

Introduction

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One winter day in 1994, I developed a bad cough and fever. As I contacted my patients to reschedule their appointments, little did I know that I was about to embark upon my own voyage of severe personal illness. This would prove to be one of the most terrifying and painful journeys I have ever endured and one which I never could have previously imagined, even as a physician.

Suddenly I found myself sitting in an emergency room, severely short of breath; yet no one seemed to recognize the extent of my distress. I waited for hours before being evaluated. Sent home from the emergency room the previous night with a diagnosis of “mild pneumonia”, I subsequently developed massive respiratory failure within 24 hours. Before long, I became completely paralyzed, unable to speak and connected to a respirator to enable me to breathe. At the university hospital where I was transferred to by ambulance, I was diagnosed with “Adult Respiratory Distress Syndrome, or “ARDS”, a disorder in which the lungs fill with fluid; I came very close to dying.

The next three months were a nightmare of pain and terror in which I was unable to communicate with those around me. Only my husband and my family, who virtually lived at my bedside in the Intensive Care Unit (ICU), had any notion of what I was experiencing. Ironically, I was placed in the same ICU bed in which my husband had treated many of his sickest patients. To this day, when I enter the very same hospital to go to work, I often look up to “my” hospital room window and recall, with intense emotion, my extraordinary experiences there.

During my illness I lost my professional identity as a doctor. A previously healthy physician, wife and mother of two little boys, I woke up one winter day to find myself with a tube in my neck to breathe, unable to speak and too paralyzed to write. I was intermittently delirious and often terrified. From my ICU bed where I stayed for months, I looked out the door and saw many healthy attending physicians and doctors-in-training. At times, I’d hear them laughing and joking from the nurses’ station. From my new patient’s perspective, I felt that none of them really understood what it felt like to be ill nor did the majority express empathy towards me in their interactions. Yet, they saved my life and I am extremely grateful for their hard efforts.

I had always considered myself to be an empathic physician. Now, I had to admit that I really understood, for the first time, how terrifying it can be to be a patient. Finally, I realized what it is like to be overwhelmed by one’s medical condition, to be helpless, and to be completely dependent upon others. My experience as a patient would probably have been worse if not for my physician-husband continuously advocating for me. Unfortunately, most patients are not fortunate enough to have such support. We hope that this book will help unravel the complexities of dealing with the doctor and will empower individuals to advocate for their needs.

I spent several years, and innumerable doctor's office visits recuperating from the effects of this illness. Thanks to superb medical care, I survived with little residual lung damage. These experiences of illness profoundly transformed my understanding of the difficulties my patients experience on a daily basis. From both sides of the hospital bed, I have come to realize the importance of communicating effectively and efficiently with doctors, preparing information to generate a complete history and knowing what to expect in return. I know how important it is to feel that the doctor is listening.

Alan Ettinger, M.D. (Co-author of the “Essential Patient Handbook”)

One day in 1994, I found myself in the waiting room of the intensive care unit, not in my role as a physician but instead as a husband. The same respirators that had been used before to support the breathing of my patients with uncontrolled seizures were now sustaining the life of my comatose and paralyzed wife, herself a physician, in whom a devastating pulmonary illness had developed.

Suddenly, as my role changed from that of healthcare provider to a patient’s family member, I felt helpless and bewildered. While I was accustomed to providing answers to my patients, now I found myself confused and scared, trying to organize my thoughts, ask the right kinds of questions, and make the best decisions under the most adverse of conditions. In what was a previously unimaginable switch, it was now me, the physician usually in charge, who was anxious, tearful, and in need of emotional support and advice.

Perhaps it is impossible to truly understand the overwhelming feelings that serious illness engenders until one has been personally touched by it. Words used by my patients such as *fear*, *depression* and *anxiety* began to have new meaning for me. Even the anger that physicians occasionally encounter from their patients became more understandable. Although my wife was awake, she was unable to move or speak, but only rarely did anyone ever try to communicate with her, to understand her needs, or to explain to her what was happening. Although I was grateful for the superb medical care she received, I felt powerless and exasperated when the staff did not respond immediately to my wife’s needs, and I worried about what was happening when I couldn’t be there. When I had to leave her to attend to our children, it made me feel guilty, as though I were abandoning her.

With few exceptions, I was also disturbed to find that most of the compassion expressed to my wife came not from doctors but rather from nurses, clergy, technicians, and housekeeping staff. It occurred to me that there must be something terribly wrong with a medical education system that fails to nurture the capacity of physicians to relate emotionally to their patients; in this case, even to a fellow physician. I wondered why doctors know all the right questions to ask when looking for causes of a headache or a low sodium level, yet are not expected to ask questions to find out how one is coping with illness and how illness is impacting upon the patient’s life?

As an epilepsy specialist, I had often asked my patients many questions. When did your seizures begin? What do your seizures look like? What antiepileptic drugs are you taking? Although I had always considered myself to be a sensitive physician, I now began to realize the importance of asking a completely different set of questions. What is it like for you to have seizures? Are you getting enough support at home? Are you very anxious about having seizures? Is there anything that we can do to help you cope with a difficult situation?

Yet, how could the realities of current medical practice (pressure to see more and more patients in shorter amounts of time, the need to maintain voluminous documentation, among many other challenges) be reconciled with an idealistic vision of providing patient care? Struggling with this question, we began to set new goals for ourselves and our patients. One goal was to enhance the efficiency of the office visit to permit more time to focus upon the issues that are of most importance to our patients. To

achieve this, we began to guide our patients in preparing their medical histories and prior evaluations before coming to the office, so that time wasted reconstructing medication doses or prior tests with no information in hand, would be avoided, and more time would be available to spend on substantive discussions with our patients.

Another objective, was to insure that we address the issues of highest importance to our patients. To discipline ourselves in this regard, we asked our patients to put in writing the issues they wanted to talk to the doctor about. Having these notations going into the medical record, insured that we discussed these concerns with our patients.

Another goal, was to insure that we attend to our patients' psychological needs. In the forms we provided patients before coming to the office, we asked patients to answer questions regarding a wide range of psychosocial aspects of their lives, and review of these questions became a standard part of our medical evaluation.

Finally, we sought to empower our patients with knowledge and understanding of the medical evaluation process, to promote a true partnership between doctor and patient. This book represents the culmination of these efforts. Here we attempt to demystify the complexities of the visit to the doctor and what comprises the medical evaluation.

Very slowly but quite miraculously, my wife's illness began to recede. She regained consciousness, her paralysis resolved, and the chest tubes were removed. Now in good health, we are blessed with an opportunity to share some insights about what we have learned from this frightening experience, and hopefully help others who are confronting the challenges of medical symptoms and difficult medical problems.