

DEDICATORY ESSAY

HONORING GEORGE ANNAS

*Jay Katz**

This book is built on two fundamental premises: (1) the American medical consumer possesses certain interests, many of which may properly be described as *rights*, that he does not automatically forfeit by entering a hospital; (2) most hospitals fail to recognize the existence of these interests and rights, fail to provide for their protection and assertion, and frequently limit their exercise without recourse for the patient. Patients should not be required to relinquish basic *human rights* upon entering a health care institution. Human rights can be protected without decreasing either the efficacy or the efficiency of medical treatment.¹

George Annas wrote the above passage in the introduction to his first book, *THE RIGHTS OF HOSPITAL PATIENTS*. The American Civil Liberties Union commissioned this book as one in a series on the rights of disadvantaged and vulnerable groups such as prisoners, women, mental patients and the poor. First books often reveal the eventual life work of an author. For George Annas this life work is a passionate commitment to protecting not just the legal rights, but the *human rights* of patients. In using the above words, he was probably already aware that he intended to arrive at a synthesis of the best that law, medicine and bioethics had to offer to safeguard the dignity of patients.

In seventeen brief chapters, George Annas instructs patients on their rights, discussing informed consent, refusal of treatment, participation in human experimentation, consultation, referral, admission and discharge. The book should have been placed at the bedside of all hospital patients so that they could have read it during the lonely hours of anxious waiting, when they were unsure of what was going to happen to them, when

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1. GEORGE ANNAS, *THE RIGHTS OF HOSPITAL PATIENTS* 1 (1975).

they were full of questions. Many of these questions the patients had not clearly articulated to themselves or, if they had, they were uncertain whether they were entitled to raise them. However, the book was not only addressed to patients. Instead, Annas' agenda was broader in scope: He wanted nurses, health-care workers, physicians, and lawyers to learn to take "more vigorous action . . . to promote and protect patient rights."² In his last chapter, he argued persuasively for the presence of a patients' rights advocate in every hospital "to assist the patient in learning about, protecting, and asserting his or her rights within the health care context."³ Moreover, in his proposed Model Patient's Bill of Rights, he advised patients that the first duty of such an advocate would be to safeguard a patient's "legal right to informed participation in all decisions involving his health care program."⁴

Of course, Annas appreciated that his proposal would introduce conflicts in hospital settings. "Informed participation" was not then, and is not now, deeply ingrained in the ethos of hospital practice. As a young envisionist, he believed that this situation would only be temporary and stated that "after a period of education, doctors and nurses will . . . afford patients their rights as a matter of course."⁵ As we now know, it will take more time to reach this goal. Nevertheless, there has been progress. Annas' writings, based on his abiding belief that the ends of medicine and American law, both dedicated to protecting citizen-patients, can be reconciled, has made a significant contribution to sensitizing health care providers that caring for patients includes respecting their personal interests and rights.

George Annas published *THE RIGHTS OF HOSPITAL PATIENTS* in 1975, shortly after he graduated from Harvard Law School in 1970 and the Harvard School of Public Health in 1972. He was appointed as Director of the Center for Law and Health Sciences of the Boston University School of Law in 1973. At that time, he had just begun to immerse himself in the world of health law, a field in which he would become pre-eminent. Already his dual mission was clear: (1) the protection of the human rights of patients, and (2) the education of health-care providers and lawyers for this inordinately difficult task.

Over the next twenty-eight years, George Annas not only taught at the

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2. *Id.*
 3. *Id.* at 210.
 4. *Id.* at 233.
 5. *Id.* at 209.

Boston University School of Medicine and Public Health — where ten years ago he founded the Law, Medicine and Ethics and Public Health Program and became its first Director — but he also published three complete books, authored more than 200 articles, authored twenty-seven book chapters, and co-authored or co-edited ten other books. His writings span virtually the entire field of contemporary health law, and many of his articles were first published as regular features in *The Hastings Center Report* and *The New England Journal of Medicine*.

A great many of his writings address recent legal cases, federal and state regulations just promulgated and commission reports just published. His work presents the issues concisely and then proceeds with passion, wit, compassion, or indignation to instruct the reader about where law and medicine have failed, or succeeded; in resolving the human issues in need of clarification.

At first, as he wrote later in his career, he “spent most of his time telling physicians that they did not take law seriously enough — that they were unfairly paternalistic and did not permit their patients to exercise basic human rights.”⁶ Later he began to emphasize “that [physicians were] taking the law too seriously — and [were] in danger of letting fear of liability replace reasoned judgment, and abdicating their responsibility to define ‘good medical care’ and set the standard for such care.”⁷ Annas makes the important point, through the use of examples, that physicians can have a considerable influence on shaping the legal standard of care. This was an influence which medical practitioners first neglected, and are only now, with the impact of market medicine on their professional and economic self interests, beginning to take more seriously.

From the very beginning of his career, George Annas has challenged the belief that “conflicts in [health law] are too difficult ever to resolve in a pluralistic society [and] that we cannot ever hope to find the ‘right’ answer to any (or most) of these issues.”⁸ While acknowledging that “the task of defining substantive principles and rules that we can live with is a complex and frustrating one,” he nonetheless believed that this task “is worthy of law and social policy” and is the only “hope [for preventing] medical law (and medical ethics) from becoming more than

6. GEORGE ANNAS, *STANDARD OF CARE: THE LAW OF AMERICAN BIOETHICS* 4 (1997).

7. *Id.* at 9.

8. GEORGE ANNAS, *JUDGING MEDICINE* xiii (1988).

simply the arbitrary exercise of power.”⁹ Many of his essays, often combining the skills of a novelist with those of an analytic thinker, are illuminating illustrations of these major concerns.

The substantive principle that has preeminently guided his analysis of health law is respecting the dignity of patients by protecting their rights of self-determination. While Annas presents and comments on conflicting viewpoints, he does not try to reconcile them or to forge a consensus that obscures more than it clarifies. Instead, he presents his own principled conclusions with uncompromising clarity, allowing the reader to engage him in debate as if they were actually sitting together. He is a unique teacher who combines scholarly, legal and ethical analyses with the passion of deeply held convictions whenever novel legal and medical issues are resolved in ways that violate patients’ human rights.

George Annas came to health law at a revolutionary moment in its history. In the early 1960s, judges promulgated the doctrine of informed consent which imposed on physicians new and unaccustomed legal duties to give patients a greater voice in the medical decision-making process. The doctrine constituted a radical departure from customary medical practices, for throughout medical history, physicians believed they should make decisions *for*, and not *with*, patients.

In general, judges had not previously questioned this professional standard of care, but focused instead on adjudicating controversies over negligence that resulted in physical harm to patients when physicians departed from customary medical practices. With the doctrine of informed consent, a radical shift took place in the standard of care. It changed from what a prudent medical physician would do (and doctors believed that the most limited disclosures on recommended treatments and their consequences constituted medical prudence) to a legal standard that emphasized disclosure and, in turn, patients’ right of self-determination.

This shift in standards comported not only with Annas’ legal education, but also with his personal convictions regarding the respect that should be accorded to a human being’s decision. He agrees with Justice Stevens that “it is far better to permit some persons to make incorrect decisions than to deny all individuals the right to make decisions that have a profound effect upon their destiny.”¹⁰ Annas’ writings interpreta-

9. *Id.*

10. *Thornburg v. American College of Obstetrics and Gynecologists*, 106 S. Ct. 2169, 2189-90 (1986).

tion of the new standards have affected the mindset of at least some physicians. For example, a physician may no longer be inclined to engage in a futile war with a competent, yet terminally ill patient "who would prefer to die a 'natural death' without the massive intervention of medical equipment and procedures that might prolong [his or her] agony for days or even months."¹¹ To the extent that such intervention is fueled by the fear of malpractice suits, Annas repeatedly reminds doctors, hospital attorneys, and even judges, that patients have the right to refuse treatment.

In a particularly poignant essay, *Prisoner in the ICU*,¹² George Annas illustrates the importance of this legal right. William Bartling, seventy years old, in failing health and suffering from at least five potentially fatal diseases, asked to have his mechanical ventilator removed because it caused him significant discomfort and pain. He was competent to make the decision, and his wife supported his position. Bartling's physicians were willing to honor his request, but the hospital's legal counsel disagreed. Counsel suggested that, while he did not dispute Bartling's competence, his statements that "I don't want to die" and "I don't want to live on the respirator" indicated ambivalence.¹³ The judge was not persuaded by the response of Bartling's lawyers that "[h]e would prefer to live, but he does not prefer to live . . . with the necessity of his every breath being sustained by a ventilator"¹⁴ The judge agreed with the hospital attorney, and ordered the patient's hands be tied to the bed railings so that he could not remove the tubes connecting him to the ventilator.

George Annas argued that since competent patients have a right to refuse treatment, the judge should have seen his role "as a protector of the individual," and not "as making a medical decision" on the basis of Bartling's dubiously optimistic prognosis. Annas concluded that "this case [was] a personal tragedy for William and Ruth Bartling; a dismal failure for physicians trying to administer humane care; and a disgrace for the judiciary"¹⁵ Strong words. However, George Annas chose them deliberately to remind us that "judges sit as judges . . . and they have a responsibility to articulate their opinions on the basis of princi-

11. ANNAS, *supra* note 8, at 13.

12. *Id.* at 317-22.

13. *Id.* at 319.

14. *Id.* at 320.

15. *Id.* at 321.

ples. Unless they do, issues . . . will be decided by emotional caprice."¹⁶ Of course, emotions intrude on judging. Nevertheless, as George Annas speculated, if the judge found it disturbing to take personal responsibility for a decision that might result in Bartling's death, he might have experienced his all too human first reaction as a signal, making him pause and reflect on a number of questions: Should he abandon principle and order Bartling to spend the remainder of his painful life chained to his bed? Is that more humane? Should he have inquired whether Bartling and his doctors had engaged in sustained conversation with one another about any possible alternatives that might prolong a more comfortable life for a while (e.g., by providing more sustained pain relief, about which doctors are only beginning to acquire expertise)?¹⁷ Whenever such cases come to court, the judge's humanity should lead him to make such inquiries and not to prolong the agony of dying by stripping the patient of his dignity at a most agonizing moment when the patient believes that it is not his life, but only his dying that is being prolonged. Is not then the patient the ultimate judge?

Many of George Annas' essays, including *Prisoner in the ICU*, were eventually published in book form under the titles of *JUDGING MEDICINE* and *STANDARD OF CARE: THE LAW OF AMERICAN BIOETHICS*. These essays cover most new developments in health law in these waning years of the twentieth century. The essays cover artificial insemination, surrogacy, the mentally retarded, death, dying, organ transplantation, AIDS, rationing medical care and more. The original articles were reprinted in these books, though they were arranged in appropriate sections to provide unity.

Annas' most recent book, *SOME CHOICE: LAW, MEDICINE AND THE MARKET*, departs significantly from his previous two books in that the essays here were not only updated, but also rewritten. In reflecting on the articles to be included, Annas realized that most of them centered on the issue of choice. In his characteristically blunt introduction, he asserts that "choice rhetoric is often more ironic than real and routinely serves to camouflage issues that would otherwise demand our serious attention."¹⁸ Thus, the theme of his book becomes the shallowness of our

16. ANNAS, *supra* note 8, at 230.

17. S.H. Johnson, *End-of-Life Decision Making: What We Don't Know, We Make Up; What We Do Know, We Ignore*, 31 *IND. L. REV.* 13, 33-34 (1998) (and accompanying notes).

18. GEORGE ANNAS, *SOME CHOICE: LAW, MEDICINE AND THE MARKET* xi

discourse on "choice," which he exposes in different contexts throughout many chapters. He makes a convincing case for his contention that so-called choices are often "hollow . . . limited, illusory or coercive."¹⁹ Not surprisingly, in light of his prior work, he further argues that the power of choice must be coupled with the language of rights to make it effective. One of these rights, since patients are often sick and vulnerable, is access to complete and accurate information about diagnosis, risks, benefits and alternatives; for without such knowledge, Annas believes, choice is illusory. Doctors must provide this information and invite patients to participate in the decision making process. Managed care organizations that try to place gag rules on doctors or, even more perniciously, try to offer doctors financial incentives for keeping costs down, must not manipulate the doctrine of informed consent which is the bedrock of the rights of patients. Annas insists that another patient right arises in today's profit-driven market economy when patients' choices are denied, even if supported by their doctors, and when time is short. This is the right to fair, quick and enforceable dispute resolution mechanisms. Without such a right, choices are meaningless.

It is a pity that the market model of providing health-care, accompanied by either implicit or explicit messages to doctors to curtail information, has arrived on the scene when physicians are still struggling to learn how to make the idea of informed consent a reality. This is an inordinately difficult task, and it is not yet ingrained in the ethos of medicine. As Annas put it succinctly, "[a]fter almost three decades of legal and ethical debate, neither the idea nor the ideal of informed consent governs the doctor-patient relationship; [while] informed consent is well entrenched in theory . . . in practice patient autonomy continues to be elusive."²⁰

Indeed, courts also remain ambivalent about how stringently to enforce the legal standard of doctor-patient communication. For example, in the recent ruling in *Arato v. Avedon*,²¹ the California Supreme Court overruled a lower court's decision that a terminally ill patient who was unlikely to benefit from further treatment should be informed of his dire prognosis.²² Annas wrote persuasively, "[i]f prognosis information is an

(1998).

19. *Id.*

20. *Id.* at 66.

21. 358 P.2d 593 (1993).

22. *Id.*

integral part of what successful treatment means — and it must be for anyone concerned about continuing to live — then prognosis information must be disclosed.”²³ In this instance, the likely futile chemotherapy treatment would only affect the quality of Arato’s remaining life. Therefore, it is a decision which only the patient should make. To be sure, physicians are aware that predictions about prognosis occasionally are mistaken, but that doesn’t mean they cannot otherwise communicate them to patients clearly and fairly. The California Supreme Court, one of the first jurisdictions to acknowledge respect for self-determination on particular therapy demands a standard set by law for physicians. The court stated that “[w]e decline to intrude further, either on the subtleties of the physician-patient relationship or in the resolution of claims that the physicians’ duty of disclosure was breached, by requiring the disclosure of information that may or may not be given in a treatment context.”²⁴ Annas correctly asserts that the law must intrude, as it did when it recognized the doctrine of informed consent, to provide patients with more than illusory choices. Nevertheless, the important right to information is not securely established either in law or in medicine.

In an intriguing chapter entitled *Metaphors, Medicine, and the Market*,²⁵ George Annas suggests a new metaphor is needed to replace the two that have traditionally guided health-care policy. The old military metaphor, he believes, has had “the most persuasive influence over both the practice and financing of medicine Medicine is a battle against death [and physicians] are trained to be aggressive, fight invading diseases with weapons designed to knock them out.”²⁶ Annas argues, for example, that when physicians emphasize longevity over quality of life, they avoid discussing with patients whether the prolongation of life is worth the suffering endured through treatment. The conduct of human experimentation is another expression of this war mentality.

Annas maintains that the newer market metaphor is just as “dysfunctional. . . . [E]mphasis is placed on efficiency [and] profit maximization.”²⁷ The role of physicians is radically altered as they are instructed by managers that they can no longer be patient advocates, but rather must advocate for the entire group of covered lives in the health plan.

23. ANNAS, *supra* note 18, at 61-62.

24. *Arato*, 858 P.2d at 607.

25. ANNAS, *supra* note 18, at 45-54.

26. *Id.* at 45.

27. *Id.* at 45-46.

As one official of Columbia/HCA put it: "Hospital operations are not much different from a ball-bearing company. We treat this industry as a business."²⁸ In response, George Annas wryly adds: "This might be plausible if bearings got sick, died, suffered and had relatives who loved and cared for them."²⁹

Instead of these two metaphors, Annas proposes a new one, the ecology metaphor: "Ecologists use words like integrity, balance, natural, limited (resources), quality (of life), diversity, renewable, sustainable responsibility (to future generations), stewardship, community, and conservation."³⁰ He believes these concepts could have a profound impact on the debate about health care. It could "help us [to] confront and accept limits (both on the expected length of our lives and the amount of resources we think reasonable to spend to increase longevity) . . . to debate the merits of rationing, and to accept the function of responsible gatekeepers to act as stewards of the medical commons."³¹ Annas and other like-minded persons have been chided by those who believe that insistence on autonomy and individual rights neglects communitarian values which require attentiveness to the limits of health-care resources and to the ways they should be allocated fairly. The ecology model addresses these problems. However, I believe that Annas also tells us that the inalienable right to liberty, embedded in our Constitution, and the individual rights guaranteed in our Bill of Rights, are also communitarian values imbedded in our society. Thus, we are faced with a clash of communitarian values that require honest acknowledgment to society, patients and their families.

In his chapter *Plagued by Dreams*,³² George Annas returns to the conduct of human experimentation, a subject about which he has written a great deal over the years. Human experimentation, most often conducted on patients, raises a critical question: What essential requirements must be met before society can justify the use of one human being for the sake of others? Annas finds an answer to this question in the Nuremberg Code, promulgated by United States judges at the conclusion of the trial of the Nazi physicians. Annas argues that "the judges meant the Code's application to be universal; and [that] it remains the most authoritative

28. *Id.* at 47.

29. *Id.*

30. ANNAS, *supra* note 18, at 48.

31. *Id.* at 49.

32. *Id.* at 153-69.

legal and ethical document governing international research standards, and one of the premier human rights documents in world history.”³³ He views the Code’s uncompromising first principle, which requires voluntary, informed, competent and understanding consent, as essential in protecting the rights of research subjects. Physician-researchers have criticized the Code, particularly its first principle, as too confining and inapplicable to their civilized practices. Annas responds by maintaining the Code should be interpreted rather than abandoned.

I agree. However, the Code was abandoned by the World Medical Association and substituted with the Association’s Declaration of Helsinki. The medical research community also abandoned it, as Annas perceptively observes, in its pervasive employment of “doublespeak concepts: experimentation is treatment, researchers are physicians, and subjects are patients. Indeed, we have encapsulated all three into a ‘new-speak’ word, ‘therapeuticresearch’ (although we retain a space between the c and the r).”³⁴ In support, he quotes from the Final Report of the Presidential Advisory Committee on Human Radiation Experiments which, in its review of recent research protocols and consent forms, made a similar point: “All too quickly the language [of the research consent form] shifted to treatment and therapy when the latter was not the purpose and was only, at best a by-product of the research.”³⁵ In his discussion of the persistent obfuscation of the distinction between research and therapy, he makes another important observation which deserves careful study: “Modern informed consent doctrine is meant to safeguard the patient’s decision making autonomy (liberty) and dignity. It is thus inappropriate to have separate disclosure requirements for therapy and research.”³⁶

I have barely conveyed the richness of George Annas’ observations on the ambiguities in motivations and actions that persist in current research practices. The many recommendations he makes, should be of valuable assistance to those interested in reforming current rules governing research on humans. *Plagued by Dreams*, and many other chapters in *SOME CHOICE*, such as the chapters on cloning, and on his and Michael Grodin’s newly founded international association, *Global Lawyers and Physicians*, reveal another facet of George Annas’ personality:

33. *Id.* at 156.

34. *Id.* at 155.

35. ANNAS, *supra* note 18, at 166.

36. *Id.* at 163.

His commitment to public advocacy. He values scholarship but he also wants it to have an impact on shaping institutions and health care policies.

George Annas is now the Edward R. Utley Professor of Health Law, and the Chair of the Health Law Department at Boston University School of Public Health. He has been ably assisted for almost over two decades by full-time faculty members Leonard Glantz, Michael Grodin and Wendy Mariner, all of whom have been widely published. In addition to his writing, teaching, and lecturing throughout the world, Annas has organized many conferences, among them the remarkable conference in 1989 commemorating the fiftieth anniversary of the opening of the Doctors' Trial at Nuremberg. This conference, organized by Annas and Michael Grodin, brought together a distinguished group of speakers to explore the significance of the Nuremberg Code from different historical, ethical, legal, and medical perspectives. The presented papers were published in book form,³⁷ and the volume represents one of the best available discussions of the history and contemporary ethical and legal status of the Nuremberg Code.

I was delighted when the editors of *The Journal of Contemporary Health Law and Policy* wrote me that they intended to devote this issue to the work of George Annas. He has been one of the most significant contributors to the field of health law at a time of major, well-nigh revolutionary, changes in the practice of medicine: Scientific advances that involve an ever-increasing number of patients in human experimentation and that have blurred the boundaries between research and practice; technological advances that can prolong pain-free or unbearably painful conscious and unconscious life; advances in reproductive technologies and genetics that place reproduction increasingly under scientific control and, thus, subject to fateful human manipulation; the increasing impact of law on medicine, beginning with the doctrine of informed consent and extending to issues of how to die or not to die; and the more recent intrusion of the market on the practice of medicine. There are more. In light of these dizzying and almost weekly developments, it is not surprising that, after his first book, Annas adopted the essay as his style of writing. This has allowed him to comment on the many novel medical and legal developments in rapidly advancing fields. Being trained in law, he wanted bioethicists, physicians and lawyers to

37. THE NAZI DOCTORS AND THE NUREMBERG CODE: HUMAN RIGHTS IN HUMAN EXPERIMENTATION (George J. Annas & Michael A. Grodin, eds. 1992).

become more aware of the role law plays, or should play, in matters that affect all citizens and society as a whole.

In the many settings in which I have encountered George Annas over the years, I have admired his boldness, intellect, compassion and moral vigor. Of course, we have not always agreed, but in countless conversations in restaurants, bars and over the telephone, we have enjoyed our commonality of views and argued over differences. We have listened to one another in somber conferences at the Holocaust Museum in Washington, D.C., at the Opera House in Nuremberg, and in academic settings throughout the United States. He has been my friend, colleague and teacher, and he surely has been that to many others as well. He is still young, and we shall (indeed, we must) hear more from him about human rights and the respect that should be accorded to patients. After all, that category will include all of us at one time or another, and at the most vulnerable moments of our lives.

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