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Abstract

William May argues for a middle course regarding euthanasia and assisted suicide, rejecting absolutist positions and makes the point that neither life at any cost nor killing to cure a disease serves society or individuals very well. Elsa Ramsden, David Hufford, Neville Strumpf, Albert Stunkard, all participate in a panel discussion after the formal lecture.

Comments

Boardman Lecture XXXIII. Editor Jane Marie Pinzino.

The Boardman Lectureship in Christian Ethics

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XXXIII

**SOME SKEPTICAL THOUGHTS
ABOUT ACTIVE EUTHANASIA
AND ASSISTED SUICIDE**

Delivered Before
The University of Pennsylvania
March 23, 1994

By

William F. May

Including Panel Discussion
and
Questions and Responses
Following the Lecture

Edited by
Jane Marie Pinzino

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**SOME SKEPTICAL THOUGHTS
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SOME SKEPTICAL THOUGHTS ABOUT ACTIVE EUTHANASIA AND ASSISTED SUICIDE

My title is "Some Skeptical Thoughts About Active Euthanasia and Assisted Suicide." Movements in Western medical ethics today usually divide into two groups—the pro-lifers and the pro-quality-of-lifers. The pro-lifers tend to see death as the absolute evil and the quality-of-lifers define suffering as the absolute evil.

I cannot wholly side with either party to the debate. As a person shaped by the Biblical tradition my reluctance derives from theological grounds. The theistic tradition as I understand it recognizes that neither life nor wealth or quality of life is an absolute good; they are creaturely goods, fundamental goods, derived from God, not God himself. Further, neither death nor suffering is an absolute evil, that is, powerful enough to deprive human beings of that which is absolutely good. Therefore, the goods and ills we know in life are finally creaturely and relative; we are free to enjoy goods, but not utterly and irrevocably desolate at their loss, commissioned to resist evil, but not as though resistance alone provides our final meaning and resource.

This position would not inevitably establish in ethics a distinctive or unique set of guidelines. It would not always call for a different, distinctive line of action, but it would open up a somewhat brighter sky under which to act—a sky cleared of the despair of those who believe that except for life, there is only death, or except for quality-of-life, there is nothing but the final humiliation of poverty. We should not view the moral life as a grim struggle of life against death or of quality-of-life against poverty. Neither should our political life disintegrate into a fierce conflict between pro-lifers and quality-of-lifers, each heaping epithets on the other, each charging the other with moral blindness. In my judgment, both absolutistic positions are ultimately too shrill to control their advocates' own excesses: one group clamors in panic for life at all cost; the other, proclaims, give me quality-of-life or give me (or them) death.

A more relaxed theological perspective suggests that decisions may need to vary in different cases: sometimes to relieve suffering, at other times to resist death. But in any event, decisions should not spring from that fear and despair which often creates the absolutist in ethics.

I do not want to argue that only a theist can hold to this perspective on ethics that I will sketch out for you this evening. A variety of other religious and secular positions might also criticize the absolutistic commitments of the pro-lifers and the pro-quality-of-lifers. I have simply attempted to acknowledge the theological source of my own reservations about the two movements.

In the debates over public policy, a theist ought not, in my judgment, side with either party in its extreme form. The first group would define the medical profession wholly by a fight against death. In my judgment however, physicians should be free to respond to patients' requests to cease and desist in the effort to prolong life when treatment can no longer serve the health of the host. Maximal treatment is not always optimal care. Sometimes it makes sense not only to withhold but to withdraw treatment. To be sure, the Commandment states, "Thou shalt not kill," but also, "Thou needst not strive officiously to keep alive." A physician does not always have the duty to fight pneumonia if such death has become acceptable to the patient in preference to imminent death by irreversible cancer. There is, after all, a time to live and a time to die and a fitting time for allowing to die, the name for which is passive euthanasia.

At the same time, I cannot side, as a general public policy, with the opposite extreme. Neither physicians nor the society at large ought to prize so highly the quality-of-life that they solve the problem of suffering by eliminating the sufferer. This is the solution to evil offered by the advocates of active euthanasia. It aims to relieve suffering by knocking out the interval between life and death, to make one dead as quickly as possible.

The impulse behind the movement for active euthanasia is understandable in an age when dying has become such a protracted, inhumanely endless business at the hands of people committed to the first extreme. But active euthanasia goes

beyond the middle course of the right to die and insists upon the right to be killed. It solves the problem of a runaway technical medicine with a final resort to technique. It opposes the horrors of a purely technical death by using technique to eliminate the victim. It insufficiently honors the human capacity to cope with life once terminal pain and suffering have appeared. It tends to doubt that dying itself can be suffused with the human.

In general, I am in favor of policies that accommodate for allowing the terminal patient (who requests it) to die, but I have serious reservations about policies that regularize provisions for mercy-killing.

Now, on the question of line-drawing, some people would argue that the distinction between allowing to die and mercy-killing is hypocritical quibbling over technique. They would collapse the distinction between passive and active euthanasia. Since the patient dies—whether by acts of commission or omission—what matters the route the patient took there? By either procedure he ends up dead. Since modern procedures, moreover, have made dying at the hands of the experts and their machines such a prolonged and painful business, why not move beyond the right to die to the right to be killed?

John Fletcher, long-time ethicist at the National Institute of Health now at the University of Virginia, has called the distinction between active and passive euthanasia a "worn-out" distinction, or if not worn-out, arbitrary and misleading. Have we not held to the distinction partly because fatal actions seem worse than fatal omissions? But everyone of us can think of exceptions to that rule. Some actions that lead to death can be acceptable. For example: large doses of morphine to relieve severe pain may be quite appropriate even though they may also hasten death. Meanwhile some omissions that lead to death are very serious wrongs. For example: deliberately failing to treat an ordinary patient's bacterial pneumonia when she could recover and live productively or ignoring a bleeding patient's pleas for help are morally unacceptable omissions.

However, in my judgment, the existence of exceptional cases that cross the boundary which generally distinguishes one practice from another does not of itself argue against respecting a line between the two practices. A particular 15-year-old

adolescent may be more mature than the average 17-year-old, but that does not of itself invalidate drawing some line, usually 16, for a driver's license. On a given piece of land, one may not see where one passes from the United States into Canada or the Southwestern USA into Mexico; nevertheless, substantial reasons may exist for drawing territorial boundary lines, even in the absence of such obvious markers as a lake, an ocean, a river, or a mountain range. Upon such fine lines civilized life often depends.

But where, in grave medical issues, should we draw the line? Is the boundary between active and passive euthanasia the right place?

I'd like to go through five arguments—the arguments for active euthanasia, and then I'd like to offer my five comments on them. Two of the five major arguments for active euthanasia surface in the terms "killing for mercy" and "voluntary euthanasia." Active euthanasianists believe that a) respect for the patient's autonomy, and b) compassion should figure foremost in the care of the dying. Those are the first two arguments: the appeal to the autonomy of the patient and the appeal to benevolence and compassion on the part of the caregiver. If we legally prohibit the practice of euthanasia, so the argument would go, we fail to respect the dignity of those who want the doctor's assistance in bringing life to an end. It's a free country, and freedom ought to extend to the choice of one's final exit. Since the patient who consents to his being killed or asks assistance in suicide presumably harms no other person, a legal prohibition against assisted suicide or euthanasia seems unjustified and arbitrary. And further, lacking the option of active euthanasia, we do not act as compassionately as we might; we impose gratuitous suffering on the terminally ill. Those are the first two arguments. Appeal to the principle of respect for personal autonomy and the appeal to compassion as the primary mark of the caregiver.

Patients in severe pain, chronic or terminal, or individuals contemplating the prospect of such a condition offer a third argument: they do not want "to be a burden to others." A somewhat different argument, isn't it? This argument, in effect, once again, appeals to the value of liberty and to the moral importance of compassion. But now the role of the players

reverses. In this case, the patient wants to exit life out of compassion for the caregivers—to relieve them of the terrible burdens of giving care and the daily limitations upon their liberty. Since, moreover, awareness that she is a burden compounds the patient's own suffering, active euthanasia or assisted suicide appeals doubly as an act of mercy: it mercifully provides caregivers relief from their burdens and the care receiver relief from being a burden.

The fourth and fifth arguments for active euthanasia surface not in the terms themselves but in the rhetoric and the literature. The fourth rests on the conviction that dying is a private, personal, intimate event, at most, a matter for the patient in relations to his or her family, friends or physician. The public has no business or interest that justifies regulating or interfering in this private event. You find that both in the literature in Holland as well as the literature dealing in this country with policies that would allow for active euthanasia.

The fifth argument, which overlaps with the insistence upon the patient's autonomy, reflects the general fear of losing control. It is control which a "how to" book on killing oneself, (a recent book, *Final Exit*, a kind of recipe book on doing yourself in), or on arranging assistance in suicide seems to reinstate. This last argument reflects a very American aspiration on which the large number of "how to" books lining the shelves of every drugstore, bookstore, and library in the country seek to cash in. We prize as a people independence and abhor dependency and loss of control. Why not then a book that reasserts total control over life, even over the last gasp of suffering, letting us design our own death. Furthermore, opening up the option of active euthanasia might also help to restore a sense of control to physicians who have seen their powers reach an intractable limit in the patient beyond the reach of their remedies.

Opponents of policies that would regularize the option of active euthanasia, (and now I offer my counter-case), have grounds for skepticism about each of the five arguments in its favor. First, behind its emphasis on the voluntariness of the act lies, what Richard McCormick has called the "absolutization of autonomy."¹ A libertarian insistence on the unconditional right of self-determination (except for those actions that

would limit the freedom of others or harm them without their consent) would, carried to its logical extreme, lift prohibitions not only against consensual acts of killing, such as voluntary euthanasia and assisted suicide, but also against dueling. If two adults have consented to it, let's assume that they are without responsibilities for other folks and so forth, why can they not engage in this action? If they have consented to it, and haven't hurt anyone else? It might also provide no grounds for prohibiting slavery, should the enslaved person consent to his or her own degradation.

Not all libertarians would push to that extreme, but they do tend to honor men and women simply as individuals, and neglect the doubleness of human existence. We are individuals, to be sure, but also parts of a whole. The whole, the society, has an interest in us, not simply when we harm others but also when we harm ourselves, an interest which grows in proportion to the magnitude of the harm. As Dan Callahan wryly observed, "Consenting adult killing, like consenting adult slavery or degradation, is a strange route to human dignity."²

Further, and this is the point I really want to get to here, because I don't think most people hold to the most extreme view, the notion of voluntary euthanasia—viewed as an expansion of the patient's right to determine his or her own destiny—may harbor an extremely naive view of the uncoerced nature of the decision. The decision and plea to be killed is hardly an unforced decision if the terms and conditions under which we deliver care for the dying is already woefully mistargeted, inadequate, or downright neglectful. When elderly patients have stumbled around in apartments, alone and frightened for decades, when they have spent years warehoused in geriatrics barracks or when they have not been visited by relatives for months, or when relatives dump them off in emergency rooms to be rid of them for a holiday, then the decision to be killed for mercy hardly reflects an entirely uncoerced decision. Their alternative may be so wretched, repellent, and disgusting as to push some patients towards this resolution of their plight.

Second, it is a huge irony and, in some cases, hypocrisy, to talk suddenly about a compassionate killing, when the aged and dying may have been starved for compassion for many

of their declining years. To put it bluntly, a country has not earned in good conscience the moral option to kill for mercy if it hasn't already sustained and supported life with compassion and mercy. Active euthanasia could be a final solution for handling the problem of the aged poor. (We have some 37 million Americans without health care insurance, the only industrialized country other than South Africa that so neglects a major portion of its citizens in the provision of acute care. The provision of active euthanasia provides too many people with an offer they might feel, given the alternative, that they cannot refuse.) I had the occasion to debate with Derek Humphrey, author of *Final Exit*, at the medical school in Little Rock. And afterwards, a woman rose, for there were lots of followers of his movement present, and she said, "I would like to say to you that if my doctor refused to follow my instructions and to kill me, I would fire him." And I said, "Madam, you're fortunate to have a doctor. My problem is the large number of Americans who do not have the option, and therefore how uncoerced is the decision?"

Further, the test of compassion lies, not in the investment of yet more money in acute care facilities (we already spend too much of the health care dollar on acute care facilities), but rather in the shift of substantial amounts to preventive medicine, rehabilitative medicine, chronic care, terminal care, and strategic home services. When I talk about people having options in their lives, those are the services that are increasingly lacking in our culture. These are the options that are required for people to have a humane alternative to a quick death. Otherwise we cumulatively kill for compassion only to reduce the demands on our compassion. Lacking adequate provision for chronic care and home assistance, we nudge towards the exit not only the solitary, neglected patient but also the patient who watches his decrepit and overburdened mate sorely attempt to give him care without humane respite. This statement about compassion does not charge a doctor or family member in a given case with less than the purest motives. I'm not trying to talk about the individual case and say there's a lack of compassion in that case. The test of compassion is not simply the individual case but the cumulative impact of a social policy.

Admittedly, this argument is partly culture-specific. One

can imagine societies that provide adequately for the stricken and the elderly and also provide legal permission for active euthanasia in those instances when a person may opt out of that care. But one hesitates to make legal provision for a form of care that provides simply a convenient final solution for its general carelessness.

While at the level of policy this argument is culture-specific, it is not relativist at the level of moral principle. It argues that we owe care always. Most of the time care takes the form of treatment and efforts to cure. At some point, treatment becomes futile, but, while we cease to treat, we should not cease to care. This is the moral principle behind passive euthanasia; that is allowing to die.

Admittedly, passive euthanasia, as I conceded at the outset, is also subject to abuse. No line-drawing solves any and all problems. But, at least, abuses of passive euthanasia clearly indicate the underlying principle that justifies allowing to die, that is, the principle of care.

Continued prohibitions, therefore, against legalizing active euthanasia should be accompanied by full and proper use of passive euthanasia. We have not fully developed the resources for the relief of pain as we should. The tests of the patient's welfare and his or her rights of self-determination should apply not only to starting the machines but also to stopping them, not only to withholding treatment but also to withdrawing it, not only to the use of extraordinary means but also to the employment of ordinary means. Otherwise passive euthanasia can lead to inappropriate treatment and patient abuse.

Furthermore, a prohibition against active euthanasia carries with it an even more intense responsibility to make sure that no patient, especially those who are being allowed to die, should be abandoned. As efforts to treat cease, efforts to care for, make comfortable, and console must intensify. Dr. Joanne Lynn, the distinguished hospice physician and member of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, wrote a fine Appendix for the Commission's volume on *Deciding to Forego Life-Sustaining Treatment*. Her essay fully details that care, which our obsession with TV spectacular medicine has tempted up to neglect: the more effective use of drugs to

control pain, even though the drugs may hasten death; the adroit management of various symptoms, gastrointestinal, respiratory, and agonal; treatments for skin problems, fever and weakness; and aids to mental function. These prosaic tasks, which high-tech medicine has tended to dismiss as hand-holding, in fact, are part of the modest efficaciousness of care.

However, medical research and education have not fully focused on the pressing needs of the dying. As Dr. Lynn elsewhere complained, "Often it is easier to get a heart transplant or cataract surgery than supper or a back rub, let alone effective pain relief."³ Or let alone care of those who are suffering emotionally, we might add here. Dr. Kervorkian may engage in overtreating his patients with assisted suicide, because he has attracted those who have been undertreated for depression. Apparently the zealous missionary never bothered to have the first nine of his patients psychiatrically evaluated before he helped them die. A 1991 *New England Journal of Medicine* editorial noted that 90% of suicides among the 30,000 suicides a year suffer from depression. "One study of 45 terminally ill patients showed that only three patients considered suicide, and when they were examined psychiatrically, it was discovered that they suffered from major clinical depression."⁴ So what we have to think about is appropriately targeted treatment for the dying patient. It seems to me that we haven't fully developed these resources. Instead of caring appropriately for the dying, the active euthanasia movement tempts us to swing smoothly from aggressive treatment to keep alive to equally aggressive treatment to kill.

Patients (often aging patients) offer a third argument for active euthanasia (less an argument than an expressed wish) that they would not like to end up a burden to others. We hear that often, don't we? At first glance, this argument seems far removed from the underlying individualism of those who argue for active euthanasia on the basis of the patient's autonomy. This plea reflects the moral sense that we are not merely individuals but parts of a larger whole, and the worry is about being a burden. We do not want to impose ourselves burdensomely on others. Far from making an imperial claim to autonomy, the person so disposed insists only on her freedom to make a decision which she deems to be for the benefit of others.

While not denying the self-sacrificial character of such a patient's sentiment or action, (one cannot pompously stumble in and trample on that kind of statement from a person), one wonders whether the total moral setting which gives rise to it actually reflects the sense that we are parts of a whole. I am truly and fully a part of a community not only when I am willing to make sacrifices for others, but also when I am willing to accept their sacrifices for me. Community is a two-way street of giving and receiving, not giving alone. In some circumstances and stages of life, we are primarily givers, at other times we should not be too proud to be receivers. At its healthiest, community depends upon interdependence, upon a reciprocity of giving and receiving. That's what it really means to be part of a whole.

Further, the painful domestic plight of the chronically dependent patient, who desperately seeks to relieve her caregivers through her own death, already reflects a society which insufficiently supports overburdened care-givers or fails to provide them with adequate respite from their labors. Our lack of social supports for home care and long-term care reflects a society harshly atomistic in its thinking. It thus demands from the unlucky a level of sacrifice which only the most saintly could sustain. While we may admire the sacrificial responses of the disabled or the dying who would spare members of their immediate circle from making heroic sacrifices, it is difficult to admire the moral commitments of a nation that would push individuals and families to these extremities, without adequate assistance and support.

The fourth argument defines dying as an intimate, private, at most, familial act and therefore inappropriately subject to public regulation and scrutiny. It's a private matter—therefore the state has no business in making laws forbidding it. This argument overlooks the public element in all of human life from birth to death. Birth is our first caterwauling public appearance, and death, our final exit from the public scene.

A society cannot plausibly wash its hands of the practice of active euthanasia and say that the doctor's cooperation in killing is a purely private matter. A huge public investment supports the training of doctors and places medical resources as their disposal. Further, the very nature of the decision to

euthanize perform implicates the society in the deed. The physician has to agree to it, and the society has to permit it. There's a heavy public involvement in this business. Daniel Callahan has pointed out that "three patients can suffer from the same condition and only one will find the suffering unbearable."⁵ The judgment reflects not simply the medical condition but the values of the patients. In effect, then, the doctor will be treating the values of the patient, not simply the disease and the request to be killed.

A doctor could not responsibly accede to the request unless he or she shared the values. Inevitably, this transaction pushes the decision out into the public arena. Quoting Dan Callahan, "Euthanasia is not a private matter of self-determination. It is an act that requires two people to make it permissible and acceptable."⁶

Further, the denial of the public significance of dying intensifies the problem of the slippery slope, the thin edge of the wedge, or the camel's nose under the tent (pick your own metaphor). If we allow this to happen, it will start small but will grow big. This is the slippery slope. And what I'm suggesting here is if you define it as a purely private act, in which the state doesn't have any business, then it's very hard for the state to monitor it to make sure it isn't abuse. Advocates of active euthanasia, it should be acknowledged, argue that they have protected against the slippery slope. In the Netherlands, for example, the law requires that the patient's condition must be irreversible, and terminal, with death imminent. The patient should also authorize his or her being killed by explicitly granting consent. The act should be performed only by doctors, and it requires the authorizing signature of at least two doctors: the doctor to perform it, and yet another doctor who is not directly involved. These various regulations serve to protect against the bizarre whims, the malice or the neglect of third parties or against the vicious, involuntary euthanasia practiced by the Nazis in the 30's and 40's. Advocates have written similar protections into the Humane and Dignified Death Acts proposed in this country and elsewhere.

It is difficult to imagine that a country as flat as Holland could produce a slippery slope. However, despite the country's many regulations governing active euthanasia, the Report of

the Dutch Governmental Committee on Euthanasia, September 10, 1991 seems to suggest that there is one.⁷ Out of the total of 130,000 deaths in the Netherlands per year, some 6,000 or 4.6% of all deaths are cases of involuntary active euthanasia, despite the restrictions against it in administrative provisions. This figure includes not simply the 1,000 explicitly identified and reported cases in active involuntary euthanasia, but also the 4,941 cases of which doctors report giving morphine not simply to relieve pain but for the express purpose of terminating life, and I would call these cases of active euthanasia. Further, "in 45% of the cases in which the lives of hospital patients were actively terminated without their consent, this was done also without the knowledge of the families."⁸ Of the 4,941 cases of morphine overdoses given with the express intent to kill, 27% were done without a fully competent patient's knowledge.

Sixty percent of practitioners failed to consult another physician before killing without patient consent, and doctors, "with a single exception, never stated the truth in the death certificates." Physicians also flouted the rules governing voluntary euthanasia. Nineteen percent of physicians disregarded the rule to consult another physician. Fifty-four percent failed to record the proceedings in writing; and 72 percent concealed the fact that patients died by voluntary euthanasia.⁹ These findings were all written up in an article by a Dutch gentleman by the name of Fenigsen who did not have an agenda but simply drew up a summary.

The tendency of Dutch practice to slip from the moorings which the country's regulations originally supplied may follow from the appeal to the intimacy and privacy of the act of dying. To insist that dying is a private act places it, in principle, beyond public regulation and control. It seems to me that it's very important for not only what the law does say, but for the reasons given for the law. Sometimes the reasons given for a law can cast a longer shadow than the law itself. If one of the reasons you're given for the law is that it is a purely private event, then there's something essentially illegitimate about the very regulations established to prevent against abuse, because you have claimed that the act is merely private in character.

Further, I think it is important to realize that as Carlos Gomez, who has written a book on the Netherlands practice

and is opposed to the act of euthanasia, has said that, "To suggest that what transpires between the physician and the patient, even at the hour of the patient's death, is an entirely private matter is, however to overlook the public institutional quality of the profession of medicine . . . for all its necessarily private and intimate aspects, . . . [it is] necessarily a *public* enterprise . . . the claim to a right to death at the hands of a physician is essentially a private claim to a public good."¹⁰ (Gomez, p.134). And it seems to me that the state has a stake in it.

Please note that the slippery slope that concerns me is not the one conventionally feared: the lethal slide from the early Nazi practice of active euthanasia to Hitler's later policies of genocide. When people talk about the slippery slope, what they're usually talking about is what happened in Germany in the 1930's, when he began to euthanize the mentally retarded and then suddenly you ended up with euthanizing an entire people. The chief danger we face in my judgment is not a demonic, totalitarian, political ideology, but rather, marketplace seduction. We need fear less the dictator who makes us do what we do not want to do (i.e. George Orwell's *1984*) than the seducer who stirs our desires to do what we ought not to do (i.e. Aldous Huxley's *Brave New World*). We are probably less vulnerable in this country to the bark of the dictator's command, "kill 'em", than to the sweet talk of money, that tells us we've got better uses for that money than to make Grandpa's life bearable. "If the Netherlands, with its generous coverage, has problems controlling euthanasia, it takes little effort to imagine what would happen in the United States"¹¹, with a population ravenously dedicated to its own quality-of-life.

Now just why is the slippery slope worth thinking about? One of the original justifications for voluntary euthanasia is control of one's own dying. But the crossing of the boundary from voluntary to involuntary euthanasia means the loss of control over one's dying. It means putting to death someone against his will or without his will. The bottom of the slope contradicts the justifying ideal at the top of the slope.

The fifth and final argument for active euthanasia reflects the American obsession with solving problems through technical control and a corresponding fear and sense of

resourcelessness before the uncontrollable. So obsessed, we seek to solve the problem of diminishing control over our lives by controlling the exit. That was the fifth argument which I suggested.

No response to this argument can dismiss technical problem-solving as an important moral resource in life. How could anyone in the country deny the importance of controlling and solving problems? But many of the problems which confront patients and their families do not admit of a technical solution. They must be faced rather than solved. However, the lack of a solution to a problem does not automatically condemn us to resourcelessness before it. We sometimes assume, to our impoverishment, that we have only two options: either controlling our lives or submitting passively to them.

Unfortunately, narrowing our moral lives to the options of control and passivity overlooks an important range of human responses—particularly to events such as death which are tinged with the sacred. Sacred occasions or holy days are set apart from other days. They are the days in which the ordinary canons of mastery and control do not work. Karl Barth once distinguished work days from holidays in the sense that on work days we make things happen; on holidays we let things happen. However, the letting things happen of the holiday is not a state of mere passivity. By "taking in" the sacred occasion—the puberty rite, the marriage, the public gathering, the day of atonement, the Good Friday service—we let the occasion, in a sense, do the work, as it defines us.

Serious illness and death often resemble the holiday and other defining moments in life that call for decorous response rather than control. The wife of a college president once said to me, "I could do nothing about the death of my husband. The chief question I faced was whether I could rise to the occasion." With one stroke, his death altered the very terms of her daily life and intimacy and transformed her from a person with a clear-cut public role in the college to one of superfluity. How could she rise to an occasion that redefined every moment of her daily life?

Further, it is not only the bereaved who may need to rise to the occasion but we ourselves in the course of our own dying.

The community needs its aged and dependent, its ill and its dying, and the virtues they sometimes evince—the virtues of humility, courage, and patience—just as much as it needs the virtues of justice, courage, and compassion in the agents of its care.

Taking the arguments cumulatively and on the whole, I am in favor of a social policy that would permit the practice of allowing to die, rather than killing for mercy; that is, which would recognize that moment in illness when it is no longer meaningful to bend every effort to cure or to prolong life, when it is fitting to allow to patients to do their own dying, with gentle assistance in the management of pain. This policy seems most consonant with the obligations of the community to care and the patient to rise to the occasion.

Endnotes

1. *The Christian Century*, December 4, 1991, p. 1132.
2. *The Hastings Center Report*, March-April, 1992, p. 52.
3. Quoted by Peter Steinfels in *The New York Times*, February 14, 1993.
4. Information offered in the same *New England Journal of Medicine* editorial and cited by Nicholas A. Pace, MD, *The New York Times*, February, 1993.
5. *The Hastings Center Report*, March-April, 1992, p. 53.
6. *The Hastings Center Report*, March-April, 1992, p. 53.
7. For the data in this paragraph, see Richard Fenigsen, MD, Ph.D., "The Report of the Dutch Governmental Committee on Euthanasia" in *Issues in Law and Medicine*, Vol. 7, Number 3, 1991, pp. 339-344.
8. Fenigsen, p. 343.
9. Fenigsen, p. 343.
10. Carlos Gomez, *Regulating Death: Euthanasia and the Case of the Netherlands*, (New York: The Free Press, a Division of Macmillan, Inc., 1991), p. 134.
11. Gomez, p. 138.

PANEL DISCUSSION

Elsa Ramsden, Professor, School of Nursing, (moderator):

It's really my pleasure to be here this evening and act as moderator. It gives me the delightful pleasure of introducing three colleagues and not being responsible for what they say. I will introduce them in alphabetical order and ask them to speak in that order and they will restrict their comments to five to ten minutes so that you can engage with the four of them in discussion afterwards. Our first panelist is **Dr. David Hufford**, Adjunct Professor of Folklore and Folklife here at the University, and Professor of Humanities at Penn State University College of Medicine at the Hershey Medical Center. Our second speaker is **Dr. Neville Strumpf**, Associate Professor of Nursing and member of the Bioethics Committee in the Schools of Medicine and Nursing and former Chair, and she's Director of the Gerontological Nurse Practitioner's Program. Our third speaker is **Dr. Albert Stunkard**, Professor of Psychiatry, Director of Obesity Research, Chair of the Bioethics Committee in the School of Medicine. So first up is David Hufford.

David Hufford

Rarely have I been given the opportunity to comment on a lecture where I have so little to disagree with over what was said. I really am in very broad agreement with Professor May's positions. So what I will limit myself to is a little underlining and some modest extensions on some of his points. Stephen Carter suggested that part of what is important about the valuing of religion in society is that for moral discourse, religious viewpoints add an important dimension to the variety of points of view. I think Professor May's position amply illustrates that. Certainly the position that he grounds in Christian Scriptural tradition is a theological position and it flows from a transcendent theological foundation in which temporal good and temporal evil are not ultimate. I think that is very appropriate. At the same time, this is a position that I have found transcends

the boundaries of particular religious traditions or religiosity in general. Because I think he makes a very good case for basic social and psychological values that also similarly argue for this point of view. It's one of those cases which I think is often found in which good theology and good social, psychological and ethical analysis lead to very similar conclusions. On the matter of autonomy, I am particularly pleased with his point about the doubleness of human existence and the overlapping social and individual aspects of human life which are, I think, the strong argument against radical positions on autonomy. The social dimension of an individual's life is strictly bound up in this cultural issue. Professor May has noted the idea that eliminating suffering by eliminating the sufferer can have negative consequences for the society. In part, this is because the sufferer is socially important. I think it's a brave thing to point out as he did that among the reasons that a sufferer is socially important is the virtues that are often called forth in suffering by the sufferer: patience, humility, courage and so forth. Now of course, that would never be a good reason for prolonging suffering. But it is an extremely good reason for the caregiver not to recoil from the sufferer, but to value the opportunity to minister to, to care for the sufferer. That also leads to another aspect of the social dimension of this issue which I think was made very well by Professor May, and that is that voluntary requests for active euthanasia are often tacitly coerced, or at least their fully voluntary nature is often problematic. And the coercion I think in this case arises from the stigmatization of the sufferer. If their social experience of themselves is as being repellent and burdensome, and at the same time if they are faced with the prospect of inadequate care for their suffering, then certainly calling the decision to accept the offer to exit sooner rather than later can scarcely be called uncoerced. And I think that it's here that perhaps the strongest case exists for the social value of the sufferer to those around her or him.

I also thought that Professor May's point about the importance or in our case, perhaps the absence of a clear social conscience before the possibility of a policy permitting mercy-killing is terribly important. The evidence from Holland of the slippery slope certainly supports the idea that complex motives

enter into and have the possibility of even corrupting what appear to be principles and compassionate practices. Our history also offers other examples of this. The illustration that immediately occurred to me was the way in which in the 70's the de-institutionalization of the mentally incompetent was in many cases coopted for expedient purposes, and in a great many cases came to serve inappropriate ends. The right not to be warehoused in an institution became for many the right to be abandoned in the community without support or treatment. That is a very slippery slope indeed. The excellence of a moral principle can never be separated, in policy issues especially, from the demonstrated inclinations of the community to support or corrupt that principle. Professor May notes the great danger of the marketplace to seduce us to do what we ought not to do, and I agree. I think we ought to be especially afraid of those arguments that provide a high moral ground for those policies which are very convenient and very economical. Active euthanasia certainly presents such a risk.

I also felt, and this is a point made very briefly but I found it especially powerful partly because of personal experience, his point that unless we have an articulate and sophisticated notion of what it means to allow to die, which includes the possibility of withdrawing extraordinary measures, we really run a terrible risk of abuse through allowing to die. And I say personal experience because this past fall my mother died of a cerebral hemorrhage, and it came on very suddenly and we rushed her to the hospital and I was with her in the emergency room, and as we went step by step in determining what was wrong, at each point I discussed with her physicians her desire not to have her life saved heroically if there were no possibility of her recovering. We went to ventilation using a ventilator in order to support her through having a CAT scan in order to determine what the prognosis actually was. Having completed that, and having a disastrous prognosis, and being told by the neurologist that there really was no point in aggressive intervention. They could have done surgery, but there was no prospect other than several days of prolongation of her suffering. We decided to stop treatment. They said at that point too that we should have her taken off the ventilator. We waited because there was some family who needed to get

in and have another twenty minutes to finish their business with mom, and then to remove her from the ventilator. Those things were done; it took about twenty minutes and then at that point we discovered that the attending physician in the emergency room, while he would have been willing not to start the ventilator, was not comfortable with withdrawing the ventilator. And it took us almost four hours before the neurosurgeons who had made the initial prognosis were available because they had gone back into the operating room. They were the ones who had to take her off the ventilator. And there was an additional four hours or so of very uncomfortable procedure. It was unnecessary, and I think that illustrates exactly what Professor May is talking about.

And then finally, I'll say that I think that one of the great strengths of the position that Professor May marks out is that it not only informs our ethical position with the terminally ill, but it embraces the kind of set of values that would change medical care in general. If, I think the phrase that he used was "the modest efficaciousness of care" in referring to palliation, reducing pain, the backrub, the meals, the emotional support—if those things came to be recognized as successful measures, which can only happen if success is not measured entirely in terms of whether the patient lives or dies, and which can only come about when we recognize that all patients are going to die, which seems kind of obvious, but when you listen to the discourse in medicine it sounds as though some patients are going to die and some aren't. But none of us are getting out of here alive. If we could embrace that and recognize that, then I think that those principles and the actions they would foster would allow not only for the more compassionate treatment of the dying, but it would also, number one, allow those providing that treatment to take satisfaction in that care without experiencing it as failure; burn-out would be less of a problem, but it would also make care of the chronically ill and the care of those with disabilities much more highly prized medical activities and specialties. And in fact not only those, but primary care in general. Many of the things right now that health-care reform is aimed at in terms of moving away from tertiary care specialties towards more modest forms of care, I think that in order to accomplish those, this change in values which is

supported I think eloquently by Professor May need to come about. So those are my thoughts and I certainly appreciate the very fine presentation of Dr. May. Thanks very much.

Neville Strumpf

I also agree that Dr. May has provided us with an extremely provocative paper and one that rejects absolutist positions and clearly makes the point that neither life at any cost or killing to cure is not possible to serve us very well as individuals or society. Unfortunately, as most of you know we have a health-care delivery system which presents us with the peculiar paradox that cure is the most compelling ideal, one that we hold in much higher esteem unfortunately than care. And I think it's part of the reason why assisted suicide is so appealing to us. When we are operating in a system that isn't very caring, and when the cure model has failed us, we see no other alternatives and I think that your paper has illustrated that extremely well.

Dr. May put forth five arguments or reasons why active euthanasia is so seductive. And I would just like to comment briefly on these arguments as they pertain to the frail elderly since that is the group of persons that I'm most concerned with. First of all, Dr. May presented some discussion that centered around the idea of killing for mercy. And I guess I would ask the question, who will qualify for such killing? Some of the individuals I see and work with are very fragile, mentally and physically. They're being tube-fed; they're often confused; they may not be able to get out of bed; frequently they are restrained. Whenever anything acute happens, they're shipped off to the hospital for a day or two and they come back into a nursing home. The question I would pose is: how much have we contributed to some of the kinds of situations that exist? The confusion, the restraint, the immobility and incapacity. We actually bear some responsibility as providers for having created those situations in the first place. And having grown frustrated with them, we would now like to remove them from our awareness.

Secondly, Dr. May talks a little about the business of autonomy and our desire to allow patients to receive the care they most desire. And on that note, you didn't say too much

about advance directives, but in some of the life-care communities in which I'm involved, there's an enormous push to get everyone to fill out their advance directive. In an effort to convince them that they are indeed choosing whatever it is they would like to have. I am partially in favor of that; I think that people do need to think about what they would like at the end of life and they need to have an ongoing conversation with their provider about that. On the other hand, many people express to me their fear and anxiety about having written such a document—we will somehow abandon them in the end. I think we'll need to give a little bit of thought to that. A colleague of mine is currently engaged in a study of nursing home residents, asking them about the treatments they would like if in fact they had to go to the hospital for an acute condition. And what has surprised all of us is the frequency with which they continue to choose treatment. I think part of the explanation for that is that their very vulnerable and fragile state has underscored for them how easily they might be abandoned. And so when asked about care and their understanding about "Will you care for me?" involves a highly interventive treatment, they say, "Yes, I want that." Because saying "no" means you're shunted aside. I think this issue of autonomy gives us something to think about in terms of how we paint that for patients.

The third position that Dr. May discusses in some detail is this business about being a burden. Certainly many older patients express to me their anxieties about being burdens to their spouses, their partners, their children and to others. I think we need again to reaffirm how we can support people in roles that are independent and interdependent and dependent and be comfortable with that. Everything is sort of couched in the phrase, "If you're a burden, it's bad." It will create such problems for everyone that the best choice is to remove yourself from the situation. I think we need to work through that a little bit more.

For the business of dying as a private occasion I would comment on the fact that most older people in our society still die in the hospital. Very few die at home. Others of course die in nursing homes. Rather than paint the picture of it being so private, I would be much more concerned with how lonely

that dying is. I had an experience several years ago of participating in someone's death in a way that I had never done it before. It was an older, professional colleague who was sure that she would die sometime in the next 24 hours. She was in a hospital and I sat and held her hand through that 24 hour process. I had promised myself that she would not die alone. As the business of acute care swirled around me, I was really struck with how often I had been in the situation in continuing to deal with the business at hand and how little I had participated in the occasion. That event was very transformative for me. So I would ask that we rethink this "cure" business and think about the occasion of dying and how we encourage the caretaker to participate in that occasion when families and others are not able to do that.

Lastly, this issue of control. I think what we need to do is restore control by enhancing possibilities for ethical decision-making and responsibility throughout the illness and dying process. I like Dr. May's point very much that we like to solve problems rather than facing them. I have a friend right now, this evening in fact, who is working with a patient, an elderly woman, a quite famous woman for the social activism that she has participated in all her life. She has no family, lives alone in Philadelphia, and she wants to stay in her home. She wants to die in her mother's bed. At this point, her lawyer is very concerned about the finances. The friends that she has feel that she can't stay in the home. But this is where she wants to be. The dialogue on this is I'm sure a very argumentative one about who should win in this situation. I suggested to my colleague to ask everyone in the room tonight, "What do you want most to happen?" I think the person most responsible for finances will want to know how they will pay for homecare. I know that my elderly friend wants to be assured that some way, somehow will be found to allow her to stay where she is. Somewhere during the course of the evening someone is probably going to wish that she was dead. One can understand why. It won't be an easy conversation. But I think it goes along with what has been said here about facing up to it and knowing there won't be an easy solution and struggle with some of these dilemmas. Those are my comments and I thank you very much for a very lively, thoughtful paper.

Albert Stunkard

Well I would too like to thank Professor May for his eloquent presentation. I was impressed with the thoughtful consideration given to the context of dying. In a society with the failings such as we have particularly in the care of the sick and the elderly and the poor and particularly by the compassion that shone through this section of the issues. As a psychiatrist, I've got to say that I was very happy that you talked about depression and recognizing depression and the possibility of treatment which is a terribly underdiagnosed condition and quite treatable.

Professor Dunning asked me to comment from the perspective of another religious tradition, and I think that was a great idea except that I think he picked a poor exponent. I think he could have gotten a better exponent of Buddhism, the Buddhist tradition. I meditate and I've read some of the books, but that's about as far as it goes. But, it is a good idea to think of it from the perspective of the Buddhist tradition because it is so different from that of the Christian tradition without the historical roots and historicity of Christianity, a tradition without a God, without a soul and without a concept of absolute good and absolute evil. I tried to do a little bit of research about Buddhist approaches to euthanasia but I found almost nothing in the literature. There are things written about Buddhist approaches to suicide and they're quite variable. In the Tibetan tradition in particular, there's a blanket prohibition and it's very much like the Ten Commandments—you're not supposed to do it and it's bad. I think the Zen and the Theravada traditions are a lot more relaxed. From that perspective I found that I resonated very strongly with what Professor May said, and I suppose that the critical issue had to do with suffering, suffering of people and compassion for them in that suffering. Suffering is in many ways a starting point for Buddhist practice. Compassion is one of the major values. I have some idea about how compassion arises from Buddhist practice and the practice of meditation. I thought it might be interesting for Professor May to talk about how compassion arises from the Christian tradition. He spoke about it some but it would be quite interesting to hear the contrasts with Buddhist origins of compassion. I think that would be fascinating for us to hear.

QUESTIONS AND ANSWERS

Elsa Ramsden

It is now my job to invite you to ask questions and raise points for William May, David Hufford, Neville Strumpf and Albert Stunkard.

Question:

Professor May, I'd like to ask you about how to operationalize social policy and a situation that medical practitioners face. There's a man who has been valiantly battling against cancer for three years. He's been treated for depression and is on anti-depressants. He's now riddled with cancer and racked with pain. He has trouble sleeping. He and his wife have asked for sleeping medication and they want a sufficient supply so that, you can guess, death would result. Would you think that it is justified to write that prescription and what issues would you want to raise?

William May

One problem is that you can identify a given case and you say you've exhausted all remedies, so you present a hard case. It seems to me that our problem as a society is that we have to think not only about a particular case. I don't know what my decision would be there if I were a physician. But it seems to me that when you're talking about the law, you have to deal with total practices, and the regularization of practices. One has to measure that particular case against the question of where you draw the line for regularized, routinized practices for the society. My last paragraph ends imagining cases where one would want to cross the boundary. But for all the reasons I gave before that, I think that boundary-crossing is better done on an individual basis, without demanding the protection of the law and the design of institutional practices that would provide me with protection. How I would answer in your case, I'd have to be there to know. You say, "How do you operationalize?" If you mean what decision you should reach, it

would depend a great deal on the extremity of the pain, whether in fact there is no possibility of further relief, whether this person is utterly inaccessible to care that is received as relief and so forth; I would be asking those questions of myself. I would want to be very, very sure that I had exhausted all resources for care before countenancing crossing the border.

David Hufford

It seems to me that the case that Herb brings up is actually a little easier than the one you presented at the end of your paper, in that the request for the sleeping medications is a reasonable request even though your inference that he's going to take it all at once is perhaps a reasonable inference. I'm not sure that anything that I heard Professor May say would require policy, law, or the ethical position to say, "I suspect that any reasonable person in your situation would plan to commit suicide with this stuff, and therefore you can only have two at a time and I'm going to have to watch you take them," which would be a real infringement on autonomy and a loss of control, and there's a point at which the privacy, the autonomy and other moral facets of the case make it such that only extraordinary and extreme measures could prevent suicide. You would not put this guy in restraints because you thought he would take his life.

William May

Yes, I think that's right. There was a discussion of "rational suicide" in philosophy, and I prefer to refer to it as "existentially understandable." That's a lousy phrase, but if you really think of it as rational, you'd almost have to talk someone into it. One would not want to go that far as a health-care provider. But on the other hand, there's certain circumstances in which it would be understandable that a person would do this. The burdens they are bearing are at such a level that it practically asks them to be martyrs or saints to bear those burdens. They have to make the decision as to whether or not they can bear those burdens. Again, I think what you have suggested is a way of resolving it in some cases. It does not resolve it in the cases of those who are comatose and so forth.

Question:

Dr. May, while I was listening to your account of the 1991 Dutch conditions study on euthanasia and the practice in that country, I couldn't help but think of Murphy's Law that if it can happen it will happen, and if that kind of active euthanasia is permitted in one country, very likely the circumstances would be as great or worse in this country. You addressed that matter rather well earlier in your statement. But don't you think, number one that those statistics could be even more serious in this country, and number two, it would be compounded if the kind of medical treatment required for certain patients is simply not allowed under a nationalized health care plan?

William May

My answer to your first question is yes. I say that the chances are more likely that it would be worse in this country—for simply lacking a health-care system that a) reaches everybody and b) articulates the range of services required that is more preventive long-term care than we offer. I think it is extremely likely, and given our attitude toward taxation, we tend to think of the government as King George III, a foreign power, instead of as our government and an instrument of national purpose, so I tend to think it would be worse.