

*Illness as Metaphor*  
and

*AIDS and  
Its Metaphors*

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for Robert Silvers

Rereading *Illness as Metaphor* now, I thought:

1

By metaphor I meant nothing more or less than the earliest and most succinct definition I know, which is Aristotle's, in his *Poetics* (1457b). "Metaphor," Aristotle wrote, "consists in giving the thing a name that belongs to something else." Saying a thing is or is like something-it-is-not is a mental operation as old as philosophy and poetry, and the spawning ground of most kinds of understanding, including scientific understanding, and expressiveness. (To acknowledge which I prefaced the polemic against metaphors of illness I wrote ten years ago with a brief, hectic flourish of metaphor, in mock exorcism of the seductiveness of metaphorical thinking.) Of course, one cannot think without metaphors. But that does not mean there aren't some metaphors we might well abstain from or try to retire. As, of course, all thinking is interpretation. But that does not mean it isn't sometimes correct to be "against" interpretation.

Take, for instance, a tenacious metaphor that has shaped (and obscured the understanding of) so much of the political life of this century, the one that distributes, and polarizes, attitudes and social movements according to their relation to a "left" and a "right." The terms are usually traced back to the French Revolution, to the seating arrangements of the National Assembly in 1789, when republicans and radicals sat to the presiding officer's left and monarchists and conservatives sat to the right. But historical memory alone can't account for the startling longevity of this metaphor. It seems more likely that its persistence in discourse about politics to this day comes from a felt aptness to the modern, secular imagination of metaphors drawn from the body's orientation in space—left and right, top and bottom, forward and backward—for describing social conflict, a metaphoric practice that did add something new to the perennial description of society as a kind of body, a well-disciplined body ruled by a "head." This has been the dominant metaphor for the polity since Plato and Aristotle, perhaps because of its usefulness in justifying repression. Even more than comparing society to a family, comparing it to a body makes an authoritarian ordering of society seem inevitable, immutable.

Rudolf Virchow, the founder of cellular pathology, furnishes one of the rare scientifically significant examples of the reverse procedure, using political metaphors to talk about the body. In the biological controversies of the 1850s, it was the metaphor of the

liberal state that Virchow found useful in advancing his theory of the cell as the fundamental unit of life. However complex their structures, organisms are, first of all, simply "multicellular"—multicitizenized, as it were; the body is a "republic" or "unified commonwealth." Among scientist-rhetoricians Virchow was a maverick, not least because of the politics of his metaphors, which, by mid-nineteenth-century standards, are antiauthoritarian. But likening the body to a society, liberal or not, is less common than comparisons to other complex, integrated systems, such as a machine or an economic enterprise.

At the beginning of Western medicine, in Greece, important metaphors for the unity of the body were adapted from the arts. One such metaphor, harmony, was singled out for scorn several centuries later by Lucretius, who argued that it could not do justice to the fact that the body consists of essential and unessential organs, or even to the body's materiality: that is, to death. Here are the closing lines of Lucretius' dismissal of the musical metaphor—the earliest attack I know on metaphoric thinking about illness and health:

Not all the organs, you must realize,  
Are equally important nor does health  
Depend on all alike, but there are some—  
The seeds of breathing, warm vitality—  
Whereby we are kept alive; when these are gone  
Life leaves our dying members. So, since mind

And spirit are by nature part of man,  
Let the musicians keep that term brought down  
To them from lofty Helicon—or maybe  
They found it somewhere else, made it apply  
To something hitherto nameless in their craft—  
I speak of *harmony*. Whatever it is,  
Give it back to the musicians.

—*De Rerum Natura*, III, 124–35  
trans. Rolfe Humphries

A history of metaphoric thinking about the body on this potent level of generality would include many images drawn from other arts and technology, notably architecture. Some metaphors are anti-explanatory, like the sermonizing, and poetic, notion enunciated by Saint Paul of the body as a temple. Some have considerable scientific resonance, such as the notion of the body as a factory, an image of the body's functioning under the sign of health, and of the body as a fortress, an image of the body that features catastrophe.

The fortress image has a long prescientific genealogy, with illness itself a metaphor for mortality, for human frailty and vulnerability. John Donne in his great cycle of prose arias on illness, *Devotions upon Emergent Occasions* (1627), written when he thought he was dying, describes illness as an enemy that invades, that lays siege to the body-fortress:

We study Health, and we deliberate upon our  
meats, and drink, and ayre, and exercises, and we

hew and wee polish every stone, that goes to that  
building; and so our Health is a long and a regu-  
lar work; But in a minute a Canon batters all,  
overthrowes all, demolishes all; a Sicknes unpre-  
vented for all our diligence, unsuspected for all  
our curiositie. . . .

Some parts are more fragile than others: Donne speaks of the brain and the liver being able to endure the siege of an “unnatural” or “rebellious” fever that “will blow up the heart, like a mine, in a minute.” In Donne's images, it is the illness that invades. Modern medical thinking could be said to begin when the gross military metaphor becomes specific, which can only happen with the advent of a new kind of scrutiny, represented in Virchow's cellular pathology, and a more precise understanding that illnesses were caused by specific, identifiable, visible (with the aid of a microscope) organisms. It was when the invader was seen not as the illness but as the microorganism that causes the illness that medicine really began to be effective, and the military metaphors took on new credibility and precision. Since then, military metaphors have more and more come to infuse all aspects of the description of the medical situation. Disease is seen as an invasion of alien organisms, to which the body responds by its own military operations, such as the mobilizing of immunological “defenses,” and medicine is “aggressive,” as in the language of most chemotherapies.

The grosser metaphor survives in public health education, where disease is regularly described as invading the society, and efforts to reduce mortality from a given disease are called a fight, a struggle, a war. Military metaphors became prominent early in the century, in campaigns mounted during World War I to educate people about syphilis, and after the war about tuberculosis. One example, from the campaign against tuberculosis conducted in Italy in the 1920s, is a poster called "*Guerra alle Mosche*" (War against Flies), which illustrates the lethal effects of fly-borne diseases. The flies themselves are shown as enemy aircraft dropping bombs of death on an innocent population. The bombs have inscriptions. One says "*Microbi*," microbes. Another says "*Germi della tisi*," the germs of tuberculosis. Another simply says "*Malattia*," illness. A skeleton clad in a hooded black cloak rides the foremost fly as passenger or pilot. In another poster, "With These Weapons We Will Conquer Tuberculosis," the figure of death is shown pinned to the wall by drawn swords, each of which bears an inscription that names a measure for combating tuberculosis. "Cleanliness" is written on one blade. "Sun" on another. "Air." "Rest." "Proper food." "Hygiene." (Of course, none of these weapons was of any significance. What conquers—that is, cures—tuberculosis is antibiotics, which were not discovered until some twenty years later, in the 1940s.)

Where once it was the physician who waged *bellum contra morbum*, the war against disease, now it's the whole society. Indeed, the transformation of war-

making into an occasion for mass ideological mobilization has made the notion of war useful as a metaphor for all sorts of ameliorative campaigns whose goals are cast as the defeat of an "enemy." We have had wars against poverty, now replaced by "the war on drugs," as well as wars against specific diseases, such as cancer. Abuse of the military metaphor may be inevitable in a capitalist society, a society that increasingly restricts the scope and credibility of appeals to ethical principle, in which it is thought foolish not to subject one's actions to the calculus of self-interest and profitability. War-making is one of the few activities that people are not supposed to view "realistically"; that is, with an eye to expense and practical outcome. In all-out war, expenditure is all-out, unprudent—war being defined as an emergency in which no sacrifice is excessive. But the wars against diseases are not just calls for more zeal, and more money to be spent on research. The metaphor implements the way particularly dreaded diseases are envisaged as an alien "other," as enemies are in modern war; and the move from the demonization of the illness to the attribution of fault to the patient is an inevitable one, no matter if patients are thought of as victims. Victims suggest innocence. And innocence, by the inexorable logic that governs all relational terms, suggests guilt.

Military metaphors contribute to the stigmatizing of certain illnesses and, by extension, of those who are ill. It was the discovery of the stigmatization of peo-

ple who have cancer that led me to write *Illness as Metaphor*.

Twelve years ago, when I became a cancer patient, what particularly enraged me—and distracted me from my own terror and despair at my doctors' gloomy prognosis—was seeing how much the very reputation of this illness added to the suffering of those who have it. Many fellow patients with whom I talked during my initial hospitalizations, like others I was to meet during the subsequent two and a half years that I received chemotherapy as an outpatient in several hospitals here and in France, evinced disgust at their disease and a kind of shame. They seemed to be in the grip of fantasies about their illness by which I was quite unseduced. And it occurred to me that some of these notions were the converse of now thoroughly discredited beliefs about tuberculosis. As tuberculosis had been often regarded sentimentally, as an enhancement of identity, cancer was regarded with irrational revulsion, as a diminution of the self. There were also similar fictions of responsibility and of a characterological predisposition to the illness: cancer is regarded as a disease to which the psychically defeated, the inexpressive, the repressed—especially those who have repressed anger or sexual feelings—are particularly prone, as tuberculosis was regarded throughout the nineteenth and early twentieth centuries (indeed, until it was discovered how to cure it) as a disease apt to strike the hypersensitive, the talented, the passionate.

These parallels—between myths about tuberculosis to which we can all feel superior now, and superstitions about cancer still given credence by many cancer patients and their families—gave me the main strategy of a little book I decided to write about the mystifications surrounding cancer. I didn't think it would be useful—and I wanted to be useful—to tell yet one more story in the first person of how someone learned that she or he had cancer, wept, struggled, was comforted, suffered, took courage . . . though mine was also that story. A narrative, it seemed to me, would be less useful than an idea. For narrative pleasure I would appeal to other writers; and although more examples from literature immediately came to mind for the glamorous disease, tuberculosis, I found the diagnosis of cancer as a disease of those who have not really lived in such books as Tolstoy's "The Death of Ivan Ilyich," Arnold Bennett's *Riceyman Steps*, and Beranos's *The Diary of a Country Priest*.

And so I wrote my book, wrote it very quickly, spurred by evangelical zeal as well as anxiety about how much time I had left to do any living or writing in. My aim was to alleviate unnecessary suffering—exactly as Nietzsche formulated it, in a passage in *Daybreak* that I came across recently:

*Thinking about illness!—To calm the imagination of the invalid, so that at least he should not, as hitherto, have to suffer more from thinking about his illness than from the illness itself—that, I*

think, would be something! It would be a great deal!

The purpose of my book was to calm the imagination, not to incite it. Not to confer meaning, which is the traditional purpose of literary endeavor, but to deprive something of meaning: to apply that quixotic, highly polemical strategy, "against interpretation," to the real world this time. To the body. My purpose was, above all, practical. For it was my doleful observation, repeated again and again, that the metaphoric trappings that deform the experience of having cancer have very real consequences: they inhibit people from seeking treatment early enough, or from making a greater effort to get competent treatment. The metaphors and myths, I was convinced, kill. (For instance, they make people irrationally fearful of effective measures such as chemotherapy, and foster credence in thoroughly useless remedies such as diets and psychotherapy.) I wanted to offer other people who were ill and those who care for them an instrument to dissolve these metaphors, these inhibitions. I hoped to persuade terrified people who were ill to consult doctors, or to change their incompetent doctors for competent ones, who would give them proper care. To regard cancer as if it were just a disease—a very serious one, but just a disease. Not a curse, not a punishment, not an embarrassment. Without "meaning." And not necessarily a death sentence (one of the mystifications is that cancer = death). *Illness as Metaphor* is not just a

polemic, it is an exhortation. I was saying: Get the doctors to tell you the truth; be an informed, active patient; find yourself good treatment, because good treatment does exist (amid the widespread ineptitude). Although *the* remedy does not exist, more than half of all cases can be cured by existing methods of treatment.

In the decade since I wrote *Illness as Metaphor*—and was cured of my own cancer, confounding my doctors' pessimism—attitudes about cancer have evolved. Getting cancer is not quite as much of a stigma, a creator of "spoiled identity" (to use Erving Goffman's expression). The word cancer is uttered more freely, and people are not often described anymore in obituaries as dying of a "very long illness." Although European and Japanese doctors still regularly impart a cancer diagnosis first to the family, and often counsel concealing it from the patient, American doctors have virtually abandoned this policy; indeed, a brutal announcement to the patient is now common. The new candor about cancer is part of the same obligatory candor (or lack of decorum) that brings us diagrams of the rectal-colon or genito-urinary tract ailments of our national leaders on television and on the front pages of newspapers—more and more it is precisely a virtue in our society to speak of what is supposed *not* to be named. The change can also be explained by the doctors' fear of lawsuits in a litigious society. And not least among the reasons that cancer is now treated less phobically, certainly with less se-



crecy, than a decade ago is that it is no longer the most feared disease. In recent years some of the onus of cancer has been lifted by the emergence of a disease whose charge of stigmatization, whose capacity to create spoiled identity, is far greater. It seems that societies need to have one illness which becomes identified with evil, and attaches blame to its "victims," but it is hard to be obsessed with more than one.

## 2

Just as one might predict for a disease that is not yet fully understood as well as extremely recalcitrant to treatment, the advent of this terrifying new disease, new at least in its epidemic form, has provided a large-scale occasion for the metaphorizing of illness.

Strictly speaking, AIDS—acquired immune deficiency syndrome—is not the name of an illness at all. It is the name of a medical condition, whose consequences are a spectrum of illnesses. In contrast to syphilis and cancer, which provide prototypes for most of the images and metaphors attached to AIDS, the very definition of AIDS requires the presence of other illnesses, so-called opportunistic infections and malignancies. But though not in *that* sense a single disease, AIDS lends itself to being regarded as one—in part

because, unlike cancer and like syphilis, it is thought to have a single cause.

AIDS has a dual metaphoric genealogy. As a micro-process, it is described as cancer is: an invasion. When the focus is transmission of the disease, an older metaphor, reminiscent of syphilis, is invoked: pollution. (One gets it from the blood or sexual fluids of infected people or from contaminated blood products.) But the military metaphors used to describe AIDS have a somewhat different focus from those used in describing cancer. With cancer, the metaphor scants the issue of causality (still a murky topic in cancer research) and picks up at the point at which rogue cells inside the body mutate, eventually moving out from an original site or organ to overrun other organs or systems—a domestic subversion. In the description of AIDS the enemy is what causes the disease, an infectious agent that comes from the outside:

The invader is tiny, about one sixteen-thousandth the size of the head of a pin. . . . Scouts of the body's immune system, large cells called macrophages, sense the presence of the diminutive foreigner and promptly alert the immune system. It begins to mobilize an array of cells that, among other things, produce antibodies to deal with the threat. Single-mindedly, the AIDS virus ignores many of the blood cells in its path, evades the rapidly advancing defenders and homes in on the master coordinator of the immune system, a helper T cell. . . .

This is the language of political paranoia, with its characteristic distrust of a pluralistic world. A defense system consisting of cells "that, among other things, produce antibodies to deal with the threat" is, predictably, no match for an invader who advances "single-mindedly." And the science-fiction flavor, already present in cancer talk, is even more pungent in accounts of AIDS—this one comes from *Time* magazine in late 1986—with infection described like the high-tech warfare for which we are being prepared (and inured) by the fantasies of our leaders and by video entertainments. In the era of Star Wars and Space Invaders, AIDS has proved an ideally comprehensible illness:

On the surface of that cell, it finds a receptor into which one of its envelope proteins fits perfectly, like a key into a lock. Docking with the cell, the virus penetrates the cell membrane and is stripped of its protective shell in the process. . . .

Next the invader takes up permanent residence, by a form of alien takeover familiar in science-fiction narratives. The body's own cells *become* the invader. With the help of an enzyme the virus carries with it,

the naked AIDS virus converts its RNA into . . . DNA, the master molecule of life. The molecule then penetrates the cell nucleus, inserts itself into a chromosome and takes over part of the cellular

machinery, directing it to produce more AIDS viruses. Eventually, overcome by its alien product, the cell swells and dies, releasing a flood of new viruses to attack other cells. . . .

As viruses attack other cells, runs the metaphor, so "a host of opportunistic diseases, normally warded off by a healthy immune system, attacks the body," whose integrity and vigor have been sapped by the sheer replication of "alien product" that follows the collapse of its immunological defenses. "Gradually weakened by the onslaught, the AIDS victim dies, sometimes in months, but almost always within a few years of the first symptoms." Those who have not already succumbed are described as "under assault, showing the telltale symptoms of the disease," while millions of others "harbor the virus, vulnerable at any time to a final, all-out attack."

Cancer makes cells proliferate; in AIDS, cells die. Even as this original model of AIDS (the mirror image of leukemia) has been altered, descriptions of how the virus does its work continue to echo the way the illness is perceived as infiltrating the society. "AIDS Virus Found to Hide in Cells, Eluding Detection by Normal Tests" was the headline of a recent front-page story in *The New York Times* announcing the discovery that the virus can "lurk" for years in the macrophages—disrupting their disease-fighting function without killing them, "even when the macrophages are filled almost to bursting with virus," and

without producing antibodies, the chemicals the body makes in response to "invading agents" and whose presence has been regarded as an infallible marker of the syndrome.\* That the virus isn't lethal for *all* the cells where it takes up residence, as is now thought, only increases the illness-foe's reputation for wiliness and invincibility.

What makes the viral assault so terrifying is that contamination, and therefore vulnerability, is understood as permanent. Even if someone infected were never to develop any symptoms—that is, the infection remained, or could by medical intervention be rendered, inactive—the viral enemy would be forever within. In fact, so it is believed, it is just a matter of time before something awakens ("triggers") it, before the appearance of "the telltale symptoms." Like syphilis, known to generations of doctors as "the great masquerader," AIDS is a clinical construction, an inference. It takes its identity from the presence of *some*

\* The larger role assigned to the macrophages—"to serve as a reservoir for the AIDS virus because the virus multiplies in them but does not kill them, as it kills T-4 cells"—is said to explain the not uncommon difficulty of finding infected T-4 lymphocytes in patients who have antibodies to the virus and symptoms of AIDS. (It is still assumed that antibodies will develop once the virus spreads to these "key target" cells.) Evidence of presently infected populations of cells has been as puzzlingly limited or uneven as the evidence of infection in the populations of human societies—puzzling, because of the conviction that the disease is everywhere, and must spread. "Doctors have estimated that as few as one in a million T-4 cells are infected, which led some to ask where the virus hides. . . ." Another resonant speculation, reported in the same article (*The New York Times*, June 7, 1988): "Infected macrophages can transmit the virus to other cells, possibly by touching the cells."

among a long, and lengthening, roster of symptoms (no one has everything that AIDS could be), symptoms which "mean" that what the patient has is this illness. The construction of the illness rests on the invention not only of AIDS as a clinical entity but of a kind of junior AIDS, called AIDS-related complex (ARC), to which people are assigned if they show "early" and often intermittent symptoms of immunological deficit such as fevers, weight loss, fungal infections, and swollen lymph glands. AIDS is progressive, a disease of time. Once a certain density of symptoms is attained, the course of the illness can be swift, and brings atrocious suffering. Besides the commonest "presenting" illnesses (some hitherto unusual, at least in a fatal form, such as a rare skin cancer and a rare form of pneumonia), a plethora of disabling, disfiguring, and humiliating symptoms make the AIDS patient steadily more infirm, helpless, and unable to control or take care of basic functions and needs.

The sense in which AIDS is a slow disease makes it more like syphilis, which is characterized in terms of "stages," than like cancer. Thinking in terms of "stages" is essential to discourse about AIDS. Syphilis in its most dreaded form is "tertiary syphilis," syphilis in its third stage. What is called AIDS is generally understood as the last of three stages—the first of which is infection with a human immunodeficiency virus (HIV) and early evidence of inroads on the immune system—with a long latency period between infection and the onset of the "telltale" symptoms.

(Apparently not as long as syphilis, in which the latency period between secondary and tertiary illness might be decades. But it is worth noting that when syphilis first appeared in epidemic form in Europe at the end of the fifteenth century, it was a rapid disease, of an unexplained virulence that is unknown today, in which death often occurred in the second stage, sometimes within months or a few years.) Cancer grows slowly: it is not thought to be, for a long time, latent. (A convincing account of a process in terms of "stages" seems invariably to include the notion of a normative delay or halt in the process, such as is supplied by the notion of latency.) True, a cancer is "staged." This is a principal tool of diagnosis, which means classifying it according to its gravity, determining how "advanced" it is. But it is mostly a spatial notion: that the cancer advances through the body, traveling or migrating along predictable routes. Cancer is first of all a disease of the body's geography, in contrast to syphilis and AIDS, whose definition depends on constructing a temporal sequence of stages.

Syphilis is an affliction that didn't have to run its ghastly full course, to paresis (as it did for Baudelaire and Maupassant and Jules de Goncourt), and could and often did remain at the stage of nuisance, indignity (as it did for Flaubert). The scourge was also a cliché, as Flaubert himself observed. "SYPHILIS. Everybody has it, more or less" reads one entry in the *Dictionary of Accepted Opinions*, his treasury of mid-nineteenth-century platitudes. And syphilis did

manage to acquire a darkly positive association in late-nineteenth- and early-twentieth-century Europe, when a link was made between syphilis and heightened ("feverish") mental activity that parallels the connection made since the era of the Romantic writers between pulmonary tuberculosis and heightened emotional activity. As if in honor of all the notable writers and artists who ended their lives in syphilitic witlessness, it came to be believed that the brain lesions of neurosyphilis might actually inspire original thought or art. Thomas Mann, whose fiction is a storehouse of early-twentieth-century disease myths, makes this notion of syphilis as muse central to his *Doctor Faustus*, with its protagonist a great composer whose voluntarily contracted syphilis—the Devil guarantees that the infection will be limited to the central nervous system—confers on him twenty-four years of incandescent creativity. E. M. Cioran recalls how, in Romania in the late 1920s, syphilis-envy figured in his adolescent expectations of literary glory: he would discover that he had contracted syphilis, be rewarded with several hyperproductive years of genius, then collapse into madness. This romanticizing of the dementia characteristic of neurosyphilis was the forerunner of the much more persistent fantasy in this century about mental illness as a source of artistic creativity or spiritual originality. But with AIDS—though dementia is also a common, late symptom—no compensatory mythology has arisen, or seems likely to arise. AIDS, like cancer, does not allow romanti-

cizing or sentimentalizing, perhaps because its association with death is too powerful. In Krzysztof Zanussi's film *Spiral* (1978), the most truthful account I know of anger at dying, the protagonist's illness is never specified; therefore, it *has* to be cancer. For several generations now, the generic idea of death has been a death from cancer, and a cancer death is experienced as a generic defeat. Now the generic rebuke to life and to hope is AIDS.

### 3

Because of countless metaphoric flourishes that have made cancer synonymous with evil, having cancer has been experienced by many as shameful, therefore something to conceal, and also unjust, a betrayal by one's body. Why me? the cancer patient exclaims bitterly. With AIDS, the shame is linked to an imputation of guilt; and the scandal is not at all obscure. Few wonder, Why me? Most people outside of sub-Saharan Africa who have AIDS know (or think they know) how they got it. It is not a mysterious affliction that seems to strike at random. Indeed, to get AIDS is precisely to be revealed, in the majority of cases so far,

as a member of a certain "risk group," a community of pariahs. The illness flushes out an identity that might have remained hidden from neighbors, job-mates, family, friends. It also confirms an identity and, among the risk group in the United States most severely affected in the beginning, homosexual men, has been a creator of community as well as an experience that isolates the ill and exposes them to harassment and persecution.

Getting cancer, too, is sometimes understood as the fault of someone who has indulged in "unsafe" behavior—the alcoholic with cancer of the esophagus, the smoker with lung cancer: punishment for living unhealthy lives. (In contrast to those obliged to perform unsafe occupations, like the worker in a petrochemical factory who gets bladder cancer.) More and more linkages are sought between primary organs or systems and specific practices that people are invited to repudiate, as in recent speculation associating colon cancer and breast cancer with diets rich in animal fats. But the unsafe habits associated with cancer, among other illnesses—even heart disease, hitherto little culpabilized, is now largely viewed as the price one pays for excesses of diet and "life-style"—are the result of a weakness of the will or a lack of prudence, or of addiction to legal (albeit very dangerous) chemicals. The unsafe behavior that produces AIDS is judged to be more than just weakness. It is indulgence, delinquency—addictions to chemicals that are illegal and to sex regarded as deviant.

The sexual transmission of this illness, considered by most people as a calamity one brings on oneself, is judged more harshly than other means—especially since AIDS is understood as a disease not only of sexual excess but of perversity. (I am thinking, of course, of the United States, where people are currently being told that heterosexual transmission is extremely rare, and unlikely—as if Africa did not exist.) An infectious disease whose principal means of transmission is sexual necessarily puts at greater risk those who are sexually more active—and is easy to view as a punishment for that activity. True of syphilis, this is even truer of AIDS, since not just promiscuity but a specific sexual “practice” regarded as unnatural is named as more endangering. Getting the disease through a sexual practice is thought to be more willful, therefore deserves more blame. Addicts who get the illness by sharing contaminated needles are seen as committing (or completing) a kind of inadvertent suicide. Promiscuous homosexual men practicing their vehement sexual customs under the illusory conviction, fostered by medical ideology with its cure-all antibiotics, of the relative innocuousness of all sexually transmitted diseases, could be viewed as dedicated hedonists—though it’s now clear that their behavior was no less suicidal. Those like hemophiliacs and blood-transfusion recipients, who cannot by any stretch of the blaming faculty be considered responsible for their illness, may be as ruthlessly ostracized by frightened people, and potentially represent

a greater threat because, unlike the already stigmatized, they are not as easy to identify.

Infectious diseases to which sexual fault is attached always inspire fears of easy contagion and bizarre fantasies of transmission by nonvenereal means in public places. The removal of doorknobs and the installation of swinging doors on U.S. Navy ships and the disappearance of the metal drinking cups affixed to public water fountains in the United States in the first decades of the century were early consequences of the “discovery” of syphilis’s “innocently transmitted infection”; and the warning to generations of middle-class children always to interpose paper between bare bottom and the public toilet seat is another trace of the horror stories about the germs of syphilis being passed to the innocent by the dirty that were rife once and are still widely believed. Every feared epidemic disease, but especially those associated with sexual license, generates a preoccupying distinction between the disease’s putative carriers (which usually means just the poor and, in this part of the world, people with darker skins) and those defined—health professionals and other bureaucrats do the defining—as “the general population.” AIDS has revived similar phobias and fears of contamination among *this* disease’s version of “the general population”: white heterosexuals who do not inject themselves with drugs or have sexual relations with those who do. Like syphilis a disease of, or contracted from, dangerous others, AIDS is perceived as afflicting, in greater proportions

than syphilis ever did, the already stigmatized. But syphilis was not identified with certain death, death that follows a protracted agony, as cancer was once imagined and AIDS is now held to be.

That AIDS is not a single illness but a syndrome, consisting of a seemingly open-ended list of contributing or "presenting" illnesses which constitute (that is, qualify the patient as having) the disease, makes it more a product of definition or construction than even a very complex, multiform illness like cancer. Indeed, the contention that AIDS is invariably fatal depends partly on what doctors decided to define as AIDS—and keep in reserve as distinct earlier stages of the disease. And this decision rests on a notion no less primitively metaphorical than that of a "full-blown" (or "full-fledged") disease.\* "Full-blown" is the form in which

\* The standard definition distinguishes between people with the disease or syndrome "fulfilling the criteria for the surveillance definition of AIDS" from a larger number infected with HIV and symptomatic "who do not fulfill the empiric criteria for the full-blown disease. This constellation of signs and symptoms in the context of HIV infection has been termed the AIDS-related complex (ARC)." Then follows the obligatory percentage. "It is estimated that approximately 25 percent of patients with ARC will develop full-blown disease within 3 years." Harrison's *Principles of Internal Medicine*, 11th edition (1987), p. 1394.

The first major illness known by an acronym, the condition called AIDS does not have, as it were, natural borders. It is an illness whose identity is designed for purposes of investigation and with tabulation and surveillance by medical and other bureaucracies in view. Hence, the unselfconscious equating in the medical textbook of what is empirical with what pertains to surveillance, two notions deriving from quite different models of understanding. (AIDS is what fulfills that which is referred to as either the "criteria for the surveillance definition" or the "empiric criteria": HIV infection plus

the disease is inevitably fatal. As what is immature is destined to become mature, what buds to become full-blown (fledglings to become full-fledged)—the doctors' botanical or zoological metaphor makes development or evolution into AIDS the norm, the rule. I am not saying that the metaphor creates the clinical conception, but I am arguing that it does much more than just ratify it. It lends support to an interpretation of the clinical evidence which is far from proved or, yet, provable. It is simply too early to conclude, of a disease identified only seven years ago, that infection will always produce something to die from, or even that everybody who has what is defined as AIDS will die of it. (As some medical writers have speculated, the appalling mortality rates could be registering the early, mostly rapid deaths of those most vulnerable to the virus—because of diminished immune competence, because of genetic predisposition, among other possible co-factors—not the ravages of a uniformly fatal infection.) Construing the disease as divided into distinct stages was the necessary way of implementing the metaphor of "full-blown disease." But it also slightly weakened the notion of inevitability suggested by the metaphor. Those sensibly interested in hedging their bets about how uniformly

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the presence of one or more diseases included on the roster drawn up by the disease's principal administrator of definition in the United States, the federal Centers for Disease Control in Atlanta.) This completely stipulative definition with its metaphor of maturing disease decisively influences how the illness is understood.

lethal infection would prove could use the standard three-tier classification—HIV infection, AIDS-related complex (ARC), and AIDS—to entertain either of two possibilities or both: the less catastrophic one, that *not* everybody infected would “advance” or “graduate” from HIV infection, and the more catastrophic one, that everybody would.

It is the more catastrophic reading of the evidence that for some time has dominated debate about the disease, which means that a change in nomenclature is under way. Influential administrators of the way the disease is understood have decided that there should be no more of the false reassurance that might be had from the use of different acronyms for different stages of the disease. (It could never have been more than minimally reassuring.) Recent proposals for re-doing terminology—for instance, to phase out the category of ARC—do not challenge the construction of the disease in stages, but do place additional stress on the *continuity* of the disease process. “Full-blown disease” is viewed as more inevitable now, and that strengthens the fatalism already in place.\*

\* The 1988 Presidential Commission on the epidemic recommended “de-emphasizing” the use of the term ARC because it “tends to obscure the life-threatening aspects of this stage of illness.” There is some pressure to drop the term AIDS, too. The report by the Presidential Commission pointedly used the acronym HIV for the epidemic itself, as part of a recommended shift from “monitoring disease” to “monitoring infection.” Again, one of the reasons given is that the present terminology masks the true gravity of the menace. (“This longstanding concentration on the clinical manifestations of AIDS rather than on all stages of HIV infection [i.e., from initial

From the beginning the construction of the illness had depended on notions that separated one group of people from another—the sick from the well, people with ARC from people with AIDS, them and us—while implying the imminent dissolution of these distinctions. However hedged, the predictions always sounded fatalistic. Thus, the frequent pronouncements by AIDS specialists and public health officials on the chances of those infected with the virus coming down with “full-blown” disease have seemed mostly an exercise in the management of public opinion, dosing out the harrowing news in several steps. Estimates of the percentage expected to show symptoms classifying them as having AIDS within five years, which may be too low—at the time of this writing, the figure is 30 to 35 percent—are invariably followed by the assertion that “most,” after which comes “probably all,” those infected will eventually become ill. The critical number, then, is not the percentage of people likely to develop AIDS within a relatively short time but the *maximum* interval that could elapse between infection with HIV (described as lifelong and irreversible) and appearance of the first symptoms. As the years add up in which the illness has been tracked, so does the possible num-

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infection to seroconversion, to an antibody-positive asymptomatic stage, to full-blown AIDS] has had the unintended effect of misleading the public as to the extent of infection in the population. . . .”) It does seem likely that the disease will, eventually, be renamed. *This* change in nomenclature would justify officially the policy of including the infected but asymptomatic among the ill.)



ber of years between infection and becoming ill, now estimated, seven years into the epidemic, at between ten and fifteen years. This figure, which will presumably continue to be revised upward, does much to maintain the definition of AIDS as an inexorable, invariably fatal disease.

The obvious consequence of believing that all those who "harbor" the virus will eventually come down with the illness is that those who test positive for it are regarded as people-with-AIDS, who just don't have it . . . yet. It is only a matter of time, like any death sentence. Less obviously, such people are often regarded as if they *do* have it. Testing positive for HIV (which usually means having been tested for the presence not of the virus but of antibodies to the virus) is increasingly equated with being ill. Infected *means* ill, from that point forward. "Infected but not ill," that invaluable notion of clinical medicine (the body "harbors" many infections), is being superseded by biomedical concepts which, whatever their scientific justification, amount to reviving the antiscientific logic of defilement, and make infected-but-healthy a contradiction in terms. Being ill in this new sense can have many practical consequences. People are losing their jobs when it is learned that they are HIV-positive (though it is not legal in the United States to fire someone for that reason) and the temptation to conceal a positive finding must be immense. The consequences of testing HIV-positive are even more punitive for those selected populations—there will be more

—upon which the government has already made testing mandatory. The U.S. Department of Defense has announced that military personnel discovered to be HIV-positive are being removed "from sensitive, stressful jobs," because of evidence indicating that mere infection with the virus, in the absence of any other symptoms, produces subtle changes in mental abilities in a significant minority of virus carriers. (The evidence cited: lower scores on certain neurological tests given to some who had tested positive, which could reflect mental impairment caused by exposure to the virus, though most doctors think this extremely improbable, or could be caused—as officially acknowledged under questioning—by "the anger, depression, fear, and panic" of people who have just learned that they are HIV-positive.) And, of course, testing positive now makes one ineligible to immigrate everywhere.

In every previous epidemic of an infectious nature, the epidemic is equivalent to the number of tabulated cases. This epidemic is regarded as consisting *now* of that figure plus a calculation about a much larger number of people apparently in good health (seemingly healthy, but doomed) who are infected. The calculations are being made and remade all the time, and pressure is building to identify these people, and to tag them. With the most up-to-date biomedical testing, it is possible to create a new class of lifetime

pariahs, the future ill. But the result of this radical expansion of the notion of illness created by the triumph of modern medical scrutiny also seems a throwback to the past, before the era of medical triumphalism, when illnesses were innumerable, mysterious, and the progression from being seriously ill to dying was something normal (not, as now, medicine's lapse or failure, destined to be corrected). AIDS, in which people are understood as ill before they are ill; which produces a seemingly innumerable array of symptom-illnesses; for which there are only palliatives; and which brings to many a social death that precedes the physical one—AIDS reinstates something like a premodern experience of illness, as described in Donne's *Devotions*, in which "every thing that disorders a faculty and the function of that is a sickness," which starts when we

are preafflicted, super-afflicted with these jealousies and suspicions, and apprehensions of Sicknes, before we can call it a sickness; we are not sure we are ill; one hand asks the other by the pulse, and our eye asks our own urine, how we do. . . . we are tormented with sickness, and cannot stay till the torment come. . . .

whose agonizing outreach to every part of the body makes a real cure chimerical, since what "is but an accident, but a symptom of the main disease, is so violent, that the Physician must attend the cure of

that" rather than "the cure of the disease it self," and whose consequence is abandonment:

As Sickness is the greatest misery, so the greatest misery of sickness is solitude; when the infectiousness of the disease deterrers them who should assist, from coming; even the Physician dares scarce come. . . . it is an Outlawry, an Excommunication upon the patient. . . .

In premodern medicine, illness is described as it is experienced intuitively, as a relation of outside and inside: an interior sensation or something to be discerned on the body's surface, by sight (or just below, by listening, palpating), which is confirmed when the interior is opened to viewing (in surgery, in autopsy). Modern—that is, effective—medicine is characterized by far more complex notions of what is to be observed inside the body: not just the disease's results (damaged organs) but its cause (microorganisms), and by a far more intricate typology of illness.

In the older era of artisanal diagnoses, being examined produced an immediate verdict, immediate as the physician's willingness to speak. Now an examination means tests. And being tested introduces a time lapse that, given the unavoidably industrial character of competent medical testing, can stretch out for weeks: an agonizing delay for those who think they are awaiting a death sentence or an acquittal. Many are reluctant to be tested out of dread of the

verdict, out of fear of being put on a list that could bring future discrimination or worse, and out of fatalism (what good would it do?). The usefulness of self-examination for the early detection of certain common cancers, much less likely to be fatal if treated before they are very advanced, is now widely understood. Early detection of an illness thought to be inexorable and incurable cannot seem to bring any advantage.

Like other diseases that arouse feelings of shame, AIDS is often a secret, but not from the patient. A cancer diagnosis was frequently concealed from patients by their families; an AIDS diagnosis is at least as often concealed from their families by patients. And as with other grave illnesses regarded as more than just illnesses, many people with AIDS are drawn to whole-body rather than illness-specific treatments, which are thought to be either ineffectual or too dangerous. (The disparagement of effective, scientific medicine for offering treatments that are *merely* illness-specific, and likely to be toxic, is a recurrent misconception of opinion that regards itself as enlightened.) This disastrous choice is still being made by some people with cancer, an illness that surgery and drugs can often cure. And a predictable mix of superstition and resignation is leading some people with AIDS to refuse antiviral chemotherapy, which, even in the absence of a cure, has proved of some effectiveness (in slowing down the syndrome's progress and in staving off some common presenting illnesses), and instead to seek to heal themselves, often under the auspices of some "alternative

medicine" guru. But subjecting an emaciated body to the purification of a macrobiotic diet is about as helpful in treating AIDS as having oneself bled, the "holistic" medical treatment of choice in the era of Donne.

#### 4

Etymologically, patient means sufferer. It is not suffering as such that is most deeply feared but suffering that degrades.

That illness can be not only an epic of suffering but the occasion of some kind of self-transcendence is affirmed by sentimental literature and, more convincingly, by case histories offered by doctor-writers. Some illnesses seem more apt than others for this kind of meditation. Oliver Sacks uses catastrophic neurological illness as the material for his portraits of suffering and self-transcendence, diminishment and exaltation. His great forerunner, Sir Thomas Browne, used tuberculosis for a similar purpose, to ruminate about illness in general, in "A Letter to a Friend, Upon Occasion of the Death of his Intimate Friend" (1657), making pre-Romantic sense out of some of the familiar stereotypes about tuberculosis: that it is a distinctive manner of being ill ("this being a lingring Disease")

and a distinctive manner of dying ("his soft Death"). A fiction about soft or easy deaths—in fact, dying of tuberculosis was often hard and extremely painful—is part of the mythology of most diseases that are not considered shameful or demeaning.

In contrast to the soft death imputed to tuberculosis, AIDS, like cancer, leads to a hard death. The metaphorized illnesses that haunt the collective imagination are all hard deaths, or envisaged as such. Being deadly is not in itself enough to produce terror. It is not even necessary, as in the puzzling case of leprosy, perhaps the most stigmatized of all diseases, although rarely fatal and extremely difficult to transmit. Cancer is more feared than heart disease, although someone who has had a coronary is more likely to die of heart disease in the next few years than someone who has cancer is likely to die of cancer. A heart attack is an event but it does not give someone a new identity, turning the patient into one of "them." It is not transforming, except in the sense of a transformation into something better: inspired by fear, the cardiac patient acquires good habits of exercise and diet, starts to lead a more prudent, healthier life. And it is often thought to produce, if only because it can be instantaneous, an easy death.

The most terrifying illnesses are those perceived not just as lethal but as dehumanizing, literally so. What was expressed in the rabies phobia of nineteenth-century France, with its countless pseudo-cases of contamination by animals newly turned "bestial"

and even of "spontaneous" rabies (actual cases of rabies, *la rage*, were extremely rare), was the fantasy that infection transformed people into maddened animals—unleashing uncontrollable sexual, blasphemous impulses—not the fact that it was indeed, until Pasteur's discovery of a treatment in 1885, invariably fatal. And while cholera killed fewer people in Western Europe in the nineteenth century than smallpox did, it was more feared, because of the suddenness with which it struck and the indignity of the symptoms: fulminant diarrhea and vomiting, whose result anticipated the horror of post-mortem decomposition. Within several hours radical dehydration shrank the patient into a wizened caricature of his or her former self, the skin turned bluish-black (overwhelming, transfixing fear is still, in French, *une peur bleue*), the body became cold; death followed the same day or soon after.

Polio's effects could be horrifying—it withered the body—but it did not mark or rot the flesh: it was not repulsive. Further, polio affected the body only, though that may seem ruin enough, not the face. The relatively appropriate, unmetaphorical reaction to polio owes much to the privileged status of the face, so determining of our evaluation of physical beauty and of physical ruin. All the debunking of the Cartesian separation of *mind* and body by modern philosophy and modern science has not reduced by one iota this culture's conviction of the separation of *face* and body, which influences every aspect of manners, fashion,

sexual appreciation, aesthetic sensibility—virtually all our notions of appropriateness. This separation is a main point of one of European culture's principal iconographical traditions, the depiction of Christian martyrdom, with its astounding schism between what is inscribed on the face and what is happening to the body. Those innumerable images of Saint Sebastian, Saint Agatha, Saint Lawrence (but not of Christ himself), with the face demonstrating its effortless superiority to the atrocious things that are being inflicted down there. Below, the ruin of the body. Above, a person, incarnated in the face, who looks away, usually up, not registering pain or fear; already elsewhere. (Only Christ, both Son of Man and Son of God, suffers in his face: has his Passion.) Our very notion of the person, of dignity, depends on the separation of face from body,\* on the possibility that the face may be exempt, or exempt itself, from what is happening to the body. And however lethal, illnesses like heart attacks and influenza that do not damage or deform the face never arouse the deepest dread.

Not every kind of alteration to the face is perceived as repulsive or shaming. The most dreaded are those

\* There can be no real argument against the aristocracy of the face, only some definitive raillery. An obsession with the pretentiousness of the division between face and body is central in Gombrowicz's *Ferdydurke*, which keeps repropounding that the body is parts, each with an independent life, and the face is just another body part. The point of view from which Gombrowicz launches his post-Rabelaisian satire on eros and on social class is that of an enforced, humiliating return to childhood—not of the enforced humiliations of illness. That is, Gombrowicz's novel is a comedy, not a tragedy.

that seem like mutations into animality (the leper's "lion face") or a kind of rot (as in syphilis). Underlying some of the moral judgments attached to disease are aesthetic judgments about the beautiful and the ugly, the clean and the unclean, the familiar and the alien or uncanny. (More accurately, these are judgments that originate before the stage at which aesthetic and moral categories split apart and, eventually, come to seem opposed.) What counts more than the amount of disfigurement is that it reflects underlying, ongoing changes, the dissolution of the person. Smallpox also disfigures, pitting the face; but the marks of smallpox don't get worse. Indeed, they are precisely the stigmata of a survivor. The marks on the face of a leper, a syphilitic, someone with AIDS are the signs of a progressive mutation, decomposition; something organic.

Sinister characterizations of the organic proliferated in the nineteenth century to describe both the disease and its cause. Specific diseases, such as cholera, as well as the state of being generally prone to illness, were thought to be caused by an "infected" (or "foul") atmosphere, effusions spontaneously generated from something unclean. Usually identified (first by its bad smell) as decaying organic matter, this disease-carrying atmosphere came to be identified with urban rather than rural squalor, and with garbage, rot, the proximity of cemeteries. These claims were eventually defeated by the discoveries by Pasteur and Koch of the role played by specific microorganisms. By 1880 the scien-

tific community no longer believed in miasma, as these effusions were called, or in spontaneous generation. (In 1883, a year after Koch discovered the tubercle bacillus, he discovered the water-borne bacillus that causes cholera.) But even after the defeat of the miasmatic theory by the germ theory of contagion, miasma lived on, shorn of its first-order causative status, as a kind of vague co-factor in the explanation of many illnesses. The conviction that living in dark, dirty cities causes (or at least produces a susceptibility to) tuberculosis is a version of the miasma theory, and continued to be given credence well into this century, long after the actual cause of tuberculosis had been discovered. It seems that something like what is supplied by miasma, the generalizing of infection into an atmosphere, is required to moralize a disease.

In the wake of its rejection by scientists, the theory inspired at least one great work of art: the opera Debussy made from Maeterlinck's play *Pelléas et Mélisande*, a sort of *Tristan und Isolde* relocated in the world of miasma. It is right that *Pelléas et Mélisande*, in which everyone avows feelings of weakness and being lost, and some are already ailing; with its old, decaying castle that lets in no light; where the ground is full of subterranean terrors and dank or watery depths into which one can fall—all the correlatives of miasma, minus the stench—seems, to us, supremely a portrait of *psychological* sickness, of neurosis. For precisely as the category of generic sickness was phased out of nineteenth-century medical

thinking by the new understanding of the extreme specificity of what causes illness, it migrated to the expanding domain of psychology. The physically sickly person became the neurasthenic or neurotic person. And the idea of an organically contaminated, objectively pathogenic environment reappeared in the notion of a psychologically contaminated ambiance that produced a disposition to mental illness.

The notion did not remain confined to the domain of psychology and, with psychology's new credibility as science, returned to reinfluence medicine. The widely held view that many or even most diseases are not "really" physical but mental (more conservatively, "psycho-somatic") perpetuates the form of the miasmatic theory—with its surplus of causality, surplus of meaning—in a new version that has been extremely successful in the twentieth century. The theory that psychological miasma (depression, funk) can cause physical illness has been tried out with varying degrees of respectability on many diseases, including cancer. And one way in which AIDS, some of whose metaphors overlap those of cancer, seems very different from cancer, that illness saturated with distinctively modern evaluations of energy and of disaster, and is experienced as a throwback to premodern diseases like leprosy and syphilis, is that no one is tempted, not yet at least, to psychologize it.