

**BIOETHICS:
HEALTH CARE,
HUMAN RIGHTS
AND THE LAW**

Second Edition

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This book is dedicated to
Sierra, Devon, Pele and Trotman LaFrance,
grandchildren all,
citizens of a brave new world.

PREFACE

This text is designed for professionals and students interested in bioethics, healthcare and the law, as viewed through the lens of court decisions, many resting on constitutional grounds. Judicial opinions concerning bioethical principles and issues are extremely important. They reflect disciplined, tough minded decision-making and translate abstraction into action. In this effort, judges must seek and be guided by the ethical values a community holds dear. Judicial commentary increasingly interprets legislation, such as the Americans with Disabilities Act, through which the community declares its ethical position and priorities. Thus, judicial decisions may be viewed as a rich and important source of literature on bioethics.

This book employs a definition of “bioethics” considerably broader than the definition usually reflected in treatments of this subject. All too often, “bioethics” is viewed as being limited to issues arising from the impact of new technology on the human body, as with reproductive technology or organ transplants, often viewed from the limited perspective of medical doctors. That is certainly included in the present volume, in such subjects as defining death, test tube babies, genetic screening, surrogacy, organ transplants and physician-assisted death. But a moment’s reflection is sufficient to establish that a proper focus on bioethics, with its concern for personhood, privacy and autonomy, would include other subjects such as maternal-fetal conflict, experimentation, repressed memory, gender alteration, same sex marriage, compulsory testing, managed care and medical necessity. Bioethics should also include matters of conscience, as they affect human biology, as with religious beliefs or transfusions or abortion or creationism.

The cases in the Table of Contents reflect the extent to which bioethical decision making by courts has come to rest upon fundamental constitutional precepts. To a surprising extent, the Supreme Court itself has been involved in the exposition of bioethics as a constitutional concern. Cases concerning life, death, abortion, sterilization and institutionalization are commonplace, as are cases dealing with privacy, autonomy and conscience. Frequently, as in the *Cruzan* and *Quinlan* cases, courts are concerned not only with the ethics of outcome but also of process — the “who” of ethics. An important contribution of this volume is to reorganize and analyze constitutional case law in terms of traditional ethical and bioethical analysis.

The “who decides” question in bioethics is fundamental and of pervasive significance. One of the essential principles of bioethics posits autonomy as a starting point for bioethical decision making. Most writers agree that ethical relations require a respect for the autonomy of others. These two concerns — autonomy and respect for autonomy — are not only involved in the relations of patients and care givers, but also in the relation between the community — represented by the courts — and individual citizens. Courts must frequently decide when to defer to the autonomy, however misguided or dubious, of competent individuals. They must also seek and respect their own limits in dealing with institutions or individuals, competent or otherwise. With these

concerns, for the individuals and for the limits of judicial processes, courts must also contend with the competing claims of others, including friends, family and health care providers. Thus, in every judicial decision, there is implicit both a consideration of what principles apply and who shall decide what those principles mean. Who will determine these questions is every bit as important as how they should be answered.

Of equal significance is the treatment in this work of the subject denominated “community,” not the “who” but the “us” of ethics. Bioethics is properly concerned with those *included* and those *excluded* in ethical entitlements and obligations. For want of a better word, those to whom we owe duties, in varying forms, may be considered to be “citizens” of our community. The community must respect the citizen, but it must also protect him or her. And the reverse is true — individuals must respect each other and the community. Any consideration of ethics must therefore begin, as this book does, with the question of who is in, and who is outside, the community and what duty — if any — is owed outsiders. This text therefore considers cases which have treated people as property or aliens or, in some fashion, less than human, as with sexual predators, the unborn or the undead. Equally important are subclasses of community members — the incompetent or mentally ill or prisoners, people who are historically subject to abuse, neglect and exploitation.

Once it is determined who is in the “community”, ethics requires describing those elements of individual personhood which must be respected. A person is not a self defining concept. Chapter II deals with the characteristics of a person — identity (memory, gender), integrity (testing), psychological control, association (marriage, privacy) and conscience (religion, belief). The cases deal with dimensions of biology and technology in these concepts, such as repressed memory and hypnosis, gender alteration, plethysmographs, ECT and psychosurgery, same sex marriage, predator identification, and ritual animal slaughter. Throughout are the recurring questions of what may the individual do? When may the community intervene? When must it hold back? When, for example, may the state amputate an incompetent woman’s leg or transfer a kidney from an incompetent brother to his brother?

The ethical relationship between community and individual is most often confronted in the physician-patient relationship, the subject of Chapter III. Here are cases on sale of body parts, warning of third parties, sexual relations with patients, therapeutic privilege, experimentation, standard of care and measuring of injury. These are problems on the edge of developing concept and caselaw. But they fit well within traditional fiduciary strictures of fidelity (conflicts of interest, confidentiality), candor (informed consent, therapeutic privilege), and competence (best efforts). This “fiduciary” framework for analysis is preferable to the customary, yet awkward, four-point analysis of beneficence/nonmaleficence/autonomy and justice for several reasons. It is a traditional description of power relations in many legal contexts. It has the potential for growth which managed care mandates. And it realistically recognizes the needs of the healthcare provider.

Finally, the fourth chapter examines a number of bioethical contexts for patients' choices: maternal-fetal conflict, self abuse, AIDS treatments, refusal of treatment and assisted suicide. The fourth chapter serves up a number of recurring, current contexts involving the concepts of the first three chapters. The emphasis is on *choice* because ethics is preeminently a philosophy of *action*. And so maternal-fetal conflict, self-abuse, AIDS disclosure, and femal genital mutilation all appear in the fourth chapter. Managed care does as well, since seeking and denying healthcare coverage powerfully impacts the conduct of patients and providers. As might be expected, the last chapter closes with death, DNR orders and physician assisted suicide — the last opportunities for choice in life.

The author contemplated a fifth chapter, on issues of public health, such as rationing healthcare, funding research and quarantining disease. While these are “ethical” issues, they are of a different order. This text is mainly concerned with individual choice and the community. Moving to a level of generality, as with rationing, loses that focus and the uniquely ethical dilemmas posed for individuals as they choose among their various interests and those of the community. Still, some community level issues are included, particularly those arising from managed care. In the most elemental of terms, managed care restricts choices by patients and physicians, intruding on a fiduciary relationship. This casebook examines that process in a number of contexts, for example the denial of HMO/MCO coverage for bone marrow transplant or peripheral stem cell rescue in the treatment of cancer on the grounds that it is “experimental,” or the denial of physical therapy to MS patients on the ground that it is not “medically necessary.”

These materials are organized for teaching purposes. Generally, there are two or three cases, each followed by notes and questions designed to highlight important issues raised, resolved or remaining for future resolution. Each unit has at least one problem presented. These are based on current factual situations from practice or the literature, involving difficult bioethical issues for discussion and resolution. Some of the problems are based on court cases; others are drawn from articles and reports in the *New England Journal of Medicine* and the *Journal of the American Medical Association*; others are from the current news media. The problems are particularly important in bringing the primary court cases to bear upon medical or biotechnical contexts and practices.

One or two comments on editing may be in order. Whenever and wherever possible, technical citations, references and language have been omitted. Also, large portions of text have been omitted from some cases. Much of the omitted text was related to procedural or technical matters which would only detract from the ethical and substantive concerns, which are the focus of this text. At all times, the text as presented is accurate and, the author hopes, remains faithful to the intent and sense of the authors. The objective at all times is to enhance ease of reading and comprehension.

The author wishes to acknowledge a considerable debt to a number of people. Chief among these are his students, past and present, at Lewis and

Clark Law School and at Murdoch University in Perth, Australia. I have found myself badly in need of instruction about the principles and practices of the health care professions. Fortunately, I have had readily at hand a number of students who themselves were nurses, physicians, emergency medical technicians, hospital administrators, nursing home administrators and other health care professionals. It has been a pleasure and a delight over the years to be taught with kindness and consideration by such gifted people.

Several people warrant individual recognition. First, my thanks go to Linda Anderson, Becky Johnson, R.N., and Robin Craig, Ph.D., my student assistants, who made invaluable contributions to this text. Secondly, as always, my thanks particularly go to Lenair Mulford and Shannon Floyd, whose word processing talents and immense patience made this manuscript possible. Appreciation goes as well to Dean James Huffman, who in perilous financial times, nevertheless found the funds to make two summer grants possible, to bring this work to fruition. A special note of thanks goes as well to Professor John Grant of the University of Glasgow, Scotland, for his many helpful comments on the human rights and international dimensions of this subject matter.

Finally, it seems appropriate (if foolhardy) to define the subject of this book. For this author, at least, bioethics is the set of values by which people make choices that affect themselves and others as biologically-grounded beings. It defines the content and boundaries of individuals; the communities to which they belong; and the relations between them. It uses the body as a lens into, and a home for, the human spirit. Bioethics assumes a person of free choice and moral conscience, with an obligation not only to others, but also to ourselves, as physical, temporal beings in an infinite universe.

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