The doctor's bag of medical miracles does not open for everyone who needs help. Some diseases are not yet treatable. Some treatments are costly or in short supply. Money often buys the best therapy yet discovered—but what should be discovered? Who deserves the first fruits of research?

Our new-found powers of prolonging life raise a host of social and financial dilemmas: among them the directions medical research should take, the long-term implications of genetic manipulation, the human price of living with incurable illness, and the staggering cost of life-sustaining treatments. These are just a few of the issues explored in this special supplement on how America cares for its sick.

AMERICA

Health Care and Self-Care

Recent developments in biological and medical science have given man new power over his own health and life-span—even the possibility of determining the genetic makeup of his children. Technological developments are transforming death from an unavoidable, natural event into a phenomenon demanding our active participation by decision-makers. More and more persons can be kept alive, with the help of machines, long after their consciousness has been lost and cannot be retrieved. This new-found knowledge brings with it new questions. Who has the authority to turn off the machine, to decide to end "life" (if existence without awareness can even be defined as life)? the technocrat-doctor? the hospital-institution-bureaucracy? the guilt-ridden family? the ever-obsolescent legal system? economic forces which allow fewer heroic efforts to save the lives of ward patients compared to paying ones?

The unlocking of the genetic code and subsequent related developments allow the breeding out of a rapidly growing list of illnesses which are partially or completely genetically determined. A test of the fluid surrounding the fetus (amniocentesis) can diagnose a fetus as defective and permit subsequent abortion. Should we allow such selected breeding for therapeutic purposes? promote it? require it? Should we encourage the development of genetic surgery and manipulation? even if it might open the door to the breeding of "superpersons"?

Beyond that are problems of allocation. If a limited number of hearts are available for transplant operations, who should get them? In view of the fact that hundreds of thousands of persons may eventually need replacement hearts, would it be better to focus research on mechanical devices (artificial hearts) rather than on organ transplants? To what extent should we tolerate research on drugs which modify behavior (for example, anti-aggression powders) and affect thoughts (LSD and beyond)? Should we continue research on subliminal communication, in which messages too rapid to be consciously perceived are flashed on TV screens, commanding persons to buy (or vote) as dictated? If we want to curb such research, how can we do so without violating the freedom of scientific inquiry?

In light of these and many other issues raised by the new biomedical technologies, Senator Walter Mondale has championed legislation which calls for setting up a temporary (two-year) commission to study such questions. The commission would be composed of 15 professionals in fields ranging from law to medicine, from theology to technology, and would be budgeted at about one million dollars a year. The bill was endorsed unanimously by the 92nd Congress in December 1971; "died" when the House did not act on it by the time the session ended; was recently resurrected as Senate Resolution 71, and is again pending. Such a commission would be a first step toward developing the sorely needed tools of effective and responsive societal guidance to biomedical ethics and policies. Even though limited in scope, support, funds and staff, temporary commissions can illustrate both the need for a full-fledged, representative, adequately endowed and staffed permanent commission on biomedical ethics and policies, and the virtue of attempting limited action until such a body is constituted.
The Genetic Fix

The Institute of Society, Ethic and Life Sciences, often referred to as the Hastings Institute, issued a report in the New England Journal of Medicine (May 25, 1972) on the ethical and social issues raised by screening large numbers of people for genetic disease. Daniel Callahan, director of the Institute, explained that “the group who formulated the guidelines for mass screening was mostly opposed to the whole idea but favored a cautious and careful approach.”

The report’s most basic criterion for assessing the merits of genetic screening programs is that no system be set up before adequate testing procedures are available “to avoid the problems that occurred initially in PKU screening.” (Mandatory screening for PKU [phenylketonuria], an inherited biochemical malady which, untreated, can result in severe mental retardation and shortened life span, was by 1971 required in 43 states, though the test is not 100 percent reliable. Many children were wrongly identified as having the disease, and quite a few who did have it passed the test as healthy.)

A hastily introduced program to test for the sickle cell trait (carried by about one out of every 500 black children) fails by the Hastings criteria. The program tests either schoolchildren, at an age when the illness very often has already struck, or newborns, a stage at which detection is difficult. Tests of couples considering having a child would make much more sense, although such programs are more difficult to administer than school programs, in which all students can be lined up at will.

Besides asking for safe tests, the Hastings group also called attention to a risk of possible psychological or social injury. The question is, How harmful will the “labeling” of persons be? As the result of mass screening tests, people will be labeled as carriers of sick genes, which may harm their social standing and their view of themselves. Social science data leaves no doubt that at least in some areas, labeling (such as who is branded a criminal and who a law-abiding citizen) has rather serious consequences.

There is little doubt that if children are told that they have an XYY chromosome structure, which occurs in about one of every 1,000 males and which has been repeatedly reported as being associated with a predisposition toward seriously deviant behavior, they could easily begin to assume that a criminal destiny is inevitable. Moreover, parents who are told that their child carries the XYY gene may come to suspect normal assertive moves as being manifestations of their child’s criminal potential; consequently, they may push their child—whatever the influence of his genes—into an aggressive, ultimately criminal, personality and way of life.

Beyond parents, teachers and self-image, such labeling is likely to affect the attitudes of practically everyone who knows about a person’s genetic test scores. This is no longer a hypothetical consideration. The undesirable consequences which the Hastings group warned were possible have already made themselves felt. In 1971 the state of Massachusetts, responding to the demands of black community leaders and their white supporters, passed a law requiring that all school-age children be tested for the sickle cell trait. A dozen states rushed to