

The Caregiving Society

Peter Augustine Lawler

In his stirring second inaugural on “America’s ideal of freedom,” President Bush called upon us to build “an ownership society.” “By making every citizen an agent of his or her destiny,” he declared, we “will give our fellow Americans greater freedom from want and fear.” With that vision in mind, he proposed to reform Social Security by bringing it under the control of each individual agent. Certainly, some reform is needed as individuals live longer, children become scarcer, and the baby boomers retire. And surely there is a large potential upside to making today’s workers active investors in their own retirements and deploying today’s assets in the entrepreneurial economy.

But there is also something deeply inadequate about viewing old age in terms of individual “ownership” of one’s own destiny. The aging society, after all, will confront us with the realities of human neediness. Freedom from “want and fear,” to the extent such freedom is humanly attainable, will require the old accepting the inevitability of their growing dependence on others, and it will require others who willingly accept the burden of caring for their elders, even at the expense of their own independence. The ownership society only makes sense if it prepares us to be *care-givers* and *care-receivers*, and if it does not encourage us to see ourselves as unencumbered individuals.

The president seemed to understand this human reality. He reminded the nation that “America’s idea of freedom ... is ennobled by service and mercy, and a heart for the weak. Liberty for all does not mean independence from one another.” But he did not explain how our dependence on others should limit the vision of the self-reliant, middle-class American. Nor did he show how our mutual neediness should limit the idea of self-ownership in our formulation of public policy. We may well have a crisis today because aging citizens look too quickly to the government and not to themselves in securing their financial futures. But we have another, surely more intractable crisis, as the individual’s need for care increases in a society where the ties of family and fidelity have often weakened and the supply of voluntary caregivers has diminished. No gov-

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ernment program, insurance policy, or personal savings account could possibly replace what Americans have done for one another without compensation.

This potential crisis in long-term care is due in part to the last century's great advances in medicine. 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 to serve as voluntary caregivers: today's baby boomers had fewer children than their parents; these grown children are more geographically dispersed; and family bonds are increasingly complicated by the high percentage of divorce. And there is no reason to believe that there will be enough professional caregivers to fill these gaps. The cost of decent professional care is increasingly daunting, and fewer and fewer of us will be able to provide it ourselves or pay others to provide it well for those we love.

But this crisis does not arise simply from demographic shifts or shortages of manpower and money. It is, at bottom, a crisis of culture, a crisis about “caring,” a product of our society's opinions on freedom, dependence, and care. It confronts us with one of the peculiar ironies of our time: The more we understand ourselves as independent of others (i.e., in pursuit of our own self-interest and self-preservation), the more dependent we ultimately become on others (i.e., more in need of the care that all human beings rely upon, especially in their old age). Our spirit of ownership and the realities of our dependence inevitably come into conflict, and this conflict is not easily resolved.

The Illusion of Independence

Self-reliance, of course, is a great American virtue. America is a middle-class nation, and it continues to become more middle-class all the time. This does not mean that we are all equal economically, or that we are all equal when it comes to intelligence and virtue. It means that we all work because we have to work, and that we are all free. We believe that all human beings have an equal right to work and no right to expect the fruits of other people's labors. And we believe that freedom means not being dependent on others or constrained by others. 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; our children are raised to be free and independent, to achieve on their own, to go their own way.

More than ever, we experience ourselves *simply* as individuals, distinguished by our freedom from what nature has given us. We are freer to escape the constraints of bodily limitation, of gender, senescence, and decline—or at least to live for an extended period of time as if we could do so. The world exists, the individual thinks, for me. In the beginning, there I was, and after me there is nothing.

But this view of ourselves as individuals remains far from complete. Despite our pretensions, we remain in many ways dependent beings. Nature eventually erodes those freedoms that depend on an active body and a flourishing mind. And there is no way we can get all the care we need through merely calculated, contractual relations with others. Perhaps the economy can be reduced largely to such consensual relationships. But it will always remain true, as Chantal Delsol observes in *Icarus Fallen*, 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 caregiving activities that go ... unremunerated.”

The individual often thinks of the care-giving life as unproductive or wasted, and he or she cannot imagine himself as a care-needing being. Care-giving and care-receiving are commonly viewed with contempt, because freedom for us means giving and receiving as little of it as possible. The happiness bestowed through caregiving does not appear to the individual to be real, and the virtue of caregiving often seems too ordinary. Our goal is not to care for those who are suffering and dying, but to reduce and eventually eliminate the amount of suffering and dying in the world. Our goal is not to help others live well with natural disability and decline, but to conquer all disability and decline.

In this view, physicians and nurses 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 is typically handed over to those who do the work of merely caring: keeping company with the patient, meeting the seemingly ordinary needs of those who are beyond medical help, sustaining those who will soon be unsustainable. Not without reason, we often rank curing over caring; we revere doctors and give little thought to those who change bedpans; we view activities based on the thoughtful acceptance of our natural limits below

those that attempt to overcome those limits; we seek solutions first and foremost and see everything else as signs of defeat.

The views of the caregiver and the producer are, in reality, both partly right. It is a tough question whether the saintly solicitude of the Sisters of Mercy or the physicians who introduced the latest medical technology into their hospitals did more to reduce the amount of suffering or increase the amount of happiness in the world. But they clearly worked best in combination. Surely the most admirable American type is some mixture of productive individual and loving caregiver. At our best, we combine technique with recognition of the permanent limits of technique. But this combination of innovative engineering and perennial wisdom is a rare human achievement.

The New Division of Labor

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). This division of labor seemed to slight both the intellectual capabilities and the freedom of women, and today we believe that either a man or a woman can both have a career and be devoted to caring faithfully for others. The traditional roles of the ambitious man and the devoted mother are arguably combined in today’s micro-managing, achievement-oriented parents.

But the old division of labor is giving way to a new one. We have turned more and more caregiving over to salaried employees, making it a species of production. Caregivers have become *workers*—social workers, healthcare 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. And 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.

We may dream of turning all caregivers into wage-earners—so that all we as individuals owe them is money for their services. But in reality, our free economy would collapse under that burden. Our medical system depends on most of the chronically ill being cared for voluntarily by women—a burden that will grow more crucial and more difficult as the baby boomers retire. Even in our individualistic times, as the Senate

Special Committee on Aging reported in 2002, “family caregivers are the cornerstone of our long-term care system ... providing 80 percent of all long-term care in this country,” with women providing “75 percent of all caregiving for family members.” Replacing “these unpaid family caregivers” with “paid home care providers” would cost hundreds of billions of dollars. And despite our society’s gender-neutral ideal, “the modern technological extension of the life span has put pressures most directly on women rather than on men.”

There is some truth in the gross caricature that the ambitiously productive men who made history ruled over the largely invisible caregivers, who left little record of their activities and even less of their happiness. But in more Christian and aristocratic times, there was also much greater awareness that production and caregiving are both *valuable* and *incommensurable*. Caregiving need not be paid, it was thought, because its value is intrinsic, and women were able to work without personal wages and public recognition because they knew that everyone understood 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 is because “the women of yesterday knew no middle ground ... between the banalities of daily life and the most profound wisdom.”

That “middling” way of life—the way of life of the productive individual, who produces the means of human happiness but knows little about the sources of human happiness—was the way of life of men. 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. But today, we *all* think of ourselves as middle-class—as free beings who work. So we tend to devalue everything below and everything above the realm of production. Below production are our invincible natural needs and limitations; above it are the invincible spiritual dimensions of our lives. Caregiving is not something we do merely out of social instinct. It requires an awareness of the relationship between human limits and human love, and a faith that attentive devotion to the frail and incompetent is a worthy and fulfilling human activity, even if its worldly rewards are not often obvious.

The Young and the Old

Caring for the old is distinct from caring for the young, and the decline of caregiving is most apparent in the way we stand before our elders. 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 unambiguously of necessity, of our limitations, of what we human beings cannot do for ourselves. There is no place for the old, for example, in David Brooks's two upbeat books about our achievement-driven meritocracy, just as there is no place for caregiving for anyone but our own children.

Yet caring for—being attentive to—those in their declining years is a crucial source of human wisdom. “Aging, like illness and death,” writes Thomas Cole in *The Journey of Life*, “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.” This conflict is distinct to human beings—a mark of both our misery and our greatness. We alone among the animals have longings that transcend the pleasures and limitations of our biological existence, and that truth is the same for all of us. While nurturing the young may have the aid of natural instinct, caring for the old requires transcending mere instinct, and meeting biological decline with more-than-biological love.

Today, being old increasingly defines who we are as a nation, while the vigor and freedom of youth is more than ever what we desire. Our enlightened prudence about healthy living and our achievements in medical technology keep more of us alive well beyond our reproductive and parenting years. Evolution might suggest that the elderly individual should die in the interest of the species or the next generation, and yet we are freer than ever to say no to being replaced. We work infinitely harder than any other species at keeping particular individuals around, pursuing longevity through technological ingenuity. We are also getting older as a society because more individuals are making the choice not to reproduce or not to reproduce much. The good news, as Boston University professor Robert Hudson explains, is that “for the first time in history” we have “large numbers of older people whose existence is centrally defined neither by work nor by illness.” The prospect of a lengthy retirement seems to present us with a new kind of freedom. The bad news is that the

freedom of old age always gives way to the neediness of old age, a neediness that grows as people live longer. We increasingly need a selfless kind of caregiving that we are increasingly less able to give. We live in a world in which the Sisters of Mercy have just about disappeared. They too have grown old without replacing themselves, and the few young sisters that remain are increasingly burdened by the old.

As we grow old, we are also becoming more repulsed by the natural effects of aging. In our individualistic meritocracy, people are often judged by how “smart and pretty” they are, and nobody is obliged to like or support or care for anybody else. Aging is generally bad for both our brains and our looks, and so to avoid failure 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 are repulsed by the sight of old age, in part, because the appearance of the old brings death to mind. But we seem to fear dependence as much as death, and we know that the downside of living in a meritocracy is that the love of others is hardly guaranteed.

For those used to thinking of themselves as free individuals, dependence is especially humiliating; we know too well that nobody really owes us a living. So increasingly we say that we would rather be dead than lose our autonomy, and we readily sign legal directives making that clear. But the choice for death made when healthy does not predict what each of us would choose when death is actually “imminent.” Precisely because we live our lives believing the self is the measure of all things, we shudder at the prospect of the self’s oblivion, and cling to every living moment as if being itself depends on our individual existence.

Some worry that the prolongation of life may turn society into “something like a giant nursing home.” And this prospect provokes a certain backlash in the name of productivity. “Longer years of life,” observes Audrey Chapman, “decrease the relative period in which people are contributing economically during their lifetimes and increase the period of dependency.” A harsher way of expressing this observation 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 offers new possibilities, such as aiding and encouraging the lives replacing ours. We know that the elderly “make substantial unpaid contributions” by providing care

for grandchildren or long-term care for a disabled sibling or spouse. 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 achievement-oriented 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. The old are supposedly free to experience life without the burdens of work and parenting, and yet the limits imposed by age itself always loom large. Their realm of freedom, they know too well, is most contingent and temporary.

Of course, it is just as American, as Carl Elliot observes in *Better Than Well*, to criticize “the cultural attitudes” that make anti-aging enhancements necessary as it is to have such attitudes in the first place. But “there is an air of futility,” he says, about all such criticism. The spiritual objection to worrying enough about wrinkles to get Botox injections is trumped by the very tangible benefits accrued by looking wrinkle-free. We cannot say that the choice is merely an aesthetic preference, because the choice to look young is also a choice for productivity. Various anti-aging enhancements may one day be regarded as reasonable conditions for employment. The choice against being as smart and pretty as technology allows is a choice 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. This 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. We will continue to devalue caregiving and caregivers, hoping to live as much as possible without them.

Between Faith and Euthanasia

The contribution of biotechnology to lengthening human life will merely reinforce these longstanding individualistic trends and successes. No vaguely death-accepting policy has any chance of success, especially as the electorate continues to age. The only possible exception is the future embrace of euthanasia, a policy that is not *death-accepting* but *death-imposing*. As Daniel Callahan observed nearly two decades ago, “Only a full-scale change in habits, thinking, and attitudes would ... make it

morally and socially possible” for any “proposal to limit health care for the aged” to succeed. But such a transformation seems unlikely. And if it were to occur, we would have reason to fear that it would be based not in *care-giving love* but *care-denying utilitarianism*, because the latter would be more characteristic of the excesses of the individual. We are thus stuck between two unrealistic views of the autonomy of the individual: The first is that the self can be autonomous forever; the second is that only the autonomous deserve to live at all.

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 people are dying of Alzheimer’s disease, an approximately decade-long process of decline toward complete dementia—or, more precisely, the 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 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 this disease because nothing else did them in earlier. Because the incidence of Alzheimer’s increases with age, the number of victims will only increase further as we extend the length of life. Virtually any other form of debilitation and death would be less of a physical and psychological burden on caregivers. And 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.

The burden of caregiving often falls on a single child or an elderly spouse—and more and more on rather elderly children. As Francis Fukuyama explains, 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.” The result is that the caregiving family member must sacrifice very sizeable amounts of time or income or both at a point when a life devoted to unpaid caregiving may well seem like a wasted one. This burden increases all the time, and it is a testimony to the good natures of American women that they still so often accept it, are ennobled by it, and find happiness in it. But the young (or youngest retirees) cannot help but grow more resentful that their otherwise free existence is more limited by the requirements of the old (or very old). “Young people,” Chapman

observes, “may question whether their futures should be mortgaged to care for those who are not making productive contributions to society.”

“The caregiver for the severely demented,” write Richard J. Martin and Stephen J. Post, “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 often lacks. But few of us are individualistic enough (or nihilistic enough) to affirm faith’s “only serious alternative, the destruction of the radically infirm.” 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. We reject the turn to euthanasia as a way of getting rid of the infirm, but we do not believe that caring for those whose lives are seemingly pointless is the best way to spend our productive years. Our anxious disorientation about what we are supposed to do provides plenty of evidence that we are more than merely individuals. This anxiety makes us miserable and opens us to the possibility of faith.

More often than we like to admit, middle-class persons with Alzheimer’s find themselves 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 those in decline are often inadequately trained and inattentive to the consequences of the changes in the person’s capabilities and moods. Such work is both underestimated and under-appreciated. Its satisfactions are both intellectual and emotional, and those who think of themselves as merely individuals stand most in need of its lessons. 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 alternatives have become rare in our individualistic time.

Surely there is little worse in the human experience than having Alzheimer’s and being alone. But the currents of our time push us almost inescapably in this lonely direction: Lives moved by a veneration of independence threaten to leave us unprepared for dependence, and thus increase the burdens and challenges of long-term care. The inability to think clearly about caregiving—or to provide as well as we 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.

Love and Ownership

Perhaps the “ownership society,” if it comes, will make matters marginally better. Rather than envisioning the social contract as an arrangement

between the individual and the state, it might free individuals to see their wealth as rooted in families, as a nest egg for the young, the old, and the middle-aged to provide for one another. Perhaps ownership will promote not only self-reliance but love, even when love requires accepting the loss of freedom that comes with giving and receiving care.

But this is more a hope than a prediction, and it may be that our apparent willingness to reform Social Security—a policy issue that can be framed in terms of today’s workers—is mirrored by our great reluctance to confront the problem of long-term care—an issue that confronts us squarely with tomorrow’s needy elders. Perhaps we falsely believe that individualistic solutions to the problem of caring for the old are really possible. Or perhaps we simply know that long-term care is a problem we cannot solve, and that all we can do now is reject those solutions that encourage independence and productivity by denying life to those with no worldly use and no voice of their own.