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As society ages, our reponsibilities to the elderly grow more complex.

Curing, Caring and Coping

– BY DANIEL CALLAHAN –

WHILE THERE ARE MANY REASONS to worry about what the future may bring—with global warming, oil depletion and international terrorism high on the list—it is imaginable, at least for optimists, that these challenges can be dealt with in some fashion or other. One problem, however, should invite no easy, comforting thoughts: aging societies. The developed countries are already feeling the early gusts of dangerous winds, and even the developing countries are beginning to notice them as well. Little guesswork is needed. The young people who will become the old people in

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coming decades are already alive. Their numbers can be counted, and those demographics cannot be changed.

The reasons for anxiety are emerging in the United States, even if so far the challenges seem manageable. There are the demographic projections: 36 million of us are now over 65, close to 13 percent of the population, and our number is expected to rise to 71.5 million by 2030, to 19 percent. Some 9.6 million of us will be over the age of 85. There are the economic implications: Medicare will grow from the present 2.4 percent of the G.D.P. to 8.3 percent in 2050; and the combined costs of Medicare, Medicaid and Social Security are expected almost to double by 2035. Then there are the medical portents: close to 50 percent of those over 85 will suffer from some form of dementia, and only 5 percent will be fully mobile. The projected long-term institutional costs alone, quite apart from medical expenses, are looking astronomical also.

Figures of that magnitude should catch everyone's eye, but their very size tends to obscure a no less important problem. How ought we, from an ethical standpoint, care for the elderly? What do we owe them in their time of need (which can go on for many years), not only in terms of government medical and welfare programs, but in terms of personal time, energy and personal resources? The President's Council on Bioethics has tried to respond to questions of that kind in its new report, *Taking Care: Ethical Caregiving in Our Aging Society*. That council, appointed by President Bush and chaired until recently by Leon R. Kass (now replaced by Edmund D. Pellegrino, M.D.), has had more than its share of controversy, most of it wholly undeserved. The council had the misfortune of getting caught in some of the nastiness of the debates about cloning and stem cell research, of wrongly being assumed to be puppets of the president and of running afoul of a high tide of technological enthusiasm, which takes any and all questioning of medical progress as nothing but hostility to science, a crime of the first order. As a matter of fact, its reports have generally received high marks, providing careful analysis and reasonable conclusions of a quality that even many of its critics have acknowledged.

The report on caregiving is no exception, even if it here and there leaves some gaps and displays some crucial ambiguities. (I should note that I was asked to read the draft of one small part of it.) It begins with an examination of the data on our aging society, summarizing what we can expect in the future: how many elderly there are likely to be and their proportion of the population, the projected costs of medical and long-term care and the many problems that will be posed for family caretakers. It then takes up the question of advance directives, consisting either of a written living will or the appointment of a surrogate, and their bearing on the decisions of physicians and family members who honor them. At the heart of the report is a chapter on the ethics of caregiving, setting forth some general principles.

Those principles are then deployed in a chapter on their relationship to the prudence needed to make appropriate use of them in difficult cases. The last chapter offers a number of summary recommendations, drawing on the previous chapters. All in all, there is a helpful movement in the report back and forth between the general and the particular, appropriate in grounding the discussion in the full range of the dilemmas of a sensitive provision of care.

LET ME EXPRESS AT THE OUTSET some of my own hesitations. While the report notes the huge financial problems an aging society will impose, particularly on public programs, it does not take us very far in confronting the inevitable rationing that will almost surely be necessary. The report adverts to it, but that is about all. The combination of rising costs, imposed by the increasing number of elderly together with ever fancier technologies to treat them, requires a national dialogue that our country has put off for too long. How are we supposed to deal with the ever-rising cost of an aging society? How are we best to balance the needs of children against those of the elderly, of education against health care, of job creation for the young against support for the retired? Liberals have avoided such tensions out of a fear of promoting ageism and appearing to treat the elderly condescendingly, as nothing other than a "burden"—which is considered a demeaning, even nasty, word. Some conservatives, not to be outdone in evasive tactics, have taken any talk of limits and rationing as nothing but "social euthanasia."

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I can well understand why the council decided to acknowledge but not take on in detail the political and economic problems of Medicare and Medicaid, which pay for long-term care; they had enough on their plate. Yet since the care of the elderly is so heavily a government problem, and its finances so directly bear on the situation of families in caring for the elderly, more might usefully have been said. It may surprise some liberals to know that the council sees

the need for strong government support. It goes nowhere near taking a conservative cost-cutting line, and there is no hint of an anti-"big government" bias.

But just how far ought the government to go? Without directly relating in any detail their observations to the economic issues, the authors of the report astutely note how an important traditional principle of balancing patient benefits and burdens is now revealing another side, a troubling one. "If the only morally permissible criteria for forgoing life-sustaining medical treatment is that the treatment is itself burdensome or ineffectual, then every affordable treatment that meets these criteria becomes a moral obligation. Every medical invention of such a sort creates a new moral duty. Progress constrains human choice as much as it expands it."

That is an invaluable insight. The Medicare program, for instance, is steadily being forced to decide whether to provide coverage for exceedingly expensive treatments (e.g., $50,000 to $100,000 a year) that bring some short-term benefits but limited long-term health gains. Its administrators know that the program cannot continue much longer to pay for every new technology that comes along, but it was legislatively organized in a way that does not allow cost considerations any role at all in determining what will be reimbursed. And Congress has resisted efforts to allow a place for those considerations—or even to talk about them—no doubt intuiting the fractious public debate this would instantly set off. "We seem," the council report notes, "to be bound by technological innovations that may not always serve what seems like a human good." That insight is surely correct, but its power is, unhappily, not ordinarily sufficient to stand in the way of technological innovations in a culture infatuated with those innovations.

I HAVE LET MYSELF SO FAR BE DISTRACTED by some points in the report that seem to me more important than the space and development accorded them; but they should not be overlooked. Why were they not more developed? I suspect because of an implicit notion of ethics that too sharply distinguishes between the sphere of personal conduct and morality and that of economics and politics. In the case of an aging society that affects our lives individually and socially, our personal morality about caring and our nation's social policies will inevitably interact with each other.

The level of medical and welfare benefits that we make available through our taxes to an elderly wife caring for her sick husband will make an enormous difference in her capacity to provide loving—and not just dutiful, angry and resentful—care and in maintaining her own health along the way. The council emphasizes interdependence as a key value in personal care for the aged, and that seems right on target. Yet if public policy is understood as the way we treat those who are strangers to us, knowing they are part of our

extended community, that will affect the private and the personal in our own lives as well. The concept of interdependence can then rightly be expanded to encompass social policy and not treat it as a separate category. The European commitment to the value of solidarity in its support of universal health care nicely captures that idea of interdependence, among family members and the larger community in which families exist.

The central theme of the report, focused on the moral values and principles we ought to bring to the care of the old, comes down to one starting point: that of providing the best care for the person now before us. "Human beings," it writes, "who are dwindling, enfeebled, or disabled in body or in mind remain equal members of the human community. As such we are obligated to treat them with respect and to seek their well-being, here and now."

Euthanasia and physician-assisted suicide are flatly ruled out, but otherwise, in pursuing its theme of the "here and now," the report seeks to balance important values: not to "postpone the end of the patient's life as long as is medically possible, but always to benefit the life the patient still has," and to recognize an obligation to "avoid inflicting treatments that are *unduly burdensome to the patient being treated*" (italics in original). Those values are explicated with great delicacy in the report's case studies. Of course every word in those assertions can be argued about and has been argued about indefinitely: "unduly," "benefit," "medically possible"—but they are the best words we have. There are more moral distinctions than angels who can dance on the head of a pin, and most of them remain relevant.

But some ambiguities arise along the way. Like many others in recent years, the report is critical of living wills as a legal instrument for the kind of care one would like to receive. The alternative is the appointment of a proxy, someone to act in one's behalf. Yet living wills were originally designed for end-of-life decisions, not to provide for any and all cases of incapacity to make decisions at other times of life. But this distinction gets lost along the way in the report. In great part that is because a primary and recurring case example is that of dementia, an important source of incapacity but not the only one. What is to be done when a person had stated in his living will that he wants life-preserving medical treatment terminated should he be afflicted with advanced Alzheimer's disease—but, when the time comes, appears to be happy and contented? It makes sense, in those circumstances, for the earlier wish to be put aside, or at least for that possibility to be seriously discussed by the person's family and caretakers.

Yet apart from that kind of unusual circumstance, the report affirms, with a hint of reluctance, the importance of a patient's prior wishes. In stressing the value, now widely accepted, of a proxy in preference to a living will, the

report cites its fostering of interdependence as the superior strength of a proxy. Yet what it seems to miss is that one reason many now prefer proxy directives is not just to affirm interdependence. Instead, it is in order that the proxy can serve as a zealous and single-minded advocate, pushing hard for what the patient had earlier stated as his desire. Living wills are being rejected in great part because they have proved to be a failure as an instrument for ensuring self-determination about the end of one's life. They are often hard to interpret and easily ignored. A proxy can represent a patient better than a piece of paper and can also deal with situations a patient may not have anticipated.

Yet it would seem to me a terrible breach of trust for a proxy to set aside the patient's earlier wishes (assuming they had been amply discussed) simply because the proxy later comes to believe it was a wrong decision or cannot bear to follow through on it. This is a difficult and delicate matter: the proxy remains a moral agent, not simply a hired gun. Short of extraordinary circumstances, the proxy should do what he or she was asked (and agreed) to do. "Living wills," the report argues, "make autonomy and self-determination the primary values at a time of life when one is no longer autonomous or self-determining, and what one needs is loyal and loving care."

That is a puzzling statement, one that would make more sense if the phrase "at a time of life" were replaced by "for a time of life." While hardly infallible, it is possible for people to come to a reasonable judgment about how they want to be treated at the end of their life—and particularly for elderly persons who have observed the deaths of many of their fellow elderly. The desire for self-determination is by no means incompatible with a desire for loyal and loving care, or interdependence, but the report leaves the impression that there is a conflict. Our dying, as the report itself observes, is personal and individual, even if its context is social and interdependent.

Perhaps my trouble in reading the text comes from one of its virtues. It works hard to make its way through some complicated issues, doing justice to values that often seem to be in conflict with one another or even to subvert one another. Reports of that kind—in the form of on the one hand, on the other hand—are easily misinterpreted. In any case, readers of the report will be invigorated by it, and that is no mean accomplishment. I know from my own experience in writing about elder care and policy that it is uncommonly difficult territory to traverse without setting off hidden land mines. Along with death, aging is one of those topics that most people take with great seriousness and often no less great ambivalence. It is easy to argue about it with others, if only because most of us have been forced to argue about it with ourselves. And there is much more such turmoil ahead. A