Surviving Health Care

A Manual for Patients and Their Families

This book serves as a tool to help patients and their families deal rationally with the perplexing and often irrational world of health care. It covers the topics and addresses the challenges that experts in a variety of health care fields believe are the most vital to meeting the challenges of decision making when people feel most vulnerable. With contributions from leading health care specialists, *Surviving Health Care: A Manual for Patients and Their Families* examines a wide array of topics, including advance planning for health care, medical emergencies, genetic testing, pain management, and care of elders. It is a unique resource that aims above all to help patients reach their best health care decisions.

Thomasine Kushner is co-editor of the *Cambridge Quarterly of Healthcare Ethics* and a bioethicist with the California Pacific Medical Center Program in Medicine and Human Values in San Francisco. She taught bioethics at the University of California, Berkeley, for fifteen years and is the author (with David Thomasma) of *Birth to Death: Science and Bioethics*, *Asking to Die: Inside the Dutch Debate about Euthanasia*, and *Ward Ethics: A Case Book for Doctors-in-Training*, along with several books on aesthetics and design.
Surviving Health Care

A Manual for Patients and Their Families

Edited by

Thomasine Kushner
To William S. Andereck and Dena M. Bravata, physicians for all seasons
Contents

Contributors ix
Preface xiii

1. Letter to Patients: On Becoming the “Good” Patient and Finding the “Right” Doctor 1
   Leonard C. Groopman

2. Becoming an Active Member of Your Health Care Team 13
   William A. Norcross

3. Information That Will Help You with Advance Planning for Your Health Care 26
   Mark R. Wicclair

4. Responding to Medical Emergencies 46
   Kenneth V. Iserson

5. What You Need to Know about Medical Errors 56
   Erica S. Friedman and Rosamond Rhodes

6. Being Informed When You Give Consent to Medical Care 69
   Ben A. Rich

7. Beware of Scorecards 85
   James J. Strain and Rosamond Rhodes

8. Transplantation 101: Negotiating the System 96
   Aaron Spital and Steven Smith
9. When the Illness Is Psychiatric  
Leonard C. Groopman  
124

10. On the Horizon: Genetic Testing  
Robyn S. Shapiro  
136

11. To Be or Not to Be – A Research Subject  
Eric M. Meslin and Peter H. Schwartz  
146

12. Information That Will Help You Make Health Care  
Decisions for Adult Family Members  
Mark R. Wicclair  
163

13. Caring for Individuals with Alzheimer's Disease: Ethical  
Issues along the Way  
Robyn S. Shapiro  
179

14. When the Patient Is a Child  
Timothy S. Yeh  
191

15. Care of Elders  
Claudia Landau and Guy Micco  
206

16. Being and Thinking  
Ilina Singh, Claudia Jacova, Paul Ford, and Judy Illes  
222

17. A Patient’s Guide to Pain Management  
Ben A. Rich  
246

18. The Hardest Decisions: When Treatment Stops Working  
Timothy E. Quill and Mindy Shah  
264

19. What You Need to Know about Disasters  
Griffin Trotter  
279

20. Making the Internet Work for You: Researching Your  
Health Questions  
Bette Anton  
294

Appendix: Patient Individual Profile  
J. Westly McGaughey, Ruchika Mishra, and Alexis Lopez  
311

Index  
317
Contributors

Bette Anton, MLS, is Head Librarian for the Pamela & Kenneth Fong Optometry and Health Sciences Library of the University of California, Berkeley. This library serves the University of California, Berkeley School of Optometry, and the University of California, Berkeley–University of California, San Francisco, Joint Medical Program.

Paul Ford, PhD, is Associate Staff in Bioethics and Neurology at the Cleveland Clinic Foundation and Assistant Professor, Cleveland Clinic Lerner College of Medicine of Case Western Reserve University, Cleveland, Ohio. He is co-editor, with Denise M. Dudzinski, of Complex Ethics Consultations: Cases That Haunt Us (Cambridge University Press, 2009).

Erica S. Friedman, MD, is an internist and rheumatologist with Mount Sinai School of Medicine in New York City, where she is also Associate Dean for Undergraduate Medical Education.

Leonard C. Groopman, MD, PhD, is Assistant Professor of Clinical Psychiatry and Medical Ethics at Weill Cornell Medical College, where he also is active in the Institute for the History of Psychiatry.

Judy Illes, PhD, is Professor of Neurology and Canada Research Chair in Neuroethics, National Core for Neuroethics, at the University of British Columbia. Her book, Neuroethics: Defining the Issues in Theory, Practice and Policy, was published by Oxford University Press in January 2006.
Contributors

Kenneth V. Iserson, MD, MBA, FACEP, FAAEM, is Professor Emeritus of Emergency Medicine, University of Arizona College of Medicine, Tucson.

Claudia Jacova, PhD, is a Postdoctoral Fellow in Neurobiology and Behavior, University of British Columbia, Canada.

Claudia Landau, MD, PhD, is Associate Clinical Professor of Medicine and Coordinator of the Geriatric Curriculum in the University of California, Berkeley–University of California, San Francisco, Joint Medical Program, Berkeley, and Chief of Geriatrics and Palliative Care in the Department of Medicine at the Alameda County Health Center, Oakland, California.

Alexis Lopez, BA, is a Research Technician with the Program in Medicine and Human Values, California Pacific Medical Center, San Francisco, California.

J. Westley McGaughey, BA, is Research Analyst, Grants and Study, in the Program in Medicine and Human Values, California Pacific Medical Center, San Francisco, California.

Eric M. Meslin, PhD, is Director of the Indiana University Center for Bioethics, Associate Dean for Bioethics, and Professor of Medicine and of Medical and Molecular Genetics at Indiana University School of Medicine. He also is Professor of Philosophy at the School of Liberal Arts and Co-Director of the Indiana University–Purdue University, Indianapolis, Signature Center Consortium on Health Policy, Law, and Bioethics. He has more than eighty publications on topics ranging from international health research to science policy, including Belmont Revisited: Ethical Principles for Research with Human Subjects, co-edited with James F. Childress and Harold T. Shapiro.

Guy Micco, MD, is a Clinical Professor in the University of California, Berkeley–University of California, San Francisco, Joint Medical Program; Director of the University of California, Berkeley, Academic Geriatric Resource Center (Center on Aging); and Co-Director of the University of California, Berkeley, Center for Medicine, the Humanities, and Law, Berkeley, California.

Ruchika Mishra, PhD, is editor of the Ethics Committees at Work section of the Cambridge Quarterly of Healthcare Ethics and a 2008–2009 Postdoctoral Fellow in the Program in Medicine and Human Values, California Pacific Medical Center, San Francisco, California.
Contributors

William A. Norcross, MD, specializes in family practice and geriatric medicine in the Department of Family and Preventive Medicine at the University of California, San Diego. He is the founder of the Physician Assessment and Clinical Education (PACE) program.

Timothy E. Quill, MD, is Professor of Medicine, Psychiatry, and Medical Humanities and Director of the Center for Ethics, Humanities, and Palliative Care at the University of Rochester School of Medicine. He is the author of numerous books and articles on issues related to palliative care and end-of-life concerns.

Rosamond Rhodes, PhD, is Professor of Medical Education and Director of Bioethics Education at Mount Sinai School of Medicine and Associate Professor of Philosophy at the Graduate School, City University of New York. She is co-editor of the American Philosophical Association Newsletter on Philosophy and Medicine and co-editor of Medicine and Social Justice: Essays on the Distribution of Health Care (Oxford University Press, 2002).

Ben A. Rich, JD, PhD, is Professor and Chair of the Bioethics Program, University of California, Davis, Sacramento, California. He is the author of Strange Bedfellows: How Medical Jurisprudence Has Influenced Medical Ethics and Medical Practice (Kluwer Academic/Plenum Publishers, 2001).

Peter H. Schwartz, MD, PhD, is a core faculty member of the Indiana University Center for Bioethics, Assistant Professor of Medicine at the Indiana University Medical Center, and Assistant Professor of Philosophy at the Indiana University School of Liberal Arts at Indianapolis. He also practices adult outpatient medicine at the Primary Care Clinic at Wishard Hospital.

Mindy Shah, MD, is an attending physician on the inpatient palliative care consult service at the University of Rochester Medical Center, Strong Memorial Hospital.

Robyn S. Shapiro, JD, is editor of the Bioethics Education section in Cambridge Quarterly of Healthcare Ethics and a health law partner with Drinker Biddle & Reath LLP. She recently completed her twenty-six-year-tenure as Professor of Bioethics and Director of the Center for the Study of Bioethics at the Medical College of Wisconsin.

Ilina Singh, PhD, is Wellcome Trust Lecturer in Bioethics and Society at the London School of Economics, London, England.
Contributors

Steven Smith, MD, is a transplant nephrologist and Associate Professor in the Division of Endocrinology, St. Luke’s Roosevelt Hospital, New York.

Aaron Spital, MD, is an academic nephrologist at Elmhurst Hospital Center in Elmhurst, New York, and Clinical Professor of Medicine at Mount Sinai School of Medicine. He has had a longtime interest in ethical issues in organ transplantation and edits the Ethics section of Seminars in Dialysis.

James J. Strain, MD, is Professor in the Department of Psychiatry, Mount Sinai Medical Center in New York City.

Griffin Trotter, MD, PhD, is Associate Professor in the Center for Health Care Ethics at Saint Louis University, where he also holds an appointment in the Department of Surgery, Emergency Medical Division. He is the author of The Loyal Physician (Vanderbilt University Press, 1997) and The Ethics of Coercion in Mass Causality Medicine (Johns Hopkins University Press, 2007).

Mark R. Wicclair, PhD, is Professor of Philosophy and Adjunct Professor of Community Medicine, West Virginia University, and Adjunct Professor of Medicine and a part-time instructor of bioethics at the Center for Bioethics and Health Law Faculty, University of Pittsburgh. He is author of Ethics and the Elderly (Oxford University Press, 1993).

Timothy S. Yeh, MD, is Director of the Division of Critical Care Medicine and Vice Chairman of the Department of Pediatrics, Children’s Hospital of New Jersey at Newark Beth Israel Medical Center. As Administrative Director of Critical Care, he supervises the operation of the Pediatric Intensive Care Unit, and as Vice Chairman, he assists in program development and planning for the Department of Pediatrics. He lectures extensively and is the author of numerous abstracts, articles, and book chapters.
Preface

Alice’s lament after falling down the rabbit hole captures what most of us feel when we are catapulted into the world of illness: “How queer everything is today! And yesterday things went on just as usual. I wonder if I’ve been changed in the night?” Suddenly, like Alice, you find yourself struggling in an alien environment, with an unfamiliar culture, where even the language is strange. How do you cope? How do you manage? How do you find your way? Like Alice, it’s natural to think, “It would be so nice if something made sense for a change.”

Making sense of and surviving the powerlessness produced by illness are what this book is about, and it had its beginning where all medical encounters start – with the patient. In this case, HK, a vibrant man in his fifties who had achieved every worldly success, in large part because of the power of his personality and his ability to tackle difficult problems and solve them in creative ways. When he began to notice a persistent pain in his shoulder and arm, he attributed it to strain from physical activity. However, it did not decrease, and when he met a colleague for lunch, he complained of having trouble climbing the steep steps outside the restaurant. Alarmed, his friend urged him to go directly to an emergency department, where it was immediately clear he was having a heart attack. That began what HK later described as a descent into chaos in which he felt powerless, frightened, and totally at the mercy of a system he did not understand. Several years after open heart surgery, bouts in intensive care, and rehabilitation, HK urged the writing of a guide for patients – present and future – to help them
navigate the unfamiliar world of health care and survive on their own terms and with their dignity intact.

There is a surfeit of self-help information on health: how to reach and maintain maximum health through diet, exercise, lifestyle regimens, and so forth. Such measures are all for the good, but what has been missing – and critically needed – is what HK wanted, a survival kit with tools to help patients and their families deal rationally with the perplexing and often irrational world of health care. Physicians tell us they find the health care system frustrating and even befuddling; it takes no imagination to discern how those of us outside the health care system feel! This manual is intended as a survival guide to help you find your way and regain control in a seemingly uncontrollable situation at a time when patients and families are at their most vulnerable.

All of us are united by our common desire to find useful information to meet inevitable health care challenges. However, it should be noted that when it comes to individual health care, one size does not fit all. Determining your own health care decisions must remain, as it should, an essential part of your relationship with your physician. Instead, what you will find here are practical suggestions to guide you through the Terra Incognita created by illness. Rather than solutions, the goal here is to afford you the kind of information and perspectives a variety of health care experts believe are your best navigational tools for reaching the best possible decisions for yourself and your family.

Because of the wide range of issues that need to be covered, as well as the breadth of information required to address them, my task as editor was to get contributors who are experts in the most challenging issues patients have to face. This volume includes chapters written by individuals not only from my own discipline (philosophy), but also from medicine, bioethics, public policy, psychology, and the law. These writers give you their personal perspectives and engage you directly and informally, as they might a friend or family member. They discuss aspects of health care planning and management both in and out of institutional settings. Their goal is to provide the resources and fill in the gaps. By knowing what to expect, how to access the environment, and what options are available, you will be better able to combat the fears and feelings of impotence and inadequacy that threaten clear decision making at the very time you need to be most effective.

You will find that just as medicine is said to be an art, there also is an art to being a patient. That means there is a time to push forward
to ensure you get the answers and information you need, but there also is a time to put yourself in the hands of others. The art of being a patient comes in knowing when the moment is right for each. The following chapters serve as a compass to guide you in determining that balance for yourself and your family.