

Taking Control of Your Healthcare

*Providing You and Your Loved Ones with the
Information You Need to Participate in Your Care*

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iUniverse, Inc.
New York Bloomington

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ISBN: 978-1-4401-7122-2 (pbk)
ISBN: 978-1-4401-7124-6 (cloth)
ISBN: 978-1-4401-7123-9 (ebk)

Printed in the United States of America

iUniverse rev. date: 10/02/09

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Introduction

The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated.

—Plato

Each day across America, people are misdiagnosed or receive incorrect information about their healthcare.

When was the last time you asked your doctor specific questions about the treatment he recommended? Perhaps you have handled your medical life and healthcare decisions with blind trust, or perhaps you're someone who likes to do their research on the Internet and ask a lot of questions. If you're in the latter category, it could be something that saves your life.

For example, Jane was a forty-year-old woman who had been told she had to have major and risky surgery after a carotid artery scan revealed an 80 percent blockage. "You have to do this surgery," the doctor said. "It's not optional. At your age, you are taking too much risk not to do it."

Jane and her husband were devastated at the thought of it. The surgery was very invasive, and they had two young daughters. They left the doctor's office in tears, feeling helpless. But then they decided to take charge of their healthcare and get a second opinion. Weeks later, after many sleepless nights, another scan revealed completely normal results. The artery was not blocked at all! This second opinion saved Jane from what could have been a life-threatening surgery and hospital stay. It could have meant the difference between life and death.

Research has shown that when medical decision making shifts from "delegated" to "shared," you are more likely to follow your doctor's instructions and pay closer attention to your care.^{1,2} "Delegated" decision making is when

1 nahq.org/journal/ce/article.html?article_id=168.

2 pubmedcentral.nih.gov/articlerender.fcgi?tool=pubmed&pubmedid=16405711.

the doctor proclaims what your care will be and you have no recourse but to follow his or her instructions. However, in order to effectively participate in your healthcare, you have to get smart and have the necessary information to make an informed decision. My co-authors and I have the necessary experience in medical research, healthcare, and mental health to provide you with the information you need to participate in your healthcare.

I am a scientist and medical educator and together with my pathologist wife, Suzanne, and my brother and sister-in-law, Larry and Joan Kreisberg, who are both mental health professionals, we provide you with over a hundred years of experience in healthcare to help you get the information you need to navigate our complicated healthcare system. We provide you with guidelines to follow and arm you with important questions to ask your doctor so he can make the right diagnosis and you can make an informed decision, approaching your care as a team.

Approximately 15 percent of all patients are misdiagnosed, which results in serious harm to about half of them.³ As discussed by Dr. Jerome Groopman, author of *How Doctors Think*, most doctor errors are due to mistakes in their thinking.⁴ Doctors can make mistakes because of snap judgments based on the first symptom, physical finding, or lab value, or by stereotyping. For example, a woman comes in complaining of anxiety. The doctor may attribute this symptom to hysteria (the so-called hysterical female), when in fact the symptoms may be a sign of a heart attack. Therefore, it's most important to provide your doctor with all the information she needs to make an accurate diagnosis and to ask the right questions so she can focus her attention on you.

We've identified key areas for you to understand so you can take control of your healthcare. The book is organized into two parts. The first part addresses general healthcare issues; the second part addresses leading illnesses. In chapter 1, we focus on the doctor's appointment, indicating which questions you can ask and how to conduct yourself during the office visit. In subsequent chapters, we tell you how to take control of your hospital stay (chapter 2), your medication (chapter 3), and your health insurance (chapter 4). We've included a chapter for taking control of your health specifically for seniors (chapter 5) and one that shows how to take control and manage chronic disease (chapter 6). Finally, we review how your emotions can affect your health (chapter 14). Specific considerations for pediatric patients are also examined. In the

3 Newman-Tucker DE, Pronovost PJ. "Diagnostic Errors The Next Frontier for Patient Safety" *JAMA* 301: 1060, 2009.

4 Jerome Groopman, M.D. *How Doctors think*, Houghton Mifflin Harcourt: Boston, 2007.

appendix, we've included important Web sites and phone numbers you can use to get the information you need to take control of your healthcare.

One piece of advice we give throughout this book is to get a second opinion, especially after a diagnosis of cancer. Allow us to share a story from our practice. Melinda called us after she found out that she had breast cancer. She had a biopsy of a lump in her breast that was found after a mammogram. Needless to say she was shaken up. We encouraged her to relax. If indeed she did have breast cancer, there were now terrific treatments for a cure, we said. But first, she had to get a second opinion. Breast cancer is not easy to diagnose if the pathologist doesn't examine many such cases in his practice; therefore, we recommended a pathologist who was the world authority on breast cancer. He disagreed with the original diagnosis and said she did not have breast cancer. This information was invaluable to Melinda. Not only did she avoid the costs of treatment and lost wages, but she spared herself the risks associated with a possible mastectomy and the radiation and chemotherapy that go along breast cancer treatment.

In another instance, Gary was diagnosed with early-stage prostate cancer, and his urologist recommended immediate radical prostatectomy (removal of prostate and lymph nodes). He called us and we recommended getting a second opinion, referring him to a pathologist with expertise in prostate cancer. This time the second opinion agreed with the original diagnosis. We then told him there were many treatment options available to him, and we recommended he speak with a urologist who was an internationally recognized authority on prostate cancer treatment. Gary traveled 1200 miles for the consultation we arranged and was advised to hold off on surgery and to keep vigilance over his cancer by repeating the biopsy every six months. That was five years ago and the cancer has not grown. These patients from all over the country come to our patient advocacy service to get the information they need to get the right care.⁵

Much of what doctors do is based more on hunches rather than on what is called evidence-based medicine. Evidence-based medicine has emerged as a way to improve and evaluate patient care. It is largely based applying on the best scientific evidence available in combination with the patient's preferences, concerns, and expectations. This allows doctors and patients to form a partnership that optimizes clinical outcomes and quality of life. Evidence-based medicine has resulted in the development of best-practice guidelines to evaluate and treat patients with similar medical conditions. Unfortunately, today, doctors still over-treat patients and ignore best-practice guidelines.

A good example of the practice of medicine getting away from evidence-

5 KreisbergandAssociates.com.

based medicine can be seen in the number of inappropriate angioplasties done each year in this country. In an angioplasty, a balloon is used to open a clogged blood vessel in the heart. There are about two million angioplasties performed in the United States each year; 800,000 have been proven necessary, based on the prevailing scientific evidence. That is, the practice guidelines developed from evidence-based medicine show that angioplasties should only be performed in patients who are having a heart attack. The remaining 1,200,000 angioplasties were elective surgeries; 160,000 were found to be inappropriate, and 500,000 were of questionable value.⁶ If you knew the risks involved with the procedure, would you have had the angioplasty? The purpose of this book is to give you the information you need to be an *effective partner* with your doctor in your healthcare so you get the right care.

Some Common Myths about Our Healthcare Systems

There are many myths about our healthcare system, myths that lead people into accepting diagnoses and treatments that aren't correct or necessary. We have all heard many of these myths, things we take for granted because they come from what we believe to be reputable sources. In order to get smart about your healthcare, it is important to understand the differences between myth and fact.

Myth 1: The United States has the best healthcare system in the world.

Fact: The United States ranks near the bottom among industrialized countries in infant mortality and adult life expectancy, two measurements of the quality of our healthcare system. What we do have, however, is the most expensive healthcare system. Incredibly, despite the costs of our healthcare, we get on average only 50 percent of the healthcare we need.^{7,8}

Due to our lack of attention to preventive care, we have a growing problem of chronic disease. One in two Americans (125 million) suffers from one or more chronic diseases, such as heart disease, diabetes, cancer, pulmonary disease, Alzheimer's disease, hypertension, and stroke. Many of these diseases are preventable. Chronic disease accounts for seven of every ten deaths (1.7 million) each year! People with chronic diseases represent all segments of society. More than 75 percent of people with chronic conditions are under

6 Shannon Brownlee, *Overtreated*, Bloomsbury: New York, 2007.

7 S. A. Schroeder, "We Can Do Better: Improving the Health of the American People," *NEJM* 357:1221, 2007.

8 Robert Wood Johnson Foundation, rwjf.org/files/publications/other/asch_nejm_20060316.pdf.