This paper was discussed at the Council's September 2004 meeting. The views expressed here do not represent the official views of the Council or of the United States Government.

CAREGIVING AND THE AMERICAN INDIVIDUAL

Peter Augustine Lawler

According to many experts, American society is on the threshold of a crisis in long-term care. People are living longer and longer, but often at the price of living with severe infirmities-bodily or mental-that render them incapable of taking care of themselves for long periods of old age. At the same time, fewer and fewer people are available and able to care for them. The cost of that care is increasingly daunting, and fewer and fewer of us will be able either to provide it ourselves or pay others to provide it well for those we love.

But the crisis in long-term care arises not only from demographic shifts and shortages of manpower and money. It is, at bottom, a crisis of our culture, a crisis about "caring," a product of our society's opinions on freedom, dependence, and care. It is in part the expression of a peculiar irony of our time: The more we understand ourselves as independent of others and so isolated from them, the more dependent we ultimately become, and the harder it becomes to give and to receive the care that all human beings depend upon, especially in their old age. For now, we do not know how to deal with this crisis in caregiving in ways that will really do justice to the needs of dependent human beings.

America is a middle class nation, and it continues to become more middle class all the time. That doesn't mean that we're all equal economically, or that we're all equal when it comes to brains and virtue. It means that we all work-because we have to work-and that we are all free. We think all human beings have an equal right to work and no right not to work. And we think that to be free means not to be dependent on others or constrained by them. We are against all forms of servitude and dependence, and we often see no real difference between paternalism and despotism. Even the rights and responsibilities of parents are quite limited and temporary, and seen to be directed toward the end of freedom; our children are raised to be free and independent, to achieve on their own. Certainly we're freer than ever to escape from the burdens that society and even nature have imposed upon us.

Another way of putting this is that, more than ever before, we experience ourselves simply as individuals. The individual is distinguished by his or her freedom, a freedom from nature, from all we've been given-including even the constraints of bodily limitation, gender, senescence, and morality itself. The individual's focus is one's own personal existence as a free or autonomous being, pursuing personal self-fulfillment. The world exists, the individual thinks, for me, as you exist for me. In the beginning, there I was, and after me there is nothing.

But the view of ourselves as individuals remains far from complete. Despite our individualistic pretensions, we remain in many ways dependent beings. There's no way we can get all the care we need, of course, through merely calculated, contractual relations with others. Maybe government and the economy can be reduced largely to such consensual relationships, but it will always remain true, as Chantal Delsol observes, that "the amount of vigilance, care, friendship, and patience that must be given any person, if he is not to be driven insane or to despair, is almost literally incredible." "Nothing today," she adds, "is more depreciated than care-giving activities that go . . . unremunerated."[1] Individuals *as* individuals may often think of such lives of caring as unproductive or wasted, and often may not see themselves as in need of such care. Indeed, caregiving, more than ever, is viewed with contempt, because freedom for us individuals means giving and receiving as little of it as possible. The happiness given and received through caregiving does not appear to the individual to be real: Our goal is not to care for those who are suffering and dying-to help us live well with our natural disabilities-but to work hard to reduce and eventually eliminate the amount of suffering and dying in the world. The individual view is that whatever we experience freed from our physical limitations will be happiness.

Physicians (and nurses), from this view, are in some measure both producers and caregivers. They aim at eradicating suffering and pushing back death mainly through the method of cure. Curing is often, of course, the most effective way of caring, and it generates the feeling of accomplishment we associate with production. But once curing becomes impossible, and all that remains is the need for care, the patient typically is handed over to those who do the work of *merely* caring, or only keeping company with and meeting the seemingly ordinary needs of those who are beyond medical help. We, not without reason, rank curing over caring and view activities based on the thoughtful acceptance of our natural limitations below those that attempt to overcome those limits.

"The caregiver," we can still say, is a very different human type than "the individual." And the view of the caregiver and that of the individual are obviously both partly right. It's a tough question whether the saintly solicitude of the Sisters of Mercy or the physicians and technicians who introduced the latest medical technology into their hospitals did more to reduce the amount of suffering or to increase the amount of human happiness in the world. But they clearly worked best in combination. Almost everyone today is some mixture of productive individual and loving caregiver. Not so long ago, the individualistic, "productive" activities were characteristic of men, and unpaid caregiving was reserved for women (and all those with a religious vocation). That division of labor seemed to slight both the intellectual capabilities and the freedom of women; it is evidence of individual progress that we believe today that there's no reason why either a man or a woman could not both have a career and devote a good amount of time to the attentive and faithful caring for others. And the traditional roles of the ambitious man and the devoted mother are arguably combined in today's micromanaged, achievement-oriented parenting.

We have also, of course, turned more and more caregiving over to salaried employees, making it a species of production. Caregivers have become workers-social workers, health care workers, daycare workers, and so forth. When caregiving is combined with technical expertise-as in the case of nurses and some social workers-salaries rise to a solidly middle-class level. But when caregiving is seen merely as the unproductive maintenance of ordinary (including profoundly disabled) lives and so requiring no special technical competencies, compensation is stuck near subsistence. Ironically, the overall effect of turning caregivers into workers is to lower their communal standing and to reduce still further the honor we accord to *unpaid* caregiving. Our individual dream may be to turn all caregivers into wage-earners-so that all we individuals owe them is money for their services-but, in fact, our free economy would collapse under that burden. Our medical system depends more than ever, for example, on most of the care of the chronically ill being given voluntarily by women. We learn from Congress that, even in our individualistic time, "[f]amily caregivers are the cornerstone of our long-term care system . . . , providing 80 percent of all long-term care in this country," and that women provide "75 percent of all caregiving for family members."[2] Replacing "these unpaid family caregivers" with "paid home care providers" could cost hundreds of billions of dollars.[3] There's no denying that "the modern technological extension of the life span has put pressures most directly on women rather than on men."[4]

It is true enough that the ambitiously productive men who made history ruled over the largely invisible caregivers, who have left little record of their activities and even less of their happiness. But in more Christian and aristocratic times, there was much greater awareness that production and caregiving are both *valuable* and *incommensurable*. Caregiving, the thought was, need not be paid because its value is intrinsic, and women were able to work without personal wages and public recognition because they knew that everyone knew in one way or another the singular and indispensable importance of what they did. "Between child-rearing and prayer," as Delsol says, "there is but a step; between selling and prayer, there is an abyss." The lives of women (both wives and nuns) were thought to be both more ordinary and more spiritual than those of men. That's because "the women of yesterday knew no middle ground . . . between the banalities of daily life and the most profound wisdom." [5]

That "middling" way of life-the way of life of the productive individual who produces the means of happiness but knows little about the sources of human happiness itself-was the way of life of men. Even for much of our country's history, as Tocqueville noticed, American women were both less and more than middle-class American men, and he presented the true philosophers as allying with American priests and American women against the misanthropic excesses of individualistic American men.[6] One reason caregiving is such a problem for us is that we *all* think of ourselves now as middle-class-as free beings who work. So we tend to devalue everything below and everything above the realm of production. Below production, of course, are our invincible natural needs and limitations, and above it are the invincible spiritual dimensions of our lives. Caregiving is not something we merely do out of social instinct, as the sociobiologists and even Thomas Jefferson claim.[7] It is both the source and result of coming to know what's good about what we've all been given by God or by nature.

The decline of caregiving is more obvious when we look at the old than at the young. Raising children combines nurturing and ambition; our children can be the most satisfying project for the future. Their lives progress as we believe history and technology progress toward wonderful and indefinite futures. But to look at the old is to be reminded rather unambiguously of necessity, of our limitations, of what we human beings can't do for ourselves. There's no place for the old, for example, in David Brooks' two upbeat books about our achievement-driven meritocracy, just as there's no place for caregiving for anyone but our children.[8] Yet caring for-being attentive to-those in their declining years is a fundamental source of wisdom: "Aging, like illness and death," Thomas Cole says, "reveals the most fundamental conflict of the human condition: the tension between infinite ambitions, dreams, and desires on the one hand, and vulnerable, limited, decaying physical existence on the other-the tragic and ineradicable conflict between spirit and body."[9] We alone among the animals have longings that transcend the invincible limitations of our biological existence, and that truth is the same for us all. Caring for the old reminds us that we are neither autonomous individuals nor merely governed by social instinct or evolutionary psychology.

Due to the success of the modern individual (and modern medicine and public health), our country is older than ever before. Both our enlightened prudence about our health and progress in medical technology keep more of us alive than ever well beyond our reproductive and parenting years. At the time when we might think that evolution suggests the particular individual ought to go in the interest of the species or at least the next generation, we are freer than ever to say no. We work infinitely harder, of course, than the non-technological species at keeping particular individuals around. And we're also getting older because we, as individuals, are making the choice not to reproduce-or not reproduce much-more than ever. The good news is that we now "for the first time in history" have "large numbers of older people whose existence is centrally defined neither by work nor illness,"[10] not to mention parenting. An aging society-one increasingly in need of a particularly selfless kind of caregiving-is not particularly devoted to caregiving. It is one in which both sociobiology and spiritual devotion describe fewer and fewer of our personal experiences. It is one in which the Sisters of Mercy have just about disappeared. They too have grown old without replacing themselves, and the few young sisters are increasingly burdened by the old.[11]

We're getting older while being more repulsed than ever by the natural effects of aging. In our individualistic meritocracy, people are judged by how "smart and pretty" they are, and nobody is obliged to like or support or care for anybody else.[12] We live in "a culture of contingency," where fewer and fewer human ties endure.[13] Aging, on balance, is bad and eventually very bad for both our brains and our looks, and so to avoid isolation and loneliness we try harder than ever to fend off and mask its effects. Any technology that keeps us looking young has an immediate and huge market. We individuals are surely repulsed by the appearance of the old, in part, because it brings death to mind. But we seem to fear dependence even more than death, and the contingency of our independence impresses us even more than the contingency of our very lives. We know that a downside of living in a meritocracy is that it's not a good time at all to be stuck with depending on the love or charity of others.

For those used to thinking of themselves as free individuals, dependence-being unable to pay one's own way-is especially humiliating; we know too well that nobody really owes us a living. Increasingly, we think we want to be and have no choice but to be autonomous individuals. So increasingly we say that we'd rather be dead than lose our autonomy, and we readily sign legal directives making that clear. We work to be old, healthy, and wealthy, creating a world where it is in some ways worse than ever to be old and not healthy (or wealthy). But the truth is that we still really don't prefer death to dependent life, and that's why the choice for autonomy or death made when healthy does not predict what each of us would choose when death is actually "imminent."[14] Because most of us clearly would rather be frail and dependent than dead, there is worry that our success in prolonging life may turn society into "something like a giant nursing home."[15]

"Longer years of life," we too easily conclude, "decrease the relative period in which people are contributing economically during their lifetimes and increase the period of dependency."[16] A harsher way of expressing this thought is that insofar as we value productivity, we devalue the old. Productivity and creativity, on balance, are characteristics of the young. People retire for many reasons, but most often because they have become short on the desire and the ability required to keep up. What happens to basketball and baseball players in their thirties eventually happens to most of us. Retirement sometimes is and certainly should be understood in terms of new possibilities for making social contributions, but they tend to fall in the direction of caregiving, for example, in finding joy in encouraging the lives replacing ours. We can even say we know that the elderly "make substantial unpaid contributions" by providing care for grandchildren and long-term care for the disabled.[17] But we also readily distinguish that caregiving from their former productivity.

The wisdom traditionally associated with age has to do with our limitations, with being chastened by experience. For us free individuals, that alleged wisdom mainly gets in the way of progress; the prudence of the old is really their inflexibility, their inability to imagine new and better futures. We have a hard time thinking about *the point* of being old, although we readily choose it over being dead.

It is, as Carl Elliott points out, just as American to criticize "the cultural attitudes" that make anti-aging enhancements necessary as it is to have them. But "there is an air of futility" about all such criticism. The spiritual objection to caring enough about wrinkles to get Botox injections is trumped by very tangible benefits accrued by looking wrinkle-free.[18] We can't say that the choice is merely an aesthetic preference, because the choice to look young is also a choice for productivity. Members of the middle-class rightly complain that their freedom is limited by their need to work, but they also realize that their work increases their freedom. Various anti-aging enhancements may well come to be regarded as very reasonable conditions for employment. The choice against being as smart and pretty as technology allows is one for needless dependence on nature, and there is no obvious reason why employers or anyone else should honor such perverse choices.

It may be objected that choosing youth-and-vigor-enhancing technology shows how dependent we are on how we look in the eyes of others. The objection makes good sense, and we have no trouble making it. But it finally limps because

we lack a standard higher than productivity from which we could defend some other choice. We will do what we can to remain productive and independent for as long as possible.

It may be, as some have argued, that prolonging human life won't make us any more happy or fulfilled. It may even make us more miserable by detaching us further from the compensations of our natural purposes. It makes sense to say that the more we work to become autonomous individuals the less defined we will be by both religion and sociobiology and the more free and less happy we will be. Maybe it is also the case, as Audrey Chapman contends, that "the desires of some individuals for a longer life may be in conflict with the best interest of their society and/or the human community."[19]

But those are no reasons to believe that the trend toward working and choosing for ourselves won't continue. We will continue to devalue caregiving and caregivers, hoping to live as much as possible without them. The contribution of biotechnology to lengthening lives will merely be to reinforce these longstanding individualistic trends and successes. No even vaguely death-accepting policy has any chance of success, especially, of course, as the electorate continues itself to age. As the current debate about stem-cell research reminds us, there may well be no moral arguments that can stand up against even wildly exaggerated promises for future cures. According to Daniel Callahan, "Only a full-scale change in habits, thinking, and attitudes would work to make it morally and socially possible" for any "proposal to limit health care for the aged" to succeed.[20] And how likely is that?!

The ironic result of our increasingly individualistic habits, thinking, and attitudes is that we are stuck more than ever with giving and receiving care. More of us than ever are dying of Alzheimer's disease, an approximately decade-long process of decline toward complete dementia or, more precisely, a total regression to infancy. Caring for a child is full of the joy of seeing natural promise fulfilled; caring for someone with Alzheimer's is watching a being gradually being emptied of his or her distinctively human content, a slow and initially very conscious surrender of all independence. The explosion of Alzheimer's is one way in which we are victims of our own technological success; old and very old people suffer and die from it because nothing else did them in earlier. Because the incidence of Alzheimer's increases with age, the number of people falling victim to it will increase as we extend the length of life. Virtually any other form of debilitation and death would have been less of a physical and psychological burden on caregivers. Even if we figure out a way to cure or prevent Alzheimer's (a prospect that seems not on the *immediate* horizon), more people than ever will live long enough to experience some form of senility or dementia and the long-term care it requires.

An aging population requires more and more care both at home and in institutions. Meanwhile, small family size and rampant divorce mean that the burden of caregiving often falls on a single child or an elderly spouse (and more and more on rather elderly children[21]), and the result is that the family member must sacrifice very sizeable amounts of time and income at a time when a life devoted to unpaid caregiving may well seem like a wasted one. This burden increases all the time, and it's a testimony to the good natures of American women that they still so often accept, are ennobled by, and find happiness in it. But the young cannot help but grow more resentful that their otherwise free existence as individuals is more limited by the requirements of the old; "young people may question whether their futures should be mortgaged to care for those who are not making productive contributions to society."[22]

"The caregiver for the severely demented," Martin and Post observe, "must be a person of faith..He or she must have some trust that caring is a source of meaning in life," and such a faith is what the individual as individual lacks. But few of us are individualistic enough to affirm that faith's "only serious alternative, the destruction of the radically infirm."[23] From a caregiving perspective, we are stuck-in a middle-class way-between faith and the negation of faith, either of which would make our lives in many ways easier. Our anxious disorientation about what we are supposed to do provides plenty of evidence that we are more than merely individuals.

More often than we like to think, the middle-class person with Alzheimer's finds him- or herself without any reliable voluntary caregiver. The result is dangerous and needlessly disorienting for a while, culminating in relatively early institutionalization. The institutional workers given the allegedly merely "custodial" task of taking care of the needs of a person in constant, confused decline are inadequately trained and often just inattentive to the consequences of the changes in the person's capabilities and moods. There's nowhere near enough sense of the importance of this work. And there is too little appreciation of the human knowledge about the human need for care and attachment that this work requires and gives to those who do it well. Its satisfactions are both intellectual and emotional, and those who think of themselves as merely individuals stand most in need of its lessons.[24] Alzheimer's victims need, most of all, to be at home with large families or attended to by the Sisters of Mercy (or their equivalent), but both the alternatives have become rare in our individualistic time.

Surely there is little worse than to have Alzheimer's and be alone, and so we learn, more generally, that old men do not live as long as, but have on average a higher quality of life than, old women today, because they end up by themselves less often.[25] But the currents of our time do tend to push us almost inescapably in this lonely direction: Lives moved by a veneration of independence threaten to leave us unprepared for depending and being depended upon, and so to actually increase the burdens and the challenges of long-term care for the dependent in our society. The inability to think clearly about caregiving-and so the inability to provide as well as we could and should for a basic human need-may be a price to be paid for all the undeniable and wonderful technological success that characterizes our time.

---

1. Chantal Delsol, *Icarus Fallen: The Search for Meaning in an Uncertain World*, trans. Robin Dick (ISI Books, 2003), 150, 154.
2. *Long-Term Care Report: Findings from Committee Hearings of the 107th Congress* (June, 2002), 13.
3. *Long-Term Care Report*, 14.
4. Richard J. Martin and Stephen J. Post, "Human Dignity, Dementia, and the Moral Basis of Caregiving," *Dementia and Caregiving: Ethics, Values, and Policy Choices*, ed. R. Binstock, S. Post, and P. Whitehouse (Johns Hopkins, 1992), 62.
5. Delsol, 153-54.
6. Alexis de Tocqueville, *Democracy in America*, volume 2, part 3, chapters 10-12.
7. See, for example, Jefferson's letter to Peter Carr, August 10, 1787.
8. David Brooks, *On Paradise Drive: How We Live Now (And Always Have) in the Future Tense* (Simon and Schuster, 2004) and *Bobos in Paradise: The New Upper Class and How They Got There* (Simon and Schuster, 2002).
9. Thomas R. Cole, *The Journey of Life: A Cultural History of Aging in America* (Cambridge University Press, 1992), 259.
10. Robert B. Hudson, "The History and Place of Age-Based Public Policy," *The Future of Age-Based Public Policy*, ed. R. Hudson (Johns Hopkins, 1997), 7.
11. For the history of the Sisters of Mercy in America, John J. Fialka, *Sisters: Catholics Nuns and the Making of America* (St. Martin's, 2003). Pay attention to Fialka's remarkable stories of their early years and the facts about their decline; ignore his analysis.
12. This, I think, is the tough subtext of the Virginia Postrel's perky and libertarian *The Substance of Style: How the Rise of Aesthetic Value is Remaking Commerce, Culture, and Consciousness* (Harper/Collins, 2003).
13. See David Brooks, "The Power of Marriage," *The New York Times*, November 22, 2003.
14. Diane E. Meier and R. Sean Morrison, "Autonomy Reconsidered," *New England Journal of Medicine* 346 (April, 4, 2002), 1087.
15. Audrey R. Chapman, "The Social and Justice Implications of Extending the Human Life Span," *The Fountain of Youth: Cultural, Scientific, and Ethical Perspectives on a Biomedical Goal,* ed. S. Post and R. Binstock (Oxford University Press, 2004), 359. To support this conclusion, the author cites Francis Fukuyama, *Our Posthuman Future: Consequences of the Biotechnology Revolution* (Farrar, Straus, and Giroux, 2002). Fukuyama says that one result of our medical success is that more and more people are reaching a point "when their capacities decline and they return increasingly to a childlike state of dependency. This is the period that society doesn't like to think about., since it flies in the face of ideals of personal autonomy that most people hold dear" (68).
16. Chapman, 354.
17. Robert Morris and Francis G. Caro, "The Young Old, Productive Aging, and Public Policy," *The Future of Age-Based Public Policy*, 94.
18. Carl Elliott, *Better Than Well: American Medicine Meets the American Dream* (W.W. Norton, 2003), 283.
19. Chapman, 341.
20. Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* (Simon and Schuster, 1987), 158.

21. According to Fukuyama, we have "created a novel situation in which individuals approaching retirement age today find their own choices constrained by the fact that they still have an elderly parent alive and dependent on them for care" (68).
22. Chapman, 357.
23. Martin and Post, 58.
24. Martin and Post, 60-61
25. See Judith G. Gonyea,"The Emergence of the Oldest Old: Challenges for Public Policy," *The Future of Age-Based Public Policy*, 80.