President's Ethics Council Rejects Assisted Suicide

BY JOYCE FRIEDEN
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WASHINGTON — Assisted suicide and euthanasia should not be considered for terminally ill patients, the President's Council on Bioethics suggests in a soon to be released report.

"If you say assisted suicide and euthanasia are not the way to fix these problems, you have reaffirmed the principles we affirmed in the last chapters of this report," said Gilbert C. Meilaender, Ph.D., council member and Phyllis and Richard Dusenberg Professor of Christian Ethics at Valparaiso (Ind.) University.

"We think that euthanasia and assisted suicide are out," agreed council member Paul McHugh, M.D., the Henry Phipps Professor of Psychiatry at Johns Hopkins University, Baltimore. "This is just an old idea that crops up again and again in society, and various people tried it, and it always fails."

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DR. McHUGH

The patients who are driven to consider assisted suicide "are the people who burn out in the process of care," said Dr. McHugh, who is also professor of mental health at the university's school of public health. "They burn out simply because doctors have been extending things too far for them, asking more than they can deliver. … Never forget that inflicting extra care on people is to ultimately burn them [out]."

Dr. McHugh said he also favored giving family caregivers tax benefits to help them financially. He added that he wished there were more role models to persuade people to think of elder care as a career. "We don't have any Florence Nightingales, any Mother Teresas to tell people this is a wonderful life."

Council member Alfonso Gómez-Lobo, D. Phil., lauded the report but said there was more work to do on the subject. "We have to think more about the way of making a distinction between ordinary and extraordinary means," said the Ryan Professor of Metaphysics and Moral Philosophy at Georgetown University, Washington. "It is important to affirm, on the one hand, the goodness of life. On the other hand, it's not an absolute good. It's frail and fragile, and there are moments in which we just have to open ourselves to the fact that we have to let go."

The council also recommended establishing a presidential commission on aging, dementia, and long-term care.

"Someone might say the last thing America needs is another commission, but this commission is really set up to be unique, understanding death not as a problem to be solved but an experience to be faced," said council member Peter Lawler, Ph.D., chairman and the Dana Professor of Government at Berry College, Mount Berry, Ga. "We as a people aren't particularly equipped to think of death as an experience to be faced. But if a commission can accomplish that, it would be quite a commission. And I'm all for that."

At the meeting, the commission heard from Robert Friedlander, Ph.D., director of the Center for an Aging Society at Georgetown. Dr. Friedlander told the council that although most of the caregiving for elderly patients is provided at home—often by family members—three-quarters of the money spent on caregiving is spent at institutions. This is partly because institutional long-term care is a mandated benefit under Medicaid, whereas home- and community-based care is not.

But "there have been tremendous efforts on the part of states to move care out of the nursing home," especially since states think care is cheaper outside of institutions, he said. "This rebalancing has meant that in the period from 1991 to 2001, the expenditures in home and community-based care in Medicaid have more than tripled, from $6.2 billion to $22.2 billion."

There also has been movement toward changing the financing of long-term care. "The past 6-8 years, most of the focus has been on tax credits for caregivers and more public incentives for the purchase of long-term care insurance," Dr. Friedlander explained.

More fundamental changes need to be made to the long-term care financing system than are currently in place, Dr. Friedlander said. "I think without structural changes, it is likely to be harder for caregivers in the future."

Further, things will only get worse as baby boomers live longer, and there are fewer children to support and care for them. "I would call these the best of times. I think when we get to the real crisis, these are going to look like the good old days."

Greg Sachs, M.D., chief of the section of geriatrics at the University of Chicago, said that when it came to caring for dementia patients, he was "less worried about the advancing number of people and smaller numbers of caregivers … and much more worried about the propensity to overtreat, to not provide good end-of-life care, and in fact, to have a healthcare system that is particularly ill-suited for the ongoing care of people with dementia."

Current financial incentives don't encourage the idea of letting dementia patients die peacefully at a nursing home, Dr. Sachs said. "When the [nursing home] patient has pneumonia and is getting close to dying, the nursing home has to provide more care … but they are not reimbursed more. Depending on where they are and if the patient is on Medicaid, if they send the patient to the hospital they can actually be paid a 'bed-hold,' and they are actually making money while the patient is in the hospital, rather than losing money from having to provide additional care."

In addition, the physician, instead of being paid at a lower rate and doing less frequent visits, "hospitalizes the patient and makes more money by seeing the patient on a daily basis and gets reimbursed at a higher rate," he continued.

"All the financial incentives are aligned for this patient to be transferred to the hospital rather than being cared for in the nursing home and being allowed to die peacefully," he said.

The September meeting was the last one at which Leon Kass, M.D., a fellow at the American Enterprise Institute, would serve as council chairman. The new chairman is Edmund Pellegrino, M.D., professor emeritus of medicine and medical ethics at Georgetown. ■

NIH Eases Stock Ownership Restrictions for Most Employees

BY MARY ELLEN SCHNEIDER
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Officials at the Department of Health and Human Services have loosened restrictions on ownership of pharmaceutical and biotech company stocks for employees of the National Institutes of Health under a final rule on conflict of interest.

But the final regulation announced at a teleconference on NIH conflict of interest regulations continues to bar NIH employees from engaging in outside consulting relationships with industry.

NIH Director Elias A. Zerhouni, M.D., called the final regulation "stringent" despite the changes to stock ownership.

"We have worked hard with the Department of Health and Human Services and the Office of Government Ethics to try to come up with rules that first and foremost protect the integrity of NIH science and are balanced in terms of our ability to continue to attract and retain the best scientists and staff," Dr. Zerhouni said.

Under the final rule, which became effective in August, about 200 NIH employees with senior decision-making authority and their families will be required to divest of all stock holdings in excess of $15,000 per company for organizations substantially affected by NIH decisions. The deadline for divestiture is Jan. 30, 2006.

About 6,000 individuals will be required to disclose more details about their financial holdings. The other approximately 12,000 employees won't be asked to specifically disclose stock holdings, according to Raynard S. Kington, M.D., NIH deputy director. Employees may be required to divest of stocks on a case by case basis if a potential conflict of interest is found.

This is a shift in the policy spelled out by NIH in February 2005 in the wake of a series of congressional hearings that exposed a number of potential conflicts of interest by NIH scientists. Under the policy outlined earlier this year, about 6,000 top NIH employees would have been required to sell off all of their stock holdings in companies impacted by NIH decisions. And the remainder of NIH employees would have been subject to the $15,000 limit.

The changes are designed to target the requirements at employees who are making decisions on grants and studies, Dr. Zerhouni said, and to ease restrictions on employees who are unlikely to have conflicts. "It's impossible to have a one-size-fits-all approach," he said.

The final regulation will also allow NIH employees more leeway to engage in outside activities with professional or scientific organizations, serve on data and safety monitoring boards, give grand rounds lectures, and perform scientific grant reviews. These activities were prohibited under the earlier policy.

The final rule continues to allow NIH scientists with prior approval to participate in compensated academic work such as teaching, writing textbooks, performing journal reviews or editing, and giving general lectures as part of continuing education programs. NIH employees can also practice medicine with prior approval.

But NIH held firm on its prohibition on relationships with pharmaceutical, biotechnology or medical device manufacturers, health care providers or insurers, and NIH grantee institutions.

Keeping in place the ban on these activities is the best way to maintain the integrity of the agency at this point in time, Dr. Zerhouni said.

While some outside consulting activities hold value for NIH and the public, he said the agency currently has no way to distinguish between those positive interactions and others such as product marketing.

The changes were praised as being "right on target" by Mary Woolley, president of Research!America. The stronger interim guidelines released in February were useful as a "cooling off period" and served as an opportunity to gather more information, she said. But the changes reflect the correct balance.

Ms. Woolley said the final regulation will serve as a benchmark for the rest of the research community.

But Sidney M. Wolfe, M.D., director of Public Citizen's Health Research Group said the changes weakened the agency's earlier attempts to get control of the problem of conflict of interest. Allowing NIH employees to participate in paid outside academic work, which frequently includes money from industry, is riddled with loopholes, he said.

The final rule does not impose restrictions on extramural scientists, but Dr. Zerhouni said it's important to have a broad dialogue about conflict of interest with the entire scientific community.

"I think this is a debate that is way beyond that of NIH," he said. ■

For more information on NIH ethics rules, visit www.nih.gov/about/ethics_COI.htm.