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### Foreword

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## FOREWORD

GABRIEL MORAN\*

Two years ago in New York City there was an intense debate about the use of graphic sexual material in educational programs concerning AIDS. In response to objections based on moral grounds, a prominent leader in the City said: "This is about living and dying, not about morality." Although I sympathized with his side of the debate, I thought that the formulation of his position was unfortunate. It only reinforced the simplistic assumption that morality refers to a collection of private rules that are far removed from the "real world" of living and dying. The public official would have been more helpful if he had pointed out that morality is about living and dying, and that our ethical principles concern public as well as private life.

Moral or ethical thinking ought to be a guide as to how to live in a world where everyone is dying. And in fact ancient thinkers tried to provide such guidance. Plato described philosophy as a meditation on death. Schools as varied as the Stoic and the Epicurean never took their eyes far from death. Modern ethics tried to reverse this attitude. It began as a flight from death into the security of the individual's possession of life, liberty and property.

Before AIDS arrived, the ecological crisis was already beginning to reveal the craziness of a system of ethics that isolates human beings from other organisms and from each other. Of course, the ecological crisis has not stopped us from our destruction of earth, air and water. But like AIDS, the problem is going to become worse and it must eventually get our attention.

It is not easy to find a glimmer of hope in either AIDS or the ecological disaster. One would wish that there were less painful ways to learn the reality of our own finitude. What both have to teach us is the value of brotherhood and sisterhood, the recognition that we need help to get born, that we cannot prosper in life without human and nonhuman support, and that, paradoxically, dying is a communal activity. Many gay men have discovered this last fact in recent years; for the remainder of the population this lesson may await them in the future.

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Much of the medical discussion of ethics takes place under the rubric of a "right to die." What began as a "right to dignity even while dying" gets truncated into a formula that can be a new and cruel burden. The dying person's first right is to be treated as a human being—to be physically cared for, to be spoken and listened to, to be affectionately held and loved until the end. Most of us are not ready for AIDS to teach us this lesson, but in a few years we may have no choice other than to turn into callous monsters or else to learn how to care for the dying who are all around us.

Reading the newspapers these days, I am often reminded of the first part of Albert Camus's allegorical novel, *The Plague*. The people of the novel's setting, Oran, scoff at the idea of a plague in a modern city. Even as the evidence mounts that this unspeakable horror is spreading and that it will overwhelm medical resources, people keep pretending that it is not really so bad, and, after all, the people who are sick must have brought it on themselves.

The townspeople in *The Plague* keep seeing hopeful signs that the plague is receding. And, indeed, it does reach plateaus, only to break out with greater fury. Most of today's non-AIDS population can go about its business, content that the plague will not touch them. The fear of a few years ago that AIDS was about to explode into the "general population" has abated, even though it is not clear why the spread of AIDS has been restrained in the United States. But who knows with absolute certainty the pace and rhythm of the plague? In any case, the hope to confine AIDS to the "non-general population" is not completely reassuring. One gets the vision of the central area of Manhattan or a large slice of San Francisco being cordoned off into death camps.

In early 1990, AIDS became the worst 20th century epidemic in the history of New York City. The burden on the medical resources of the City is already overwhelming, and everyone knows that the strains are increasing every day. This horrible bind is for the most part met with deafening silence. One would like to think that the population and its leaders have been stunned into awed silence by the mystery, complexity and challenge of AIDS. The more likely explanation is that there are so many distracting things to talk about in New York and Washington. Silence on AIDS is complemented with endless chatter about mergers, divorces and the drift of the markets. The fact that more than fifty per cent of AIDS sufferers in New York City are non-white unfortunately does not stimulate

attention being paid or political capital being expended on their behalf.

These sober reflections bring me to some introductory comments on the three superb essays that follow: "A Decade of a Maturing Epidemic: An Assessment and Directions for Future Public Policy" by Larry Gostin; "Ethical Challenges of HIV Infection in the Workplace," by Arthur S. Leonard; and "AIDS, Health Insurance, and the Crisis of Community," by Robert Padgug and Gerald Oppenheimer. The essay by Gostin is a comprehensive picture of what has become a consensus of most health officials, but what is also a scandal of inaction on the part of political leaders. The essay by Leonard is focused on the workplace and the responsibility of employers, but the essay leads to the broadest questioning of our whole system of health care provision. The essay by Padgug and Oppenheimer concentrates on the health insurance industry as a crucial part of that health care system.

"A Decade of a Maturing Epidemic" traces in a careful and precise way what has been learned about AIDS and what are the steps needed to face this challenge. What emerges in the essay is a frightening conflict between public health and public opinion, along with a political leadership that is swayed by the latter. Gostin reports that what has been shown in practice is that people can be educated about AIDS and that they can and do change their behavior accordingly. But much of public opinion is controlled by the desire for punitive action. The groups most hit by AIDS do not have the public's sympathy. Even children with AIDS do not seem to bring forth much compassion.

Gostin takes up the question of mandatory testing and gives a detailed analysis of the arguments in its favor. He decides against the attempt to force people into testing; the far more effective approach is voluntary testing accompanied with counseling resources and treatment centers. Similarly, Gostin examines the debate over providing clean needles to drug users. While admitting that we still have much to study in this area, he advocates as a minimum the relaxing of laws concerning the distribution and possession of needles. (New York City has abandoned its experiment of providing needles after starting a program that was so half-hearted and restricted as to be a bad joke.)

Gostin finishes his essay with a section on confidentiality, a concern that is also central to Arthur Leonard's essay. Both authors appeal for clarification at the state and federal levels. The right to inform another party of the results of a positive

testing for HIV should be restricted to those immediately and urgently affected by this information. People rightly fear that extension of the circle of confidentiality could obstruct them in their ability to earn a living.

Leonard's essay is especially concerned with the difficult economic issues of HIV in the workplace. He elaborates a set of ethical principles that employers, like the rest of us, should live by. He carefully distinguishes what can be expected from the law. But he also hopes that employers will go beyond the observance of the letter of the law so as to do justice to those who are HIV positive and those who have AIDS.

In many cases, as Leonard states, it is not an unreasonable economic burden for the employer to retain an experienced employee who is not disabled in relation to the work. Ultimately, however, the individual employers cannot cope with the economics of the situation. Here again, AIDS presses us to consider its full context: the exclusion of tens of millions of people from health insurance and minimally adequate health care. The contrast between the extraordinary medical technology that the United States possesses and the provisions of health care to the poorest quarter of the population is a scandal.

"AIDS, Health Insurance, and the Crisis of Community" uncovers some of the reason for our unbalanced health care system. The authors trace a half century of narrowing the population that is covered by health insurance. The alarm of a few years ago that health insurance companies were in a condition of imminent collapse has proved to be unfounded. But that seeming good news ironically reveals what is wrong with health insurance: it tends to exclude many of the people who most need it.

Padgug and Oppenheimer argue that the history of turning over health insurance to the richer part of the private sector is indicative of a crisis in our meaning of "community." The authors point out that AIDS sufferers tend to be from groups already placed beyond the boundaries of society's care. Gay men are often pushed into the last resort of Medicaid (where available) or are forced into inventing their own health care system. At the end of their essay, the authors propose some practical steps for sharing the burden more equitably, a movement that might engender a new sense of community.

Those of us charged with educating the public in ethical and religious matters have an obvious but difficult task that is indicated by these essays on public policy. How do we develop

a more compassionate attitude that would support, even demand, more compassionate laws? According to the Gallup Poll, about forty per cent of the population agrees with the statement: "I sometimes think that AIDS is a punishment from God for the decline in moral standards." At face value, the statement is bad enough: the picture of a rather vindictive God who visits plagues on humanity. Just below the surface, I fear, is a worse sentiment: *Those people* got just what they deserved, and I am glad that my picture of God is thereby confirmed.

When one speaks to individuals who are suffering with AIDS, there are few theological sources that seem relevant. Mostly, one has to rely on the Book of Job. The assumption that anyone can provide religious justification for someone else's suffering is itself insufferable. When sitting with a person dying of AIDS, long stretches of silence are sometimes all that is possible. But there remains plenty to be said about the reform of our institutions so that individual suffering is not exacerbated by political and economic injustice. Clear minds and patient pressure are needed, the qualities embodied in the following essays. We are tempted toward furious outbursts followed by exhausted silence, but what will count in the difficult decade ahead is sustained attention to some realistic changes in our public life.

