



Defending the Dignity of Those with Dementia

"When our ability to think rationally or choose freely becomes clouded or even eliminated by dementia, we still remain at root the kind of creature who is rational and free, and the bearer of inalienable human dignity."



I once heard a remarkable story from a woman named Cecilia sitting next to me on a long flight. She told me how her mother had suffered from dementia for many years, eventually reaching the point that she could no longer recognize any of her children when they would visit at the nursing home. She looked at me with a twinkle in her eye, though, when she added, "But there's always someone in there." When I asked what she meant, she continued:

"I love singing, and as an African-American, I've got a strong voice. I sometimes visit nursing homes near my house just to sing for the patients, to do something different and break up their routine a little. I still remember 12 years ago, I decided I would sing for my Mom. She didn't have a clue who I was, and didn't respond to much of anything, because the dementia was so advanced. She seemed almost catatonic. By chance I had come across one of her old hymnals with the Baptist songs we used to sing in church as kids. She used to know most of them by heart. Well, those old hymns stirred up something inside her, and after I started singing,

she suddenly picked up and began to sing along with me! Yup, there's always someone in there."

Cecilia's story about her mother runs up against a cultural tendency today, namely, to dismiss those struggling with dementia as if they were no longer persons. These patients, however, clearly deserve much more from us than the kind of benign neglect (or worse) that they occasionally receive.

Most of us probably fear ever getting a diagnosis of dementia for ourselves or for those we love. We worry about "surrendering our core" or "losing our true self" to the disease. Many of us wonder how our loved ones might treat us under such circumstances.

Steven Sabat, writing in *The Journal of Clinical Ethics*, challenges the reduced expectations for quality care for those with dementia:

"Is his or her personhood recognized and supported, or neglected in favor of the assumption that it barely, if at all, exists...do we assume that the afflicted rarely if ever recognizes the need for company, for stimulation,

Making Sense of Bioethics

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for the same sort of treatment he or she would seek and be given as a matter of course in earlier, healthier, days?"

Sometimes we may be tempted to view the situation from our own vantage point, rather than the patient's. In a report on care for the elderly, physicians Bernard Lo and Laurie Dornbrand put it this way:

"Family members and health professionals sometimes project their own feelings onto the patient. Life situations that would be intolerable to young healthy people may be [made] acceptable to older debilitated patients."

Sabat notes how this raises the prospect of reducing the patient to a kind of object:

"The dementia sufferer is not treated as a person; that is, as one who is an autonomous center of life. Instead, he or she is treated in some respects as a lump of dead matter, to be measured, pushed around, manipulated, drained, filled, dumped, etc."

The medical profession in particular faces a unique responsibility towards each individual with dementia, a duty to approach each life, especially in its most fragile (and uncooperative) moments, with compassion, patience and attention. When our ability to think rationally or choose freely becomes clouded or even eliminated by dementia, we still remain at root the kind of creature who is rational and free, and the bearer of inalienable human dignity. We never change from one kind of being into another. Parents who have children born with a serious birth defect or behavioral problem would never suggest that their defect or impediment transforms them into another kind of being, into an animal or a pet. It never renders them "subhuman," even though their behaviors, like those of advanced dementia patients, may at times be frustrating and very hard to bear. As Cecilia reminded me with such clarity on the plane, "there's always someone in there."

Pope John Paul II in a beautiful passage from *Evangelium Vitae* (*On the Gospel of Life*) speaks of "the God of life, who has created every individual as a 'wonder.'" We are called to foster an outlook that "does not give in to

discouragement when confronted by those who are sick, suffering, outcast or at death's door." Those suffering from dementia challenge us in a particular way towards the beautiful, and at times heroic, response of love, "perceiving in the face of every person a call to encounter, dialogue and solidarity."

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