

Alzheimer's & Grace

Stephen G. Post

*This seeing the sick endears them to us,
us too it endears.*

— Gerard Manley Hopkins

The author of Psalm 71 begs the Lord, "Cast me not off in the time of old age; forsake me not when my strength fails me." And in the Decalogue we hear this precept of the Lord: "Honor thy father and thy mother." Both the ancient prayer and the ancient command have been given a modern edge of urgency by the current increase in our life expectancy and the special illnesses that age brings with it. Among the most challenging of these illnesses is dementia.

A conservative estimate is that at least 30 percent of people over age eighty-five have Alzheimer's disease, the major cause of the dementia syndrome. The leading symptoms of dementia are, frankly, terrifying: loss of memory, of language, and of reasoning ability. We all feel at least a slight anxiety about dementia because these dreaded symptoms seem to assault our very identities, to dissolve the autobiographical narratives that constitute the very story of our lives. But are there hints of a deeper purpose underlying the universe even in the deep forgetfulness of dementia, hints for both those afflicted and those who care for them?

One lesson, for me, is that people with dementia remind us that we are all deficient in spiritual memory, that we are largely forgetful of the Creative Presence that set up a universe to give rise to creatures like ourselves. Religion is in large part an effort at memory enhancement through speech, symbol, and ritual. The Prophets were sent to *remind* Israel of its covenants with the Lord; Christians celebrate the Eucharist with the words of Jesus, "Do this in *remembrance* of me" (Luke 22:19). The Book of Common Prayer contains these eloquent words: "Heavenly Father, in whom we live and move and have our being; we do humbly pray you so to guide and govern us by your holy spirit, that in all the cares and occupations of our daily life we might *not forget you, but remember* that we are always walking in your sight."

St. Augustine is the great theologian of memory. His awe at human memory is clear in the tenth book of his *Confessions*: "All this goes on inside me, in the vast cloisters of my memory. In it are the sky, the earth, and the sea, ready at my summons, together with every-

thing that I have ever perceived in them by my senses, except the things which I have forgotten. In it I meet myself as well. I remember myself and what I have done, when and where I did it, and the state of my mind at the time."

Augustine saw memory as an aid to our salvation. Despite all our false pursuits of happiness in possessions or accomplishments, our hearts remain restless, seeking true happiness in God, and to aid that search there is within us a "still faint glow of light" that is nothing other than a memory, however dim, of a blessed state of true happiness that preceded the fall.

Those whom severe dementia has made deeply forgetful do forget much that is crucial to life as ordinarily lived: they may even forget those who love them most, and this is terribly painful to the forgotten ones. Yet they may have fleeting moments of a "still faint glow of light" when they recall vague traces of those who love them. We, who love them and are forgotten, may have by analogy some deeper apprehension of the life of the loving but unremembered God who, if religious thinkers such as Abraham Heschel or the "process" theologians are correct, calls out to each one of us, "Forget me not."

Observers estimate, and my personal experience confirms, that 90 percent of Americans who are diagnosed with dementia pray. They are, it seems, thrown back onto whatever faith they have in the loving and beneficent purposes underlying the universe. They are shaken existentially, and many begin this final phase of their lives with a profound recovery of spirituality.

I think of Peter, a member of a focus group in a project about coping with a diagnosis of Alzheimer's, who said, "Oh, I was devastated that I lost the technical ability to do my job and the sense of pride that comes into play. And I think pride sometimes is an evil factor because it weighs on your mind and it tells you that you are worthless and it kind of destroys your self-worth." Peter goes to his Roman Catholic church every Sunday, and every day he reads from a prayer book:

It's a daily prayer book and each day of the week it has a prayer. And every morning when I wake up I read the prayer for that particular day. And, like I say, before when I was working, I would never read anything like this. You know, it was the farthest thing from my mind. But now every morning I read it faithfully. Monday's prayer I happen to like most because it kind of applies to us here. Happy disease? It says my Lord God, I do not see the road ahead of me. I cannot know for certain where it will end. I know that you will lead me by the right road, though I might know noth-

ing about it. Therefore, I trust you always. I will not fear. For you are with me and you will never leave me to face my perils alone. And this gives me a sense of reassurance.

There were no such prayers prior to Peter's diagnosis. Indeed, his dementia has been accompanied by something like a spiritual conversion:

I'd say, why did you let this happen to me? I had such a good career. Everything was going fine for me. He would say to me probably, "Well, why did you fight it? I was trying to lead you in this direction." Oh, I didn't realize that. Well, I've come to the conclusion that everything has a purpose, so the Good Lord, He knows the best for you. So maybe this was to slow me down to enjoy life and to enjoy my family and to enjoy what's out there. And right now, I can say that I'm a better person for it, in appreciation of other people's needs and illnesses, than I ever was when I was working that rat race back and forth day to day.

Though dementia may seem to be an attack on the self, it has brought to Peter an unsought and unexpected discovery of self.

For many who are, like Peter, in the course of progressive dementia, litanies, prayers, and hymns often have a deep emotional significance. Perhaps more contemplative and spiritual capacities are elevated as the capacity for technical, instrumental rationality fades. It is evident that people continue to benefit from rituals that connect them with their spirituality. It is my belief that divine love never abandons the deeply forgetful, which is to say that it never abandons anyone and is therefore truly unlimited.

I recall an old Catholic man with advanced dementia who could not speak unless a rosary was placed in his hand and someone started to recite the words of the Hail Mary. Then, surprisingly, he would go through the entire rosary on his own, saying each prayer in order. The fragmentation of selfhood resulting from the deterioration of the mind requires spiritual mending. Is it possible that people with dementia might be spiritually enriched, even as they dwell within the depths of despair?

The Lord has purposes in the domain of dementia, however mysterious these might be. And these extend to caregivers, who in remarkable moral creativity work unselfishly with the remaining capacities of the deeply forgetful. Their love provides a kind of grace, and is itself often sustained by faith in a higher purpose. Caregivers can learn, in their difficult work, that persons with dementia are not so different from

the rest of us: they need to be loved, to feel good about themselves, to be respected, to be stimulated emotionally and relationally, to feel secure, to be included in activities, and to find moments of delight in the abundance of natural beauty.

A caregiver's immersion in what we might call the culture of dementia can bring to light the complicated emotional and relational experiences of those afflicted. There is the assertion of will or desire, usually in the form of dissent. There is the ability to express a range of emotions, including positive ones. There is initiation of social contact (for instance, a person with dementia has a small toy dog that he treasures and places before another person). There is affectional warmth—for instance, a woman wanders back and forth in her facility without much socializing, but when people say hello to her she gives them a kiss on the cheek and continues her wandering. There is a remarkable appreciation for pet dogs and plants, which has resulted in sections of many nursing homes implementing the so-called "Eden Alternative" of a naturalistic environment with friendly animals.

Individual memory and rationality may fail, but quality of life in community remains a moral and practical goal. Just as a lost limb can be replaced, to some degree, by a prosthesis, so the loving care of family, nursing home, and church can become prosthetics for the loss of fluency of tongue and mind.

But as more and more of us find ourselves called upon to provide such prosthetic support to afflicted parents, relatives, or friends, we may find it a challenge to remember that such patients are never less than persons. There is in most of us a spark of reason, and much was achieved for universal human moral standing by the great Stoic philosophers who emphasized this *logos* in us all. Yet their insight may lead us to arrogance, if we make the worth of a human being entirely dependent on rationality. As Reinhold Niebuhr wrote, "Since the divine principle is reason, the logic of Stoicism tends to include only the intelligent in the divine community. An aristocratic condescension, therefore, corrupts Stoic universalism." Equal regard under the love of God, coupled with the remaining emotional, relational, and symbolic-expressive aspects of persons with advanced dementia, leads us to reject the rationalistic outlook captured in the expression "I think, therefore I am." In its place a less arrogant conception is possible: "I feel and relate, and under God, I am."

People with cognitive disabilities need the sense of safety and peace that love creates; care for them must therefore provide loving attention, which reveals their value to themselves. We must set aside the distorted position that a person's worth, dignity, and sta-

tus as a human being depend entirely on cognitive capability. We must develop a view of personhood that takes into account the emotional, relational, symbolic, and even spiritual capacities of the person. We live in a culture that is dominated by heightened expectations of rationalism, clarity of mind, and productivity. We internalize these expectations; thus when someone we love is diagnosed with early dementia, our reaction is likely to be despair. Our goal, however, must be to remember that the deeply forgetful are neither “shells” nor “husks”; they have not become subhuman; they remain part of our shared humanity. About this we must be clear, lest we succumb to the banality of evil.

And there can be evil. Dementia is an affront to our values of hypercognition and economic productivity. Why tolerate “useless eaters” and “life unworthy of life”? In Berlin in 1939 the T-4 Project began under the direction of Werner Hyde, a professor of psychiatry. In T-4 an estimated 94,000 psychiatric patients (all of them “Aryan” and roughly half of them with dementia) were suffocated in gas chambers or left to freeze in vats of ice water as part of a research project on hypothermia. Public outcry in Germany put an end to T-4 in 1941, but the methods were transferred to Dachau and Auschwitz, where the authorities applied them to other so-called inferiors. We must never forget that the true authority, that of the kingdom of heaven, classifies no one as “inferior.”

A woman I know wrote me the following note after her father had passed away from Alzheimer’s:

Looking back over the years, we feel we did some things well, some things not so well. We realize times were often difficult. However, there were good times too, seeing his face light up when we walked into the room, seeing his smile, watching him laugh, seeing him enjoying music or some other activity, receiving those big hugs, watching him sleep so peacefully after hours of restlessness, hearing him say ‘I love you too!’ or when he was no longer able to speak seeing the love in his eyes as he squeezed your hand so tightly! Yes, these and other memories are cherished. We’re so thankful we were able to help him during his journey. All who knew him will remember his wonderful smile and Christian integrity. We’ve been told by many how he positively touched their lives in spite of, and even during his illness. We’re convinced an Alzheimer’s patient feels and yes, even comprehends, far more than we realize. Personally, we feel they never lose their need to be loved.

How in practice can we transmit to them our love and the love of God? As caregivers, we should talk

even to the most cognitively disabled, calling them by name and expecting a response (which, sometimes surprisingly, may come). We should speak with a warm and calm voice, with a joyful facial expression, bending down to make eye contact, communicating with them rather than around them. We can use pictures, music, hymns, Scripture, poetry, meaningful symbols, and short simple prayers. Above all, we can affirm the existence of the deeply forgetful, no matter how diminished that existence may seem. We are not obliged to reorient them into our reality, but we are obliged to be an attentive presence in theirs. Why? Because we remember not only the Psalm about aging and the commandment about parents, but also the words of Jesus about the infinite value of small acts of kindness: “Amen I say to you, whatever you did for one of these least brothers of mine, you did for me.”

Stephen G. Post is Professor of Bioethics at Case Western Reserve University and President of the Institute for Research on Unlimited Love (www.unlimitedlove-institute.org). He is also the author of Unlimited Love (Templeton Foundation Press, 2003) and The Moral Challenge of Alzheimer Disease (Johns Hopkins University Press, 2000).

St. Benedict After September 11

John M. Owen IV

Philosopher Alasdair MacIntyre closed his 1981 book *After Virtue* by posing what might be called the St. Benedict option. As a society, we retain the vestiges of traditional moral language but not the communities and practices that produced that language. Moreover, our elites think that justice has no grounding apart from individual feelings. The Enlightenment project of replacing tradition with self-grounding moral rules has failed, and no grand replacement has emerged. According to MacIntyre, such a society is “not waiting for Godot, but for another—and doubtless very different—St. Benedict.”

To conservative American Christians—evangelical Protestants and orthodox Catholics—MacIntyre’s diagnosis sounded right. Christendom, the *res publica Christiana* inaugurated by the Emperor Constantine