

Our Parents IN CRISIS

Confronting Medical Errors, Ageist Doctors,
and Other Healthcare Failings

Ann G. Sjoerdsma



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COVER PHOTOGRAPHS: On front: 1) The author's parents attend an international scientific symposium in Milan, Italy, in 1964; and 2) relax on a deck in their back yard in North Carolina in 2007. The family photograph is courtesy of Britt L. Sjoerdsma.

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To my precious parents, with love

Also by
Ann G. Sjoerdsma



STARTING WITH SEROTONIN

*How a High-Rolling Father of Drug Discovery
Repeatedly Beat the Odds*

Through the Ages . . .

“We don’t stop playing because we get old; we get old because we stop playing.”

—GEORGE BERNARD SHAW (1856-1950)

“To get back my youth I would do anything in the world except take exercise, get up early, or be respectable.”

—OSCAR WILDE (1854-1900),
in “The Picture of Dorian Gray”

“In spite of illness, in spite even of the archenemy sorrow, one can remain alive long past the usual date of disintegration if one is unafraid of change, insatiable in intellectual curiosity, interested in big things, and happy in small ways.”

—EDITH WHARTON (1862-1937),
in her autobiography “A Backward Glance”

“I feel particularly inspired by the realization that aging is a transitional phase, rather than a phasing out. . . . I continue to realize that old age is a time of great fulfillment—personal fulfillment—when all the loose ends of life can be gathered together.”

—MAGGIE KUHN (1905-95),
founder of the Gray Panthers

“Aging and death do seem to be what Nature has planned for us. But what if we have other plans?”

—BERNARD STREHLER (1925-2001),
USC biology professor and founding editor-in-chief of
“Mechanisms of Aging and Development”

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Acknowledgments and Notes

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I am also grateful to the Georgetown University School of Medicine for the mini-medical schools that it hosts twice a year and to the Georgetown faculty and Washington, D.C.,-area physicians who teach the “mini” classes. This medical-education program for the public, which has become a popular tradition, is superb. I have attended four Georgetown mini-medical schools and plan to attend more. They stimulate and enlighten.

The Georgetown mini-medical school stands alone, in content and concept, but other medical schools offer comparable programs. I greatly benefited from a Johns Hopkins University mini-medical school on aging and from a class about aging in a U. Va. mini-medical school. All three schools also present lectures that are designed to educate the public about cutting-edge medicine. I thank the organizers behind these events for their community interest and outreach. I value your efforts.

In my narrative, I tried to acknowledge those people who reached out with expertise, kindness, educated advice, and other help to my parents, my siblings, and me during difficult times. I only named a handful of them. With these exceptions, the names of all physicians, nurses, caregivers, and other healthcare personnel in my book are fictional. I also used pseudonyms for friends and friends’ relatives. My heartfelt thanks to the people who truly cared for us.

Outside of my narrative, I am grateful to my dear friends who gave me emotional and intellectual support during the times I describe, as well as during my writing trials: Jim and Mary Cary, Madeleine Fagan, Lynne Durbin, Ann Young, Karin Nelson, Jack Bowers, Carol Adams, Ann Cavanaugh, and my special journalist friend, Cate Kozak, who talked me up whenever I thought about quitting.

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Thank you so much, one and all.

This book would not exist if my father hadn't encouraged me, advised me, and read some of my early chapter drafts, including Chapter Seven, which in its first version even put *him* to sleep.

"The book is great when you're reading the personal story," Dad said when he returned chapters to me, "but then you hit that aging science and stop dead in your tracks." At the top of my chapter-seven draft, he had written: "TOO ACADEMIC!" I got busy on a rewrite, one of several.

Dr. Al was my best reader and editor, as well as my inspiration. My heart is filled with love, gratitude, and admiration for him. I dedicate this book to my wonderful, one-of-a-kind father and to my beautiful mother, who modeled the grace and calm in a crisis that I learned as a child and later applied as an advocate.

Medical-scientific breakthroughs happen—not nearly as often as scientists and newspaper and other media reporters would lead you to believe—but they do happen. Medical guidelines and recommendations also change. At the time that I was writing, all of my medical claims were current. To be certain that some of those in a fast-evolving field are still the latest word, you may have to do a little homework.

—ANN G. SJOERDSMA

Preface

Old Age is Not A DIAGNOSIS

So Get Your Ass Off The Cot

In his tell-all memoir, “Becoming a Doctor: A Journey of Initiation in Medical School,” Melvin Konner recalls a lecture by a gerontologist who “had been brilliant, outrageous, and funny.” The star lecturer spoke during Konner’s preclinical years, when medical-school students are fire-hosed by information, but not yet burned out on patients and the demands of their upper-class clinical rotations.

This exceptional gerontologist, Konner relates, “used to shout at us, ‘You think life expectancy is threescore and ten! You think old people are *supposed* to die! You’re lying there at three A.M. in the on-call room and your beeper rings. There’s a patient in the E.W. with chest pain. It’s an eighty-two-year-old man! You do a lightning calculation. This guy’s life expectancy is minus twelve years! You turn over and go back to sleep.’

“Well let me tell you something! This guy’s life expectancy is not much different from that of a sixty-five-year-old. This guy’s life expectancy may not be much different from yours! This guy is a survivor! He’s here at eighty-two because he’s tough! And he’ll be here at ninety-two for exactly the same reason! So get your ass off the cot and down to the E.W. and save his goddamn life!”

“... This brilliant man,” Konner reflects, “had indelibly impressed on us that old people are not sick because they are old. They are sick because they are sick. Our job is to find out what is wrong with them. Age has no bearing on how much someone deserves a diagnosis, and old age is not a diagnosis. Even the slightest shift in expectations, based solely on age, could bias us and become a dangerous, unprofessional,

self-fulfilling prophecy.”ⁱ

I have spent more than 12 years as a healthcare advocate, companion, sounding board, and watchdog for my parents. Thanks to these two remarkable people, I intimately understand that old age is not a diagnosis. I also know how hard it can be to get a doctor’s ass “off of the cot” because of ingrained ageist thinking.

In my advocacy, I have encountered the expectations, biases, and dangerous and unprofessional prophecies that are rooted in medical ageism. I’ve also encountered the pitfalls of today’s highly specialized and fragmented U.S. healthcare system: the disconnections between physicians; the lack of continuity in treatment; the costly errors and misdiagnoses, and so many more failings than even I, a skeptical lawyer, journalist, and daughter of two physicians, ever imagined.

If a doctor ever asks you, one of your parents, or another older loved one, “What do you expect at your age?,” ask him or her, “What do *you* expect?,” and then find another doctor. Life is hard enough without having to put up with ageist nonsense from people who should know better.

Old age is a fact in a story that differs among storytellers. Here is mine.

i. Melvin Konner, *Becoming a Doctor: A Journey of Initiation in Medical School* (Penguin Books, paperback, 1987), pp. 303–04. Konner was a 35-year-old Harvard professor of anthropology when he decided to pursue a medical degree and enrolled at (thinly disguised) Harvard Medical School. He never practiced medicine.

Chapter One

2002: Proceed Until APPREHENDED

Or You Might Lose Your Mother

My mother complained on Tuesday, May 28, 2002, of a “really bad” headache “in the front,” she said. Mom rarely has a headache, nor does she complain.

“I think she’s getting some kind of flu,” my father suggested on the telephone that evening.

I had spent the Memorial Day weekend with friends in Charlotte and faced a week of work. At the time, I had a lucrative contract as a telecommuting legal-journal editor. I promised Dad I’d drop by tomorrow evening and wished my mother, who celebrated her 78th birthday on May 5, a quick recovery.

My parents and I live a half-mile apart in the lush woods of Southern Shores, a year-round community on the north end of North Carolina’s Outer Banks. I moved there first, after taking a newspaper job in nearby Norfolk, Va., which I considered a dreary, never-in-a-million-years-would-I-live-there town. I preferred to live in North Carolina on the beach that I’d known since I was a child. I transplanted from Baltimore and knew that Mom and Dad intended to retire to Southern Shores; the only question was when.

I dropped by to see Mom Wednesday night and was dismayed to learn that she now had a severe sore throat and cough and still could not relieve her painful headache with medication. She lay on the floral sectional couch in the family room. “I’m just so tired,” she said. Earlier, she had felt nauseous and vomited a bit. She also had stopped eating, claiming to have a bad taste in her mouth. Although her headache worried me a lot, I reasoned, optimistically, that the other symptoms seemed like an “everyday” virus. My parents agreed.

On Thursday evening, I found Mom sitting up and conversing. Dad knew of other people who recently had suffered debilitating headaches, including a repairman with whom Mom had contact. Something must be going around. Mom ate a dish of apple cobbler with ice cream and gave me a kiss when I left. I felt hopeful that the worst was over. The next day I had a lively telephone conversation with her. My brother, Al, talked with her, also, and thought she had more energy. Mom paid some bills that day. She was getting better.

Over the June 1-2 weekend, I busied myself at home. When I saw Mom Sunday night, I was shocked.

SUNDAY, JUNE 2

When I think back on the early days of my mother's mysterious medical crisis, I am struck by two things: 1) the changeable course of her flu-like illness; and 2) the trust I had in my parents' ability to care for themselves. Not only did I lack necessary medical knowledge, I didn't know the lengths to which my intelligent parents would go to avoid acknowledging how sick Mom was.

Both were retired physicians. Physicians confront clinical facts, right? They deal with truths as they are, not as they wish them to be. Wow, was I off-base.

My mother was an introspective, warm, and unflappable psychiatrist, caring but reserved. Trained in Freudian analysis, she formerly treated adults of all ages and young children, whom she adored.

When my three siblings and I were growing up, Mom saw patients several nights a week in our home. This was the 1960s, before "patients" became "clients." The patient would ring our doorbell, enter the front hallway, which had been cordoned off from the living room by a folding door, and sit down to wait for the psychiatrist. After each consultation, Mom would type up her notes, and I would steal into her inner sanctum and read them. My violation of confidentiality aside, I viewed each patient as an individual with a problem that I felt certain my mother could fix, and I wanted to know his or her story.

My father was a prominent scientist-physician—and medical pioneer—whose clinical expertise I had long regarded as limitless. Trained in cardiology, internal medicine, and pharmacology, Dad had a textbook command of anatomy, physiology, and medicine. Interested in drug discovery, he earned a reputation during the 1950s and '60s

as the Father of Clinical Pharmacology for his cutting-edge “rational” research in the National Heart Institute of the National Institutes of Health in Bethesda, Md.

Rational research was based on biochemical mechanisms—that is, on how the body works, on a chemical level, about which little was then known. When he started out, Dad wanted to *design* therapeutic agents—drugs—not engage in the time-worn practice of random screening with pharmacologically active plant extracts. He eschewed trial-and-error for rational theory.

Dad’s first target was high blood pressure (hypertension), which regularly debilitated and killed people. He thought he might be able to lower pressure by blocking a key enzyme in the metabolic pathway of serotonin, which had been discovered, but not elaborated upon. This thinking, which did not prove to be true, nonetheless led to ground-breaking research on serotonin and other molecules, some of which, like serotonin, became known as important neurotransmitters, and to the breakthrough antihypertensive drug, Aldomet®.

After 20 years with the NIH during its “Golden Age of Research and Development,” my father spent 20 years as an executive in the pharmaceutical industry, in Europe and the United States. His most recognizable drug achievement is probably the antihistamine Allegra®. Although no longer hands-on with research during its development, he initiated and oversaw the basic-science and clinical work that resulted in Allegra; without him, it would not exist.

Dad loved to brainstorm with other scientists and excelled at reason, logic, and creative thinking. If anyone could deduce what was happening to Mom, it would be my often audacious and tough genius father. But that proved not to be the case. Dr. Albert Sjoerdsma, M.D., Ph.D., was too emotionally involved to care for the patient in his own bed.

Still he was worried. When Mom could not recall any of the evening news she had watched Sunday, his worry became alarm. I, too, found her mentally confused, as well as lethargic. Again, she lay slumped on the sectional, but now her pale-blue eyes showed no life, no sparkle. She had become dead weight and couldn’t move without assistance. Her body ached and shook with chills.

“Mom, you’re much sicker than you think you are,” I insisted repeatedly, as she scoffed at my suggestions to call 911 or to go to the hospital.

Dad, too, discouraged medical intervention, persisting in the belief that this mystery virus would run its course.

My older sister Leslie, a registered nurse in Florida, had speculated that Mom had viral meningitis, and it seemed obvious to me that an infection of some kind was affecting Mom's brain, altering her cognition. So why was Dad minimizing its seriousness?

I sized up our options at 9 o'clock on a Sunday night: We could take Mom to the emergency department (ED) of the newly opened Outer Banks Hospital (OBH) in Nags Head or to the ED at Albemarle Hospital in Elizabeth City, which was an hour away. Having no experience with either, each presented unknowns. The local press about the OBH had been sharply critical, so I hesitated to take Mom there, but a drive to Elizabeth City seemed worse.

Reluctantly, I yielded to my father's suggestion. We would transport Mom to the nearby Kitty Hawk medical center, an urgent-care way station, first thing in the morning.

That night, I went against my better judgment to act immediately, but I wasn't a doctor, and, even though Dad had warned me all my life to "stay away from hospitals and doctors. . . . They'll make you sick"—or worse: "They'll kill you."—I wasn't yet ready to substitute my judgment for a medical professional's.

I also didn't understand what it meant to my father, however brilliant, to see his wife of 52 years so sick. I didn't appreciate how grief and the denial he summoned to combat it clouded his reason. In the anxious days ahead, I would have to confront my powerful father and his altered psyche, as well as doctors whose knee-jerk perceptions and ageism prevented them from doing enough to save my mother's life.

My "caregiving" would require all of the intellectual chops and moxie I had acquired in life, and then some. Whatever I did, I owed it to my mother to pull out the stops.

MONDAY, JUNE 3

The morning of Monday, June 3, Mom sat for 90 minutes in a wheelchair, holding her sagging head wearily in her hand, as we waited for a bed to open up at Beach Medical in Kitty Hawk. I silently cursed every sniffle in the crowded waiting room. Urgent? Give me a break. My mother was nearly immobile.

I had helped Mom to wash, dress, eat breakfast, use the toilet, and