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Ethics and Health Care: Rethinking End-of-Life Care

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Abstract

America is undergoing a demographic revolution, with a rapidly aging population blessed with greater longevity. While this is a triumph of modern medicine, it also presents an unprecedented ethical and fiscal challenge for individuals, families, medical professionals, and policymakers. In particular, Americans need to think carefully about care at the end of life. How should we think about life and death itself, the role of family and religion, and the duties of medical professionals and the use of advanced technology in the provision of end-of-life care? What is the role of freedom and personal responsibility? The Center for Policy Innovation asked two leading scholars of ethics and health policy to engage in an exchange on these issues.

This paper, in its entirety, can be found at **http://report.heritage.org/cpi_dp04**

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Daniel Callahan: The Kind of Problem We Face

End-of-life care has emerged of late as a peculiarly compelling and vexing issue of ethics and health policy. It is compelling because almost every adult these days has had some experience with the death (usually in old age) of a spouse, parent, or grandparent, sometimes good, sometimes bad. It is rarely easy, and those deaths remind us all too bluntly that it will eventually be our turn.

It is a vexing issue because, despite at least 40 years of intense medical and public debate, we still have problems dealing with it, and they may be getting worse, not easier. I want to argue that, at bottom, it is the stance taken by American medicine toward death—and with the support of the public—that is the root problem, exacerbated by our kind of health care system.

When end-of-life care in the context of modern medicine was identified as a serious problem in the late 1960s and 1970s, it was because, by then, most people were dying in hospitals in the company of high-technology medicine. Complaints arose about a lack of choice on the part of patients, doctors indifferent to the pain and suffering of those in their care, and cold, impersonal deaths lacking all dignity in a cocoon of tubes and wires. The solution was thought to be the empowerment of patients to have a say in how they died, better education of physicians in the care of the dying, and the wider availability of palliative care and of hospice programs.

Those three solutions were fostered, and considerable progress has been made. Some 25 percent of the population has a living will, over a million people a year die in the care of hospice, and medical schools now work hard to foster more caring physicians trained to communicate better with patients.

While those efforts have helped, however, they are far from solving the problem. Some 75 percent of the public, despite intense educational efforts, do not have a living will, and most have only had vague talks with family members about how they want to die; most physicians still resist an open discussion with patients and families about death;

and the majority of patients in hospice go there much too late, usually no more than five to 15 days before they die. Why? Because doctors, patients, and families drag their feet in acknowledging that death is on the way, and that is an important reason why so many of us personally know of, or have heard about, some miserable deaths where the dying went needlessly on.

But can't we just manage dying better than we now do? The ideas and initiatives for doing so are many, in addition to those already mentioned. Since most deaths are now the result of chronic disease and multi-organ failure, a better coordination of care is needed: the elimination of fee-for-service medicine, which rewards physicians for their use of medical technologies but not for talking with patients; efforts to help patients die at home rather than in hospitals (and the development of more low-cost technologies to make that possible); and comparative effectiveness research to identify the most efficacious and least costly treatments.

Even so, I believe those efforts will either fail or not make a great difference unless the medical establishment and the American public recognize some hard truths, most of which reflect some deep values of our kind of medicine and culture. The most important is that American medicine since the end of World War II has in effect declared a war on death, an unlimited pursuit of medical progress. To pursue that goal, it has supported medical research—nicely symbolized by the National Institutes of Health with an annual budget of $30 billion—to seek a cure for all of the killer diseases, notably cancer, heart disease, stroke, kidney failure, and diabetes.

The public, polls have shown over the years, fully supports that effort. The media have pitched in, reporting and touting the great "promise" and "breakthroughs" of the medical crusade. We now live some eight years longer on average than we did 40 years ago, death rates are declining for many diseases, and new technologies to keep us alive longer continue to flow forth.

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On the surface, those developments look good, but that story has taken an unexpected turn. The idea of unlimited medical progress that admits of no upper boundaries is not turning out as hoped. We have not found, nor are we anywhere near finding, cures for the major killer diseases. What "progress" *has* given us is an enhanced ability to keep sick people alive at a high cost financially and a no less high cost in terms of pain and suffering at the end of life. In a 2008 study of the impact of research on costs that has been too little noted, the Congressional Budget Office concluded that "examples of new treatments for which long-term savings have been demonstrated are few.... [I]mprovements in medical care ... paradoxically increase overall spending ... because surviving patients live longer and use health services for more years."

More and more, our end-of-life care looks like the trench warfare of World War I: heavier and heavier economic and human costs with increasingly less ground being won.

Another feature of the quest for unlimited progress is that technological advances have made it harder and harder to determine with any precision when a patient is actually dying. There is almost always something that can be done technologically to give a dying person a few more hours, or days, or even weeks before he actually dies.

The desire on the part of physicians to engender hope, an ancient medical value, and on the part of patients and families no less to want hope—few of us want to die—has the power to lead too many sick patients and families down a seductive primrose path. Reports of just that happening, even with patients who have made their desires known through living wills or an appointed surrogate, are too common to be ignored. The combination of physicians tethered to a "technological imperative" (make use of all available technologies to fight death) and a "research imperative" (a supposed moral duty to fight death from disease) is a powerful barrier to jump in the search for a peaceful death.

What can be done to shift the direction of end-of-life care, both to reduce costs and to enhance the possibility of better deaths? One important recent development is to refine the ancient art of medical prognosis. When a patient is critically ill and likely, but not certainly, going to die, what are the chances he can be helped? And if he is helped, will that outcome be good or bad? In short, what is the path ahead, and what are the alternatives?

Even more fundamentally, a better balance between care and cure is needed. Cure as a goal won the postwar prize, pushing aside care as the goal of medicine. Care must be brought back to the forefront. Moreover, as those families who take care of Alzheimer's patients know,

the family can suffer as much as, and often more than, the sick person. They need support, and some of it will have to come from government.

And yet, in the end, our hardest task may be that of accepting death as an unavoidable part of the human condition. If what I say about the war on death makes sense—that it is unwinnable and apt to wreak havoc if that reality continues to be medically denied—then we need an alternative goal to put in its place. I happen to believe that, at 82, I have lived a long and full life and that, while my death beyond this point may be a source of sorrow for my family and friends, it will not be a loss to society. The future belongs to the young, who bring new life and vitality to the human species.

Now, it is quite true that I may change my tune when death appears on my doorstep; that happens with people. But then nothing I have said should be understood to mean that dying can be made simple and be suffused with a guaranteed calm and indifference. No, it is likely always to remain hard for human beings, but maybe not so hard as it has now become. We have traded off earlier, quicker deaths for later, drawn-out deaths. That bargain needs to be reconsidered.

Peter Augustine Lawler Responds

Daniel Callahan's penetrating article identifies with precision the kind of problem that end-of-life care is for us. It's all about the attitude toward death that is prevalent in American medicine, and that clinical attitude mirrors the one found in sophisticated American life. We're more resistant than ever to the thought that we're all biological beings born to die. American medicine has, as Callahan says, declared unconditional war on death, and there's no rest until death surrenders.

The goal actually might not quite be ultimate victory, although surprisingly many of us share the trans-humanist faith that something like personal immortality will come when "the Singularity" abolishes the alienating distinction between man and machine. The real goal might be something more like indefinite longevity, the abolition of fixed life spans and the resulting comforting thought that nobody need die at any particular time.

IN THE END, OUR HARDEST TASK MAY BE THAT OF ACCEPTING DEATH AS AN UNAVOIDABLE PART OF THE HUMAN CONDITION.

Somewhat unexpectedly, the war against death has bogged down. The cost in resources and human lives continues to escalate, but little real progress is being made. People are living somewhat longer, but the necessity of personal death remains with each of us. What Callahan calls "the major killer diseases" are still killing us, and cures aren't around the corner. I might be a bit more optimistic than Callahan about heart disease and cancer being on the run, but there's no prospect at all for a cure for Alzheimer's.

So our main real progress has mainly produced a kind of perverse and very temporary kind of indefinite longevity. We have new and usually painful—not to mention costly—ways of keeping very sick people alive just a little bit longer. They allow the physician to say the person is not dying, to keep hope alive that death is not the person's imminent fate. The impulse to cure has overwhelmed the inclination to care, to attend to the real condition of and what's best for the lovably unique and irreplaceable person before us who will die.

In our techno-bourgeois society, measurable productivity—keeping bodies moving as long as possible—is valued more than the incalculable benefits of voluntary care-giving. We're less moved than ever by the ancient and Biblical thought that the only power that can ever vanquish the sting of death is the power of love. Who can deny that Callahan is correct when he says we need a better balance between care and cure?

I have to admit to being more than a bit disappointed by Callahan's flat conclusion. Accepting death, he says, is the hardest thing. Socrates thought learning *how* to die takes a whole life. Callahan's mode of acceptance seems to be kind of Darwinian: He's had a "complete life," and at this point his extinction "will not be a loss to society." It will be, he admits, to his loved ones. That we all get replaced is what's best for the species, and in the end we should be ready—if reluctantly—to step aside for the benefit of society and the species.

In my view, Callahan's thinking of himself as basically part of society and his species does nothing less than contradict the basic principles of our Declaration of Independence. I agree with him that physicians and families should be more realistic in facing up to the fact that death, in particular cases, is unavoidably near. We shouldn't be dispensing huge doses of misery for a few more days or months of life.

But I can't agree with the thought that a particular person must or should die earlier than he or she might in order to benefit society. I can be criticized for preferring the extension of my own life—for pursuing my indefinite longevity by all means available, even to generating

biological replacements and at the expense of the social fabric. But according to the individualism of the Declaration, I can criticize anyone who thinks of me as social fodder for choosing my extermination in pursuit of some social goal.

Who can deny that the pursuit of indefinite longevity is in some ways bad for the species and society? It's closely connected to the birth dearth, and it's undeniably eroding the loving connections that tie together generations. But it's also true that we want to keep persons who love and are loved around as long we can. The idea of a "complete life," it seems to me, is just too Darwinian to apply to free persons. Free persons in the modern world are in techno-rebellion against the nature that is out to kill them, and no Darwinian can explain their personal behavior.

So the war against death will continue, and it's even more good than not. Its personal limit has to be personal love much more than serene acceptance. Callahan, for example, has every right to prefer what's best for his loved ones to what's best for society and the species. I, for one, want to have him around a whole lot longer, and I affirm all reasonable efforts by medical science to achieve that personal goal.

I could go on to say more about belief in the personal God who saves each of us from biological death. But not now.

Peter Augustine Lawler: The End of Life in Our Highly Personal Time

Any sensible and sensitive person realizes that we try too hard to keep people alive as long as possible. That's one reason why health care is so expensive. But the expense would be worth it—and as free and dignified persons, we should bear it—if the cost, pain, and effort produce undeniable personal benefit. Physicians themselves, we notice, more often than other Americans forgo chemotherapy and other forms of medical torture that give promise, at best, to give them a little time and a lot of suffering. They know enough to choose to be well—or well enough—for as long as they can.

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So it's easy to criticize physicians for prescribing for others what they wouldn't prescribe for themselves. They can easily respond that their personal choices are *merely* personal. They have no warrant to tell other people what to do with their lives, and they have no right to tell them that there's a standard higher than the prolongation of one's own life.

The physician as a physician is for health and against death. He or she is stuck in our high-tech time with the capacity to keep a lot of very sick people alive for a sometimes rather indefinite amount of time.

The physician as a physician chooses health over sickness, but sickness—even irreversible, painful, highly debilitating sickness—over death. So physicians often choose—or don't tell patients and their families not to choose—*for* much worse sickness in order to choose *against* death. The criticism is not that they choose suffering over death, but that they choose suffering that has little to no chance of fending off death for more than a moment.

We, with good reasons, might criticize physicians for having made medicine too technical or impersonal. Even "the doctors of the soul"—the psychiatrists—often don't attend much to people's souls anymore. They used to use the Socratic or Freudian method of endless talk to figure out what's really wrong with someone deep down. That method is expensive and unreliable. From the view of today's science, it even verges on quackery. Better to chemically manage the symptoms, to mess with the body, than even to acknowledge the soul.

It's an exaggeration to say that the respected discipline of psychiatry has degenerated into the dispensation of pills by ordinary physicians—but it's only an exaggeration. Psychiatry has mainly lost interest in truthful self-knowledge. It's mainly about the alleviation of misery. Part of the misery we all share, of course, is coming to terms with our invincible mortality, our natural limits.

If moods are nothing but collections of chemicals, then psychic misery is readily corrected by remedying the chemical imbalance. Health or human flourishing pretty much becomes the absence of misery. Similarly, it's both a blessing and a curse that we can do so well these days in managing both the emotional and the physical pain of dying.

It's increasingly typical to die in a hospital drugged up—often drugged to unconsciousness. Physicians in some cases—with, for example, chemotherapy that will have very unlikely or very temporary positive results or dialysis for people with dementia—are torturing people in the name of mere life. But sometimes that torture is perversely

therapeutic; it's chosen in preference to the psychic misery that we must endure in the absence of medical hope. In other cases, physicians act as if even consciousness itself is worth surrendering for good to avoid misery.

One problem with "terminal sedation" is that it artificially hastens death for the convenience of the living. The bigger problem is that it's too often the choice of unconscious comfort over being who we really are. It's not a choice for dying well—for, as Socrates says, learning how to die and being in love with unique and irreplaceable persons who, like us all, live for a moment between two abysses.

That's not to say that more and more of medical treatment doesn't properly attend to the alleviation of the misery of sick persons, and drugs in the right measure often make possible a good death. Some with cancer who are relieved—but not too much—of emotional and physical pain can die in love with family and friends and God, and nobody can deny in the hospice era that we're thinking more in terms of good deaths, even if not enough. Hospices, everyone knows, would be used more frequently and effectively if people were more accepting of death, if they understood better when to give up in their techno-fight against death.

In that respect, we should want our physicians to be less technical and more personal in their instructive advice. But it's a question whether they can conceivably be trained to accept that Socratic or religious challenge in the case of their patients. We imagine that in a more humane and religious and better educated time, they must have been personally authoritative and sensitive, but we have to add that the techno-challenge faced routinely by physicians today is unprecedented.

That challenge is not so much that our technological and even biotechnological progress has conquered, or is about to conquer, death or has even pushed the limits we have been given by nature back all that far. The challenge is that being seriously sick—having, say, heart failure—is no longer a quick and definite prelude to death. The more we think we have the rational control required to fend death off for just a bit longer, the more we can choose for ourselves and others not to die, the less able we are to be accepting about the death that is the destiny of us all.

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We expect too much from physicians if we think they can turn that techno-cultural trend around. Their often amazing and seemingly miraculous successes in the prolongation of life can't help but fuel it.

The success of modern technology in general and our increasingly personal self-understandings cause us to see death as less necessary and more accidental or avoidable. Consider, for example, that Socrates courageously confronted the city of Athens on behalf of wisdom and virtue at the age of 70. He did so in a time when there was no prospect at all that he could live much longer. What if a physician burst in on him early in the morning of his trial and relayed the good news that the latest advances in regenerative medicine would give him another 70 years? Or even another five years?

Socrates tried to convince us that philosophy is about learning how to die, and his example is supposed to convince us that fear of death—fear of personal oblivion—must be resisted in the name of what makes life worth living. But Socrates accepted death as a necessity, not as a good, and it's hard to know whether he would have been as courageous in a time when death seems less necessary or definite than ever.

The deep problem we face when it comes to "end-of-life" issues is that we live in a highly personal time. That is, let me emphasize, more good than not. Our sophisticated theorists, both liberal and libertarian, tend to think that nothing trumps keeping the people who are around right now alive and free—and by free we mean, among other things, as free as possible from being determined by nature. People today think of themselves less than ever as part of wholes greater than themselves—as part of families, communities, countries, churches, or, of course, the species. They also think of themselves less as deeply relational beings and more as free or autonomous individuals. That means the strong tendency is there for one to think that one's death—one's personal extinction—is the end of being itself.

The upside of our highly personal thinking is that we refuse to do what the Fascists or Communists did: treat people as expendable parts. We even recoil at those persons in the past who slaughtered people over questionable conceptions of the soul or ridiculous causes. So, although we find it impossible today to speak of the soul, we do retain the Christian

belief—usually without belief in Christ—that each person is unique and irreplaceable.

We could accept personal, biological death a lot better, of course, if we retained the Christian belief that each person, having been created by a personal, providential Creator, is more than a biological being and that, for each person, biological death is thus less an end than a beginning. But physicians, of course, can't bring back that either comfortable or true belief.

It's good that we believe what Daniel Callahan apparently does not: People have every right to live as long as they can. The old have no obligation to step aside for the young, either for the benefit of society or for the benefit of the species. There's no such thing as a "complete" human life in this world. Free persons always want more, for reasons both narcissistic and relational, and it's somehow in the nature of free persons to be in rebellion against the cruel and random nature that is out to extinguish all personal beings. Free persons, of course, can believe that their deep longings can be satisfied only by a personal Creator, but there's no denying that the personal longings persist even as that belief erodes.

Our society is aging. We have more old and relatively unproductive people and fewer young and productive ones. Nobody knows how to reverse that trend. There is some connection that has not been fully explored between our techno-pursuit of indefinite longevity and our birth dearth, and it's natural for the young to become resentful of the burden the frail aged will impose on them.

Partisans of limited government will be increasingly concerned with burgeoning medical costs, especially in the last years and months of life, but there's still no duty for any person to die. Nature, in truth, provides no fixed guidance for how long free persons might live, and we free persons consent to medical and technological efforts to extend life as long as we can. We can't artificially impose some age limit on when lives should end, and we have no certainty about any natural limits on our personal, techno-pursuit of indefinite longevity.

WE COULD ACCEPT PERSONAL, BIOLOGICAL DEATH A LOT BETTER IF WE RETAINED THE CHRISTIAN BELIEF THAT EACH PERSON, HAVING BEEN CREATED BY A PROVIDENTIAL CREATOR, IS MORE THAN A BIOLOGICAL BEING AND THAT BIOLOGICAL DEATH IS THUS LESS AN END THAN A BEGINNING.

The only limit to personal freedom we can affirm is personal love. Callahan is perfectly right that the impulses to cure disease and prolong life have to be limited by personal care, by what's best for a free being with a soul, but there's no social or socio-biological standard higher for us than what's best for each of us as the free, lovable, and dignified person.

Daniel Callahan Responds

Reading Peter Lawler's interesting paper made clear to me two points. One of them is that I see no fundamental disagreements between us—well, maybe one. Both of us are trying to wrestle with some basic tensions in medicine on end-of-life care, often pitting two goods against each other, looking for the right balance. The other point is that his response helped me to clarify something I have long wrestled with in thinking about death: its place in our community and common life, not just our individual lives.

Let me deal first with some quibbles. I do not believe that the motive for terminal sedation is "the convenience of the living." How can he know such a thing? I understand it as a desperate effort to relieve a patient of otherwise unbearable suffering, a last-ditch effort when all else has failed, and it is misused if it aims at the patient's death.

Contrary to Lawler's assertion, I believe that "people have a right to live as long as they can," and I agree with him that there is no "duty to die," an obnoxious idea I have never held. But the important question is less about rights, I think, than about having a prudent and wise understanding about how far and in what ways we should try to extend our lives in the face of critical illness.

What I find missing in Lawler's response is a view on the place of death in our life as a community, its social meaning and ethical implications. While I suspect he no doubt has some thoughts on that, his response comes across as wholly individualist. "The old," he says, "have no obligation to step aside for the young, either for the benefit of society or for the benefit of the species."

While I would not use the term "step aside," I do believe that there are reciprocal obligations between young and old: Each age group has duties toward the other. The young need to provide help and resources to the old when they are sick and infirm, both by their personal help and support of government health care and Social Security for them. The old need to do what they can to avoid harming the young in their need for care and to leave behind them a

viable and honorable society, offering them at least as good a life as they had. Some 6 million grandparents in our country care for the children of their children. It is often a shame that they have to do so, but it is to their great moral credit that they are willing to do so.

When we think about the future of Medicare and Social Security, we should keep in mind that it will be the young who will pay for that program with their taxes—and at the same time as they are paying the costs of caring for their own children (or, increasingly in the future, when parents with young children will be called upon to aid ailing or destitute parents). Finding a good moral balance there will not be easy.

I have argued elsewhere that it is possible to speak of a "complete life," by which I do not mean having done and seen everything and having all one's desires fulfilled. But by my age, the early 80s, most of us have a good shot at most of the benefits a human life can bring: children, work, love, travel, friendship. Note that I said "most of." Can we wish for more? Of course.

WHEN WE THINK ABOUT THE FUTURE OF MEDICARE AND SOCIAL SECURITY, WE SHOULD KEEP IN MIND THAT IT WILL BE THE YOUNG WHO WILL PAY WITH THEIR TAXES AT THE SAME TIME AS THEY ARE PAYING THE COSTS OF CARING FOR THEIR OWN CHILDREN OR THEIR AILING OR DESTITUTE PARENTS.

But will or should our death be considered a social tragedy if there is still more we might have had? I think not, and I ask the reader to compare the experience of the funerals of people my age and up with those of children and young adults. The former brings regret and sorrow, but rarely tears. Most (but of course not all) elders, by my age and in my experience, accept death, wanting no excessive treatment to keep then alive. They do not expect their children to treat their death as an unmitigated evil. People are born and people die.

That is the rhythm of life, long ago recognized in the great religious writings and traditions. Sooner or later, we get the point.

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