

SOLIDARITY WITH THOSE SUFFERING

The Ethics of Dementia

Possibly one of the first things a student of Catholic ethics — or at least a student of medieval Catholic ethics — learns is the dictum *Virtus in medio stat* (virtue stands in the middle). The Aristotelian formulation of this principle recognizes that virtue entails a balance or proportion that can be destroyed either by the vice of defect or by that of excess.



**FR. THOMAS
NAIRN**

Aristotle himself used the example of health or strength and proposed that “either excessive or defective exercise destroys strength, and similarly drink or food which is above or below a certain amount destroys health, while that which is proportionate produces, increases and preserves health.”¹ This idea has come to be called the Aristotelian mean.

As we try to assess the responsibilities that those in Catholic health care and other caregivers have toward persons who are suffering from Alzheimer’s disease and other forms of dementia, I believe that this idea that “virtue stands in the middle” can be a helpful one.

THE VIRTUE OF SOLIDARITY

Simply put, solidarity implies that “all are really responsible for all.”² Normally, this has been interpreted within the context of social ethics, understanding that solidarity governs relations of interdependence aimed toward the common good. However, the church also has acknowledged that solidarity is a “moral requirement inherent within all human relationships”³ and also speaks of “intergenerational solidarity.”⁴

It was Pope John Paul II who described solidarity as a social virtue.⁵ If solidarity is indeed a virtue that affects relationships between generations, can the notion of the Aristotelian mean give some guidance to caregivers in serving those who suffer from Alzheimer’s disease?

THE VICE OF DEFECT: CONDONING NEGLECT IN THE NAME OF AUTONOMY

Americans have a love affair with autonomy. Autonomy is a foundational principle of contemporary biomedical ethics.⁶ Questioning it seems almost un-American. The idea of autonomy, however, carries with it the connotation of non-interference. As members of Catholic health care, we need to ask whether our respect for those in our midst who are aging should entail non-interference. Marshall Kapp, JD, MPH, at the time professor in the Medical School of Wright State University, Dayton, Ohio, has explained: “Placing too much reliance on empowerment of the elderly can lead, if we are not careful, to the implicit condoning of neglect of the elderly if they do not exercise their power sufficiently. Individualism and independence, if too rugged, may turn to health care nihilism.”⁷

Respecting the dignity of a patient with Alzheimer’s disease can never simply mean that caregivers demand the exercise of an autonomy that is more harmful than helpful to the patient. Rather, a true respect for the person entails an acceptance of the concrete circumstances in which the person finds herself or himself. Solidarity and

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respect do not deny the fact of increasing dependence, but they recognize mutual reliance and reliability.

When viewed from the perspective of the virtue of solidarity, what respect demands is an attitude of sensitivity and attention on the part of caregivers. Such an attitude will not usurp decision-making when people are capable and willing to exercise it. Sensitivity and attention thus will not interfere with the elderly person's autonomous actions when appropriate. This same attitude, however, means that caregivers do not force autonomy upon a person who is incapable of exercising it. The attempt to empower in this sort of situation can easily become abandonment — the neglect and “health care nihilism” that Kapp spoke about.

THE VICE OF EXCESS: OPPRESSIVE CARE

The other extreme can be called the vice of oppressive care. Stephen Post, PhD, director of the Center for Medical Humanities, Compassionate Care, and Bioethics at Stony Brook University School of Medicine in New York, describes oppressive care as forms of care based on the assumption that persons with Alzheimer's disease “are so disabled that they must be protected from the dangers and risks of life.”⁸ Post adapts his idea

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from the writings of Stanley Hauerwas, PhD, DD, the Gilbert T. Rowe professor of theological ethics at Duke Divinity School, Durham, N.C. In his original essay, dealing with those who have mental handicaps, Hauerwas explained that oppressive care “subjects the retarded to a cruelty fueled by our sentimental concern to deal with their differences by treating them as something less than human agents. Too often this strategy isolates the retarded from the rest of society in the interest of ‘protecting’ them from societal indifference.”⁹

This point of view adds the unnecessary isolation caused by the actions and attitudes of caregivers to the isolation that Alzheimer's disease already occasions.

Oppressive care concentrates on differences rather than similarities. It subtly — and often not so subtly — makes a distinction between “them” and “us” based on cognitive capacity. Ironically, this form of care enhances differences by “doing for” patients rather than being with them.

Even the usually legitimate desire for a cure for Alzheimer's disease can fall into the trap of oppressive care if it continues to call attention to cognitive ability as the primary means for determining what counts for quality of life. It diverts attention from what Post calls “the critical moral task of changing attitudes and providing forms of care that attend to non-cognitive aspects of the self.”¹⁰ If we believe that those with Alzheimer's disease for whom we care lack an essential quality of life simply because they lack cognitive ability, then we will do nothing to enhance the quality of life they are capable of enjoying.

THE VIRTUOUS MIDDLE

Between condoning neglect in the name of autonomy and oppressive care stands the virtue of solidarity. Post has suggested that when dealing with Alzheimer's disease patients, “the medicalized care of ‘doing to’ is easier but often less called for than the basic interactional care of ‘being with.’”¹¹ He continues:

“Care, building on the foundation of solicitude, includes joy, compassion, commitment, and respect: care rejoices in the existence of the person with dementia ... care responds supportively to the needs of the person with dementia ... care is loyal even as the loved one fades from the sphere of familiar self-identity and becomes al-

most unknowing and therefore unknown, but still remembered.”¹²

Such “being with” gets to the heart of the virtue of solidarity.

“Being with” also seems to get to the heart of Christian morality. Our Catholic moral tradition is a relational morality. As such, it can guide caregivers by recourse to the virtue of solidarity and the related virtues of justice and faithfulness. Bringing together solidarity and justice, the caregiver gives to the Alzheimer's patient his or her

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due. Bringing together solidarity and faithfulness¹³ motivates the caregiver to think outside of the box in asking what is due the person suffering from Alzheimer's disease.

What does solidarity in this context look like, practically? Kapp explains the importance of a "negotiated sharing of authority" between caregiver and patient that begins early in the course of the disease.¹⁴ Similarly, Post articulates six principles that he describes as the core of an ethics of dementia:

1. Something can be done for (and with) individuals with dementia.

2. Many factors can cause excess disability in individuals with dementia. Identifying and changing these factors reduce excess disability and improve functioning and quality of life.

3. Individuals with dementia have residual strengths. Working with them to build on these strengths improves their functioning and quality of life.

4. The behavior of individuals with dementia represents understandable feelings and needs, even if the person is unable to express them. Identifying and responding to these needs reduce the incidence of behavioral problems.

5. The physical and social environment affects the functioning of people with dementia. Providing the appropriate environment improves their functioning and quality of life.

6. Individuals with dementia and their families constitute an integral unit. Addressing the needs of families and involving them will benefit both the person with dementia and the family.¹⁵

As the virtue of solidarity moves the caregiver from "doing for" to "being with," it indeed becomes the virtuous mean between the twin vices of neglect of and oppressive care for the person with Alzheimer's disease. It is this Aristotelian mean to which we need to strive.

FR. THOMAS A. NAIRN, OFM, PhD, is senior director, ethics, the Catholic Health Association, St. Louis.

NOTES

1. Aristotle, *Nicomachean Ethics*, Book 2, Chapter 2.
2. Pope John Paul II, *Sollicitudo Rei Socialis* (1987), section 38.
3. Pontifical Council for Justice and Peace, *Compendium of the Social Doctrine of the Church* (2005), section 193.
4. See, for example, *Compendium of the Social Doctrine of the Church*, section 195.
5. John Paul II, *Sollicitudo Rei Socialis*, section 38. See also Karol Wojtyla, *The Acting Person* (Boston: D. Reidel Publishing Company, 1979), 284-85.
6. See, for example, Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (New York: Oxford University Press, seven editions between 1979 and 2012).
7. Marshall B. Kapp, "Medical Empowerment of the Elderly," *Hastings Center Report* 19, no. 4 (July/August 1989): 6.
8. Stephen G. Post, *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying* (Baltimore: The Johns Hopkins University Press, 1995), 9.
9. Stanley Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (Notre Dame, Ind.: University of Notre Dame Press, 1986), 162.
10. Post, *The Moral Challenge of Alzheimer Disease*, 11.
11. Post, *The Moral Challenge of Alzheimer Disease*, 8.
12. Post, *The Moral Challenge of Alzheimer Disease*, 8-9.
13. Post himself talks of "creative fidelity." See Post, *The Moral Challenge of Alzheimer Disease*, 8.
14. Kapp, "Medical Empowerment of the Elderly," 6.
15. Post, *The Moral Challenge of Alzheimer Disease*, 11.

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