HEALTH CARE WITHOUT MEDICARE

A New Practice Manual for Community-Based Care Management

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FOR

Nurses, Social Workers & Therapists
Long-Term Care Managers
Elder Law Attorneys & Finance Specialists
Physicians
Students & Family Caregivers

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Introduction

Science has enabled all of us to live longer, healthier lives. By any measure, its success has been dramatic. Death by infectious disease is slowly disappearing from the medical landscape. In our trauma centers we are resurrected from injuries, illnesses and conditions that once would have been fatal. Average life expectancy is one and a half times longer today than it was just a century ago. We have all become marvels of modern science.

But our success has its price. As more of us live longer, we are more likely to develop chronic health problems. People with chronic illnesses and accompanying physical impairments, most of whom are over age 65, consume more health care. In the United States in 1999, the measurable cost of direct medical treatment–70 percent of which is given to chronically ill or disabled people–was nearly $1.2 trillion. This equaled approximately 13.5 percent of the U.S. Gross Domestic Product, nearly triple its percentage forty years ago.

It is clear that we can no longer afford the amount and kind of medical treatment on which we have grown so dependent. Our current health care approach is too expensive. And it does not meet the needs of the bulk of health care consumers. Ours is an acute-care system. It was not designed to treat illnesses that do not go away. Yet most consumers of health care services have chronic conditions. Today, we bend the needs of the chronically ill to meet the needs of the system, not the reverse.

Chronic illness requires chronic care. For several reasons, chronic care is not a health care system priority. It is neither high-tech nor high-profit. It isn't emphasized in medical schools, and it doesn't draw a lot of venture capital. But chronic care is the most important and the most overlooked issue in health care today. Unless we figure out how to provide adequate amounts of it, the health care and long-term care systems we have built over the last forty years will fail, because the less chronic care we provide, the more high-tech, high-cost, acute care we are going to need. And the more high-tech care we provide, the less we can afford. A health care system focused solely on acute care is on a one-way, dead end street. If ever a paradigm needed shifting, this is it.

The challenge we face in caring for our frail-elderly, chronically-ill, and disabled citizens will soon become the central political, economic, and ethical dilemma of our time. Many professional caregivers know the crisis is already upon us. It is less a crisis in health care itself than it is a crisis in consciousness. Outdated definitions of both health care and the health care professional's role are greatly to blame for our predicament. The problems can be solved, but first we need to change how we think about health care, prevention, and health care responsibility.

So where do we begin? How do we meet the growing needs of the most vulnerable among us and at the same time pay for the other infrastructures we need to thrive as a society? How do we resolve the conflict that is building between our human-service imperatives and our other societal needs?

As George Orwell wrote in his landmark novel 1984, "If there's hope, it lies in the proles." Our modified health care motto might become, "If there's hope, it lies in the patients." For years we have taught patients and their families a lot about compliance and precious little about self-reliance. Their dependency, the life-blood of our acute-care system, is untenable. It must now be transformed from dependency to interdependency. Patients now need to help their caregivers care for them, not just the reverse.

This book is not about changing our health care system. It is about changing our basic health care approach. It offers a model that empowers caregivers and patients to manage chronic illness and disability and to prevent illness exacerbation and injury outside the boundaries of system-based health care. Unlike system-fix approaches, this book argues for people-based health care that emphasizes the patient-caregiver partnership. It argues, too, that a people-based, preventive mode of care will never develop inside the current system of government programs and private, managed-care arrangements. The system is intractably fixed in a medical treatment paradigm that requires third-party reimbursement. And it appears to be incapable of change.

Chronically-ill and disabled individuals and their caregivers will need guidance if they are to move from system supports (third-party insurance, government subsidies, and so on) to self-supports. This book trains the professionals who will offer this guidance. It advances the premise that through education, counseling, and planning, chronic-care patients and their families can effectively manage most chronic conditions in community rather than medical settings. Better self-care management, coupled with supportive care planning, can prevent the worsening of illness or injury and the costly institutionalization that results. It can lower health care costs for our society, foster continued independence for the chronically ill, and reduce stress and inconvenience for caregivers.

This book is about two distinctly different tasks, care planning and care management. Care planning is to care management what architecture is to construction. They are interdependent and complementary enterprises; most health care and mental health professionals who do both rarely differentiate between the two.

Today, most care planners and care managers provide these services after completing specialized training in one or more health care subspecialties. But while a single, core discipline gives them a good foundation, it only provides the foundation. To become effective, most nurses, social workers, physical therapists, and others will need advanced training in the other lifecare disciplines including estate planning, financial management, insurance, and so on. At the present time, most do not pursue such training; such training hardly exists because few recognize its potential value. This lack of awareness stems primarily from today's restrictive and simplistic definition of health care as medical treatment only.

The knowledge base for long-term care planning comes in relatively equal parts from medical treatment, social work, legal services, financial planning, insurance, and the counseling professions. It also requires knowledge of housing alternatives, architectural modification, and the fast-moving field of supportive technology. The knowledge base for ongoing care management is more heavily weighted toward the clinical skills of medicine, counseling, and medical social work. Indeed, care management is often virtually synonymous with home health care.

In this writing, our aim is to dispel confusion, not to contribute to it. We have chosen to do this by using two terms throughout the book that we believe make sense. `Community LifeCare Planning` refers to the knowledge and skills that care planners and care managers must master if they are to help their chronically ill, impaired, or disabled clients achieve their most often-stated goals. Invariably these goals are to preserve independence (translated as the prevention of hospitalization and nursing-home placements), to preserve assets, and to maintain as comfortable a lifestyle as possible. We use the term `care manager` to refer to the practitioners of Community LifeCare Planning. While we differentiate between care-planning and care-management tasks, it is simply too cumbersome to consistently hyphenate these two references throughout the book.

In choosing the term care manager, we achieve three things. First, throughout the text we are able to distinguish practitioners of CLCP from the lawyers, physicians, accountants, financial planners, long-term care and health care practitioners with whom they collaborate. Second, we avoid the titling game all together and, we hope, offend fewer people in the process. Third, by following the K.I.S.S. rule (Keep It Simple, Stupid), the book is made shorter and easier to read.

Thus, we distinguish the practitioners from the knowledge and skills they need to practice. In so doing, we hope to create legitimacy and an identity for the care-management profession itself. Other theories and approaches will doubtless emerge over the coming years, just as different schools of psychotherapy have. We should welcome this evolution, this development of better ways of achieving good care plans and good care-management outcomes. But while many different types of professionals practice psychotherapy, they often share a core expertise and methodology, regardless of their credentials. Their orientation serves as a base for individual expression. We seek to create a similar foundation for a similarly adaptable profession.

As mentioned above, many professionals practice some variation of Community LifeCare Planning. They include social workers, nurses and physical therapists, as well as non-medical professionals such as paralegals and insurance advocates. When any of these professionals decide to become care managers, they face challenges similar to those faced by the one-event athlete who has decided to become a decathlete. They encounter a new scoring system and a new set of rules. To "win" as care managers, they must develop additional skills and broader capabilities. Community LifeCare Planning is their new field of training.

Community LifeCare Planning (CLCP) is the effort to help frail elders, the chronically ill, and the physically disabled to live in the least restrictive community setting of their choice through the strategic use of personal, family, and community resources. CLCP is always best provided through teamwork, usually by clusters of lifecare professionals. Practicing CLCP involves communication, advocacy, clinical services, education, planning, and advice. The care manager's greatest skill may not be in providing the services themselves, but in connecting clients with the specialists who are best able to help. Community LifeCare Planning is an all-encompassing term. "Community" connotes the broadest venue of practice as well as a sense of social connection and social responsibility. It also implies an all-inclusive approach that combines the ethics and purpose of each profession contributing to it rather than being driven exclusively by medical, psychosocial, legal, insurance, or financial considerations. And combining "community" with the terms "life" and "care" engenders a deeper sense of mission. Most people want to live and be cared for in their communities; today, CLCP is essential to achieving this desire.

This book serves many purposes. It is a training manual for care managers, a primer for a new profession. It fills a training void for those who wish to serve the Community LifeCare Planning effort. But by describing the strategies and skills of CLCP in depth, it also familiarizes the other members of the care planning team–health care, legal, and financial planning professionals–with the team care planning approach. A care manager's goal is most often to help the specialists–the physicians, the lawyers, the financial managers–achieve their goals of maintaining their patient/client's health and independence, while preserving assets and preserving choice. In our view, it is as important for care managers to learn CLCP as it is for all lifecare professionals to understand how they can work together more effectively. And last, but certainly not least, lay caregivers will also benefit greatly from reading this book, as gaining care-management information will help them to help their loved ones.

In preparing this comprehensive guide to CLCP, we have sought contributions from several professionals. Each of these players was set the task of formulating what he or she thinks a good care manager should know about his or her profession. As such, this book is a collaborative effort, just like CLCP itself. It grew out of the cumulative experience of its contributors, leaders in their respective fields who recognize the value of Community LifeCare Planning, and are eager to move the care-management profession from infancy to maturity as quickly as possible.

CLCP clears the way for health care change by challenging notions underlying current care models. It challenges the myth that patients and caregivers are impotent in the face of debilitating illness and a health care system teetering on the brink of collapse. It rethinks the standards of need for institutional care. It puts health care back into the hands of caregivers, patients, and families. And it regards the patient as the true care manager, because people support what they help create.

Ultimately, any health care system is partly an arbitrary arrangement. Our current system is a work in progress; it did not exist a hundred years ago, nor will it exist in its present form a hundred years from now. But the essence of health care is now and will always remain the expression of compassion between one human being and another. Human compassion is at once the foundation of healing and the most common thread of our evolution. Its expression provides all the quality improvement we need. Without it, there is no health care "system;" there is no care.

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