

PUTTING PATIENTS FIRST

Best Practices in
Patient-Centered Care

Second Edition

EDITORS

SUSAN B. FRAMPTON

PATRICK A. CHARMEL

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*This book is dedicated to Laura C. Gilpin (1950–2007),
poet, nurse, and friend, and to the love she inspired
in all who knew her and who were touched by
her kindness, caring, and respect.*

ACKNOWLEDGMENTS

We would like to express our deepest gratitude to the true pioneers of patient-centered care, including Planetree's founder, Angelica Thieriot, whose eloquent Prologue in this second edition chronicles her personal journey as a patient, which led her to advocate for the rights of all patients. A key colleague in that journey of turning vision into reality was Laura C. Gilpin, to whom this book is lovingly dedicated. Laura's unfailing dedication to patients and to those who care for patients touched everyone she worked with in her early years as a nurse and in her last two decades working with Planetree hospitals around the world. And to the late Harvey Picker (1915–2008), founder of The Picker Institute, an organization, like Planetree, committed to a health care system in which caring, kindness, and respect are believed to be essential elements in the delivery of excellent care.

We continue to be indebted to so many, who, over Planetree's thirty-year history, have helped to nurture, shape, and guide the vision to become the international organization it is today. We are especially grateful to Planetree's founding board of directors, to the initial model sites, and to the organizations, including The Henry J. Kaiser Family Foundation and The San Francisco Foundation, whose support made the establishment of the original Planetree model site possible.

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Susan B. Frampton and Patrick A. Charmel
The Editors

THE EDITORS

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health care in a healing environment. Under his leadership, Griffin has appeared on the *Fortune* magazine list of the 100 Best Companies to Work for in America for nine consecutive years, was named a 2007 Premier/CareScience National Quality Leader, and has received the 2005 and 2007 Health Grades Distinguished Hospital Award for Clinical Excellence. Griffin was also a recipient of the Total Benchmark Solution's Top 100 Quality Award in 2006 and was named one of the Solucient 100 Top Performance Improvement Leader Hospitals in 2007. He is coauthor of *Putting Patients First* (Jossey-Bass, 2003), which received the American College of Healthcare Executives Health Care Book of the Year award in 2004.

In 2005, he was appointed by the U.S. Secretary for Health and Human Services to the twenty-one-member National Advisory Council for Healthcare Research and Quality. He is chairman of the board of directors of the Connecticut Hospital Association and is a member of the board of directors of Qualidigm, a CMS-contracted quality improvement organization. Charmel is vice chair of the board of governors of the Quinnipiac University Alumni Association.

In 2006, Charmel was the recipient of the John D. Thompson Distinguished Visiting Fellow Award at Yale University. He is a recipient of the James E. West Fellow Award from the Boy Scouts of America. He was inducted into the Junior Achievement Free Enterprise Hall of Fame in 2002, and he is a recipient of the Dean Avery Award, given by the *New London Day* newspaper, which recognizes individual commitment to the public's right to know.

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XX The Contributors

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MICHELE A. SPATZ, MS, earned her master's degree at the University of Illinois Graduate School of Library and Information Science, where she was inducted into Beta Phi Mu, the International Library Science Honor Society. After receiving her degree, Spatz was the first librarian to earn tenure at the University of Illinois College of Medicine in Peoria, working there as reference librarian and then branch library director.

While there, she chaired a regional consumer health information project for central Illinois in the early 1980s. In the fall of 1991, she moved to The Dalles, Oregon, to establish the Planetree Health Resource Center, a community-based consumer health library, for Mid-Columbia Medical Center. She has served as the resource center's director since it opened in June 1992. Spatz is the author of the recently published book *Answering Consumer Health Questions: The Medical Library Association Guide for Reference Librarians* (Neal-Schuman Publishers). She is active locally, regionally, and nationally as a writer, teacher, committee member, and consultant.

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PROLOGUE

WHAT PATIENTS CAN TEACH US ABOUT IMPROVING THE QUALITY OF HEALTH CARE

The genesis for the idea of Planetree came out of a hospital experience I had in the late 1970s. I became seriously ill with an unidentified virus and spent two weeks in a leading hospital in the San Francisco Bay Area. I survived with a fervent intention to change the way hospitals treat patients.

The following year was spent trying to parse out which elements of my hospital experience had been the most negative and figure out how they could be improved. I also set out to speak with anyone who had experience in changing institutions, especially in health care: dreamers, innovators, and paradigm changers.

From those conversations came the members of the original board of Planetree and a specific philosophy of care, an apparently obvious—but in fact forgotten—point of view: hospitals exist to make people better, to help them heal. All the other motives—profit, employment, training, efficiency, and so forth—are ancillary to the main purpose and will only be well served if the principal objective, healing, is kept in focus.

Alienation, fear, hopelessness, loneliness, and dehumanization were the emotions that overwhelmed me during my hospital stay and led me to feel that I would never get out alive.

The first impression came at reception, where seemingly uncaring clerical personnel put my husband and me through endless questionnaires and forms as I fought against nausea and the fear that I would pass out. I was then led to a room that faced an air well, furnished only with a mechanical contraption that served as a bed and a metal chair. I felt that I had arrived at a Gulag.

During the two weeks that I was there, I never saw the same nurse twice. Other than my doctor, who came early in the morning to shake his head and talk about me as if I weren't there (once saying to my husband, "I'm afraid we're losing her"), anonymous people came and went, giving me pills, drawing blood, and answering my fearful questions with "I don't know, you'll have to ask your doctor."

My mother-in-law sent me an orchid, which became the center of my attention. It was the only refuge from the bleak and sterile ugliness that surrounded me. I stared at it as if to save my life.

My fever and general discomfort kept me awake most of the night, but often, overcome by exhaustion, I would fall asleep at dawn only to be awakened an hour later and served a totally unhealthy, inappropriate, and inedible breakfast.

What would I have needed? What would have been truly healing? These thoughts occupied my mind over the next fifteen years as many wiser, more experienced minds than mine joined the effort to continue to evolve the philosophy of care that is Planetree.

During the period of gestation that followed my hospitalization, I spent many hours in the library researching the history of hospitals. The paths we took to arrive at the current state of affairs became clear. From the hospices of the Middle Ages to the horrifyingly septic institutions of the nineteenth century, through largely well-intentioned and useful changes, we had arrived at the modern, efficient, dehumanized institutions that prevailed in the 1970s. As in many other aspects of life, however, the most inspirational hospitals were the original ones, the ancient Greek Aesculapian hospitals.

In sharp contrast to the barren environments of modern hospitals, ancient hospitals were set in sacred groves, on spectacular sites. Their stated purpose was to awaken the vital healing energies with beauty, art, music, theater, and poetry. Through herbal potions and ritual, they connected their patients to their inner wisdom, and after one night of dreaming in the Abaton (as records meticulously carved in stone say), many patients were either healed or understood how to heal themselves and were discharged. For those who needed more care, a regimen of exposure to the arts, appropriate physical therapies, and herbal potions had a notable rate of success. One of the crucial elements, I imagine, was hope and the positive support of the Aesculapian priests, whose vocation it was to heal.

As I reflected on my experience, some of the issues that came up as needing urgent attention were

- The need for an aesthetic environment, especially one that has elements of nature
- The importance of quality human contact, continuity of care, and family involvement
- The crucial need for empowerment, human dignity, and control

All of these are aspects of the physical, human, and psychological environment.

Out of the six hundred or so people I met with in that early period were people who became the founding board. Among them was Dr. John Gamble, then chief of medicine at Pacific Presbyterian Hospital. He had been involved in an earlier attempt to humanize health care, called the Patients Involved and Responsible (PIR) node. His wisdom, leadership, and political expertise were essential to the success of Planetree.

Roslyn Lindheim was a professor of architecture at the University of California at Berkeley. She had a lifelong interest in healing environments and had designed a number of innovative hospital units. As part of her research for Planetree, she checked herself into a hospital for two days, an experience she found terrifying and demoralizing even though she was in perfect health.

Stewart Brand, futurist and publisher of the *Whole Earth Catalogue*, brought his boundless intelligence to bear every time the flow of ideas got snagged on some less-relevant point and put us back on track. His lifetime of thinking outside the box created a matrix for the group's creativity. He also brought us our founding director, the brilliant and effective Ryan Phelan, without whom none of our ideas would have become realities.

Jill Goffstein had founded a very successful alternative school, and Suzanne Arms had single-handedly started the alternative birth movement with her book *Immaculate Deception*. Their boldness was based on experience in making change, and it proved to be invaluable.

Dr. Don Creevy, in his obstetrical practice, modeled the ideal Planetree doctor: one who takes time to thoroughly inform his patients, who grants women their right to have the birth experience they want, who makes it safe for them to do so, and who generally expresses the caring and attention that healing requires.

Victoria Fay brought her impeccable taste and sense of color and design to the first Planetree interiors.

Phelps Dewey knew about business and the financial aspects of institutions—an element of crucial importance to our success.

Dr. Fred Hudson brought us more medical expertise and many powerful contacts in the community.

Dr. Aileen Aicardi, beloved pediatrician, provided her professional viewpoint and wisdom.

Joan Barbour shared her knowledge as a health educator and came up with the name, *Planetree*, in honor of the tree on the island of Cos under which Hippocrates taught the first medical students.

Mary Crowley, Gretchen de Witt, and Betsy Everdell were of immeasurable help in providing us the community support and fundraising capabilities without which the project would not have succeeded.

Lee and Adrian Gruhn and Cyril Magnin were our very first donor board members, our very own angels.

The experience in humanistic care and health education provided by Drs. Jordan R. Wilbur and David Sobel were indispensable for our envisioning of Planetree.

Together, we attempted to address the question of how to create healing environments, a discussion that I am happy to report continues to this day in the many splendid Planetree sites and in the spirit of this book.

Angelica Thieriot

INTRODUCTION

PATIENT-CENTERED CARE MOVES INTO THE MAINSTREAM

In the approximately six years since the first edition of *Putting Patients First* was written, patient-centered care has moved from an emerging trend in the health care delivery systems of countries including the United States, Canada, and the Netherlands to a defining characteristic of quality patient care in an ever-expanding number of countries around the world. This move into the mainstream after decades on the fringe is largely the result of the convergence of several evolving social and economic realities:

1. The aging of baby boomers and the associated rise in consumer expectations around the health care experience
2. Unprecedented access to health information fueled by the Internet
3. The demand for greater transparency in reporting of outcomes and new governmental incentives to report these results for widespread dissemination to the public
4. Increased demand for timely and convenient access to costly medical technologies and pharmaceuticals that continue to drive health care costs—including both out-of-pocket costs for patients and employer contributions—increasingly skyward

As we struggle to balance these pressures within what many patients and providers describe as an understaffed, overwhelmed system, providing caring, kind, and respectful service has become even more of a challenge. What began eons ago as a personal calling to provide care to the ill, distressed, and injured has become a trillion-dollar business in the United States alone, with third-party payers in many cases now determining the nature of the patient-caregiver relationship and the extent of their contact with each other. The healing partnership between patient and physician has been reduced to seven-minute office encounters in many settings, and the majority of nurses in hospitals spend more time on documentation than in actually providing care at the bedside (Advisory Board Company, 2003).

Despite these challenges, a growing number of hospitals, clinics, continuing care facilities, and physician practices have found ways to create exemplary patient and resident-centered cultures. They have transformed the experience of care to include what so many other industries have mastered: choice, convenience, personalization, quality, and service. These aspects of a consumer-centric approach mirror the six core elements that the Institute of Medicine declared to be necessary to the delivery of quality patient care—that it be safe, timely, efficient, effective, equitable, and patient-centered (Institute of Medicine, 2001).

Truly patient-centered organizations have figured out how to address the very human needs of patients who come to us when they are most vulnerable, looking for support, comfort, and hope. These organizations see the big picture and attend to the smallest, and yet often the most meaningful, details of the patient experience. They find ways to decrease emergency room wait times and to provide comfortable, attractive furniture in areas where waiting occurs. They offer twenty-four-hour visitation throughout their facilities and support the active involvement of the patient's family, providing adequate space for them as well as meaningful roles and responsibilities as valued members of the care team. They openly share information with patients and their designated caregivers, encouraging them to review their medical charts and contribute their own progress notes, respecting the fact that we can never know another person as well as we know ourselves. These organizations are converting to electronic medical records and are developing interactive systems that connect information between departments so that patients no longer have to respond to the same requests for personal information over and over again. They have taken down the physical barriers in facilities between patients, families, and staff, while attending