sense of attachment to God may vary.

Romans 8:31-39 is particularly powerful in this context. It reminds us that nothing in life or in death or in all of creation can separate us from the love of God in Christ Jesus. Dementia cannot do that, no matter how deeply it ravages someone's mental capacities. This is particularly important when a person with dementia no longer seems to know Christ, or, as can sometimes happen, when a person says terrible words, maybe even blasphemous words, as

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their dementia deepens. I have had people ask me in tears if their mother or father has lost their salvation because of the things that they have said in the depths of dementia. This is the disease. It is doing terrible damage to the brain and to the person. The consequences can be horrendous to see and to hear. But *nothing in life* (or in death) can separate us from the love of God in Christ. Christ will carry them through even this.

A little earlier in Romans 8:26-27 we also have a powerful reminder of how we can trust that the Holy Spirit continues to be at work in and for the person with dementia, and those who love and care for them. Paul presents the Holy Spirit as the one who intercedes in and for us when we cannot. The Spirit is interceding when all a caregiver can do is weep. The Spirit is praying in and with the person with dementia when all they can do is groan. The Triune God does not abandon someone with dementia; he is alongside those who love them. Our gracious God is faithful even when we cannot be.

## **WE CAN BECOME GUARDIANS OF SOMEONE'S PERSONHOOD**

While God is the *guarantor* of our personhood, and it is in this that we rest our ultimate hope for people with dementia, we can be *guardians* of their personhood now, in the meanwhile. To get a sense of what this might mean, here is another question that might seem rather curious:

What makes you who you are? What makes you “you”?

When we hear that question, most of us jump immediately to “inward” things, such as our ancestry, personality traits, and personal preferences. But it shouldn't take long for us to realize that none of us would be who we are apart from the people who share our lives to varying degrees. Likewise, we soon realize that a significant part of what makes each of us unique is how we express that outwardly. Think of things like the clothes you like to wear, whether you have a beard or not, the way you do your fingernails, your hairstyle, your favorite watch that never leaves

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your wrist. We shouldn't trivialize these kinds of things about ourselves. We are whole people, body as well as soul, and our physical aspects are very important in the situation of dementia. These outward things become key expressions of someone's personhood and dignity as inner awareness of themselves begins to crumble away. The deeper the relationship we have with someone who has dementia, the more aware we will be of these various facets of what makes them who they are, and the better guardians of their personhood we will become as the disease progresses.

As Christians we can draw on deep roots for this understanding of our identity as relational. We also have a holistic awareness of a person that goes beyond simply equating personhood with mind. Scripture gives us a foundation to push back vigorously against any understanding of personhood that reduces someone to simply a thinking individual, and thus moves toward categorizing someone with dementia as a non-person.

First, we need to remind ourselves that God has made human beings for relationship. This, and not reason, for example, is at the heart of what it means to be in the image of God. Nowhere in scripture is the image of God identified with any single faculty or capacity that we possess. Genesis 1:26-28 makes it clear that what distinguishes human beings from all other creatures is that God sets us apart for a unique relationship with himself. It is especially important that God is the one who establishes this relationship. That is one of the reasons why the Bible indicates that the image of God persists in all human beings. We can distort the image of God in ourselves, we can reject our side of the relationship, but we cannot destroy the image of God because God, who has established a relationship with human beings, remains in relationship with us, even if we turn aside from him. This is true whether that turning aside is deliberate, or, as in the situation of severe dementia, someone may simply no longer be able to know about God's relationship with them or theirs with God. That the image of God is primarily about the relationship that God establishes with us,

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which can never be lost, is profoundly good news for people with dementia and those who love and care for them. No matter how badly this disease ravages someone's mind, they remain someone with whom God is in relationship. They continue to have the human worth that goes with being made in the image of God.

Besides having this primary relationship with God, we are also created to be in loving relation with one another. We cannot be who we are apart from the network of relationships in which we are set. This means that if the time comes when I am not aware of being me anymore, those other people who know and care for me can be guardians of who I am on my behalf.

When we are walking with someone down the dementia road, we hold their identity for them when they cannot keep hold of it anymore. So, every time we retell that special story from their lives and ours, every time the photo album comes out and you go through it with them, every time you put on what you know is one of their favorite pieces of music, you are re-bestowing their personhood on them when they cannot keep it for themselves. Very often it is only in the moment, but for that ten minutes or less, by grace the person with dementia may reconnect with who they are through what you say and do.

## THE IMPORTANCE OF PHYSICAL THINGS

There are all sorts of good things we can do in the early stages that will be beneficial for the person with dementia and will also help family and friends to be better guardians of their personhood as the disease progresses. Soon after a diagnosis is a great time for the person with dementia and their family to put together a scrapbook, including things like photos of places where they have lived, places they went to school, and favorite vacation spots, some church bulletins, something related to favorite hobbies, and so on. Include a list of favorite songs or kinds of music.

A memory box is another helpful idea. This is a shoebox containing about twelve small items that are deeply meaningful to the person. As a wonderful illustration of this, a gentleman with dementia would spend hours lovingly holding and stroking a pocket watch, smiling all the while. It was his favorite item to choose from his memory box. The watch had been his grandfather's, who had given it to his father, who in turn gave it to him when he turned twenty-one. No one knew how much of that history the gentleman could still recall, but his deep joy in that beloved object and his peace of heart while he held it were evident to everyone.

In the early stages of dementia, it is also good to help the person to rethink their devotional habits, to prepare for a time when written and spoken words will become difficult. Make a list of key Bible verses, hymns, and songs, and maybe also a compilation of favorite prayers, so that later, friends and family will have access to them when the person with dementia can no longer read for themselves. Also, think about getting something physical to be associated with prayer time. Our Roman Catholic friends may have rosary beads; a good suggestion for Protestants might be a prayer shawl or a hand cross. This new habit of feeling the shawl or holding the cross can become incredibly important later as a physical thing that is associated with prayer and the intimate presence of God, even if there are no more words.

As many of these ideas remind us, physical objects and our physical selves matter for our identity and wellbeing. This becomes all the more important in the later stages of dementia when memories fade away and words become few.

The importance of the physical should be obvious to us as Christians. We should have no hesitation in affirming that our full personhood is physical, not just spiritual or rational. Sadly though, some aspects of our culture and heritage can push us to-

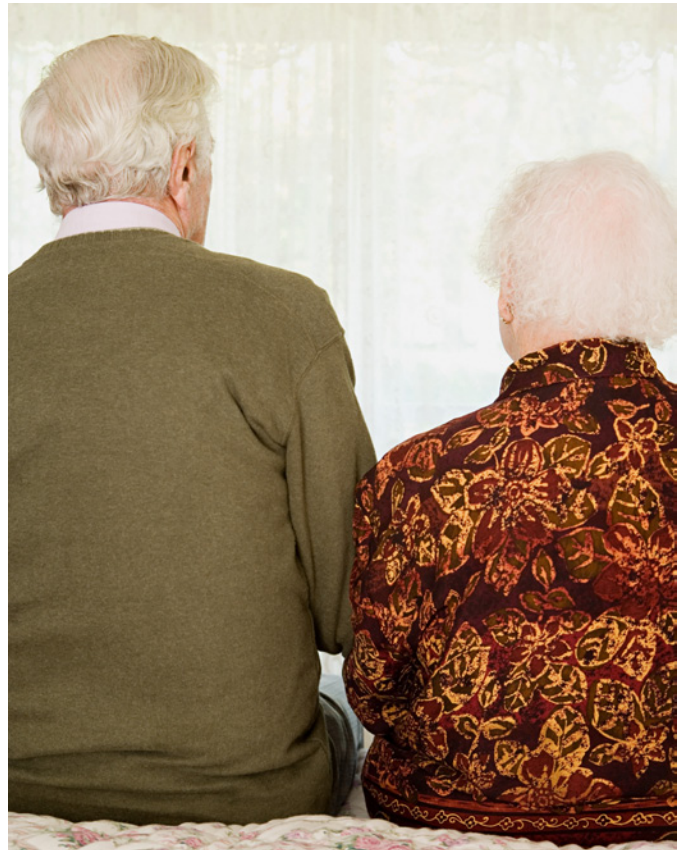


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wards denigrating the body and physical things to such an extent that we only see value in the mind and the spiritual. We need to be on our guard in case these tendencies become unscriptural. As Christians we must never let ourselves fall into any way of thinking that makes it seem like only our minds or our souls matter to God, and that he doesn't care so much about our bodies. Our bodies matter deeply to God. From the beginning God delighted in created physicality and called it good. Most obviously, in the incarnation the Son of God took on flesh for us, and his triumph over death is a *bodily* resurrection. Our bodies matter so much to God that he takes on a body and raises it to glory. That will be our future too.

This is extremely important when we think about the situation of someone with dementia, and when we try to honor and care for them as their minds disintegrate. For their sake and for those who love and care for them, we need to remember that the mind isn't all that makes someone who they are. It is obviously an enormous part, and we rightly lament the terrible losses caused by dementia. But physical things matter too, and our physical selves matter. When a friend of mine was struggling most with his wife's end-stage dementia, he spoke of how almost everything about her seemed to have gone, but it still gave him profound comfort just to look at her face. For all the inner change in his wife, "When I look at her face," he said, "I still see the same beautiful woman that I married."

Scripture confirms for us as Christians what the healthcare professionals insist upon in dementia care: that physical things are tremendously important to the personhood and dignity of someone with dementia. Part of walking faithfully with someone with dementia is to honor the physical side of who they are. The simplest of physical things show respect for someone's dignity and unique personhood, such as being able to wear their favorite clothes, or having their hair styled the way that they love. One of my favorite stories to show the importance of this is of an older gentleman who moved into a dementia care home. He was visibly distressed, as manifested in fretting with his hands. He was always plucking at his wrists. Staff at the care home assumed that this was simply one of the symptoms of his stage of dementia, when restless hand movements are common. But a friend of his, a guardian of his personhood, came to visit and knew what was wrong. Throughout his life, this gentleman had never thought he was properly dressed unless he had his cufflinks in! So the next visit, the friend brought a set and put them in. The gentleman smiled radiantly, patted his wrists, and visibly relaxed. His fretful hand gestures ceased and he was at peace. His friend told the care home staff, and from that day on, the cufflinks went in.

We also need to remember the importance of all the senses. Let's start with hearing. Many of us who have walked with people with dementia have experienced what the neurologists tell us about the extraordinary power of music. We have seen people

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who no longer know their spouse, but who can sing every word of every verse of a beloved hymn or song. We have seen people who seem to be completely unresponsive sit up and smile and even tap along when they hear a favorite piece of music. And then, touch. To be touched well is a beautiful gift. This is obviously something that needs great sensitivity and care, but a loving touch on a hand or an arm might be the only touch that someone receives all day that is not simply to do with toileting, bathing, dressing, or feeding. Sight is probably the most obvious for many of us. Looking at photos can prompt memories. Seeing a grandchild might not mean recognizing who she is, but it might transport grandma to the time when she was a young mom and prompt a flood of stories. Finally, don't forget the taste and smell of food! While taste perception does decline with dementia, still, as long as it is medically appropriate, the smell, taste, and texture of a favorite food can bring deep joy.

The more we know of the fullness of what makes someone who they are –very much including the physical aspects of their identity, not just their minds – the better guardians of their personhood we can be.

But as the disease progresses, what might have allowed someone to recover a sense of their identity, even if only for a brief time, no longer elicits a response. Even then – especially then – family and friends continue to be the guardians of their personhood for them. This may become an extremely demanding calling. It helps to keep us faithful in that calling if we realize that we have the great dignity and honor of holding something of the identity of the person with dementia on their behalf.

The response of the other person is never the only straw that we are clutching onto in order to preserve the fragments of their personhood. They are not the only keepers of their identity. We

play our part as guardians of their personhood by doing what we can to love the person with dementia and honor and preserve their identity and dignity, until God, who is the guarantor of their personhood, takes them to himself to be more fully who they truly are than we can know, until we see him too.

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## SUGGESTED RESOURCES

De Haan, Robert. *Into the Shadows: A Journey of Faith and Love into Alzheimer's* (2003). Grand Haven, MI: Faith Walk Publishing. De Haan, who was a Christian psychologist, describes his experience of caring for his wife from the earliest stages of her Alzheimer's diagnosis through to her move into assisted living and skilled nursing care.

Mace, Nancy L. & Rabins, Peter V. (2017). *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss*. 6<sup>th</sup> ed. Baltimore: Johns Hopkins University Press. This is regarded as the "go-to" book for caregiving advice.

Mast, Benjamin. *Second Forgetting: Remembering the Power of the Gospel During Alzheimer's Disease*. (2014). Grand Rapids: Zondervan. This author explores helpful and accessible ways to connect faith and scripture to the experience of people with dementia and those who care for them.

Swinton, John. *Dementia: Living in the Memories of God*. (2012). Grand Rapids: Eerdmans. This very dense book reflects on changes in medical approaches to dementia and the field of dementia care and explores a number of theological themes in relation to people with dementia.

Two websites with a great deal of information and many resources:

<https://www.alzheimers.net>

<https://www.alz.org>



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