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. Perhaps 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 groundbreaking 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

walk to my parents' car. I also had packed an overnight bag for her and emailed Al, Leslie, and my younger sister, Britt, that Mom would likely be hospitalized that night. She was aware and communicative, but occasionally confused and very lethargic. The young nurse who assisted Mom curbside called her "hon" and spoke in that annoying sing-song voice that nurses and other healthcare personnel use with old people. Like they're talking to babies, not adults.

While I wanted medical answers that day, I had not yet assumed the leadership that I would. Needing to attend to some work and errands, I popped in and out of the clinic until early afternoon. When Dad called at 1:30 to tell me that Dr. Washburn,* the urgent-care physician, had diagnosed a urinary tract infection, I became furious.

Mom had a 102-degree fever. According to my father, Dr. Washburn, an internist with 25 years of practice, had ordered blood work, a urinalysis, and a chest X-ray. The urine sample that he obtained—which, Dad pointed out, was uncatherized and, thus, impure—showed pus, i.e., the presence of white blood cells, suggestive of a urinary tract infection, to which my mother, like many older women, was prone. Dr. Washburn prescribed Tylenol®, an intravenous administration of fluids (dextrose in water), and the broad-spectrum antibiotic, Rocephin®, which in generic form is ceftriaxone.

This was ridiculous, I thought. A *UTI?* Hadn't Dad explained Mom's symptoms in detail to the doctor? Didn't Dr. Washburn understand how seriously ill she was? What about the confusion, the lethargy, the headache? How could *all* of that be caused by a UTI?

I quickly called my R.N. sister: What can I do? Dad refuses to see how sick Mom is, and Dr. Washburn is blowing her off. I needed solid medical advice. The diagnosis didn't add up.

Encouraged by Leslie, I drove back to Beach Medical, found my mother hooked up to IVs and sleeping, and asked to see the doctor. My eye fell on a nurse's notation in Mom's medical chart: Patient complains of "aches in her head," it said.

In her normal state, my mother would never talk like that. That the nurse quoted her and apparently thought nothing of this unusual description suggested little-old-lady patronizing to me. My sister had instructed me to personalize Mom for the doctor and nurses, explaining: "They don't know who she is. They've never seen her before. You have to tell them about her." And so I tried.

*See note in Acknowledgments about names of people in the book.

I told Dr. Washburn he was seeing "a shell of my mother, 180 degrees from her usual self." I detailed the course of her symptoms since May 28 and sought to characterize her baseline, how she behaved before her illness. She swam every day, drove a car, walked her dog, cooked, read Dickens, played "Jeopardy!" She had never shown signs of dementia.

Concerned that he would dismiss me as emotionally overwrought, I measured my tone and remained calm: "I'm a rational person," I flatly told him. "I logically evaluate the evidence. I don't panic." My mother is *very* sick, Dr. Washburn, more than you understand. Please find out why.

His response crushed me. He offered to do a CT scan of Mom's brain and to "hospitalize her, if you want." If *I* want? What about *you*, the medical expert, what do *you* advise? During my head of steam, I had told Dr. Washburn how opposed my parents were to hospitalization, how they seemed to minimize the seriousness of Mom's illness. Didn't Dr. Washburn understand the pressure I was under? Apparently, he had no clinical opinion beyond the UTI diagnosis. I felt abandoned.

I authorized the CT scan, a process that involved my repeatedly informing the consent-form taker that I wasn't concerned about dementia. My mother might be old, but she was acutely sick, not demented. Why did people seem to doubt me? Were they all ageists, buying into a prejudicial stereotype that when older people have cognitive problems they must be demented? Or did they question my credibility?

A technician wheeled Mom off, and, after a restless wait, the scan came back "negative." I didn't press for details. Mom received IV fluids and Rocephin continuously until 7 p.m. and noticeably perked up. She regained color in her face and even ate a sandwich. Dr. Washburn further prescribed oral Cipro®, which had been in the news as the anthrax antibiotic, and he and my father agreed to watch Mom for the next 12 hours—meaning until 9 a.m. tomorrow. The nurse who wheeled my mother to the car instructed her: "Now eat, honey." More patronizing, more sing-song babytalk.

About two miles down the road, Mom lapsed into confusion, and my heart sank. I pleaded with my parents to turn around and drive to the hospital, but both dismissed the idea, my father admonishing me: "*You* don't get to decide."

I walked Mom to the front door of my parents' home and thought

she seemed even weaker than she had in the morning. She stared in horror at me when I told her that I regretted the decision not to hospitalize her.

Once inside, she started having chills. I begged my father to call 911 if she deteriorated during the night, and then I left, wrung out from the day's confrontations. Thirty minutes later Al called, having learned about Mom's fever and chills and becoming desperately concerned. I agreed, but I couldn't fight with Dad any longer about hospitalization.

I considered driving Mom to Johns Hopkins, the University of Virginia, Duke, or Chapel Hill, but I couldn't do that alone. I went to sleep with a prayer in my head.

Please, Mom, please just hold on.

Tuesday, June 4

The paramedics arrived like a SWAT team around 9:30 a.m. on Tuesday, June 4.

Shaking with chills, Mom had slept fitfully during the night. Around 5 a.m., she fell off of the toilet, unable to rise without Dad's assistance. He called me about 7:30, and I rushed to see her, alarmed to discover how rapid her breathing had become.

Mom seemed somnolent, but mentally aware. I wanted to call 911 immediately, but Dad insisted on driving to Beach Medical and seeing the useless Dr. Washburn about a referral. My old-school doctor father believed in going through physician channels. Later he called home to report that Washburn had called Dr. Logan at the Outer Banks Hospital in Nags Head, and an ambulance would soon arrive for Mom.

I washed and fed my mother and explained to her what was going to happen. As I waited for the paramedic team, I accepted that I had two patients on my hands. My father had refused to call 911. He was either too shaken or too stubborn to be trusted. I needed to take advantage of his vast medical knowledge, but go over his head—and help him to cope.

During the paramedics' careful transport of Mom down the front-porch steps, an emergency-medical technician about my age commented on the "role reversal" that adult children experience with their parents. "They become the children," he said.

While I appreciate that he was trying to be empathetic, I don't agree with him and hate when people say this. There's no role reversal

between aged parents and adult children. There's a role adjustment. The parent-child relationship, like all relationships, evolves.

Dad and I drove to the OBH in separate cars. We checked in at the ED, answering the usual paperwork questions, and waited "for the nurse, who will come get you." I never did that again. After 90 minutes, during which I presumed Mom was undergoing a battery of tests, I questioned the wait, received an apology, and went into the patient area. It was about 12:45 p.m. Now wearing a green hospital gown, my mother lay on a hard, narrow bed, exhausted and attached to IV fluids, but not to an antibiotic. I was astonished. Where were the life-saving antibiotics? Where was the doctor?

Remarkably, Dr. Logan had left, without consulting us about Mom's history or advising us about her condition. He apparently had obtained the records from Beach Medical, repeated the tests she had yesterday, and skipped out, without ordering any treatment except fluids. What was he thinking? Was this more ageism? More of the old woman hasn't been eating enough? Or was he just inept? Indifferent? Already, the OBH was living up to its reputation in the community.

Dad and I insisted on talking to a doctor, and Dr. Barnett obliged. Somewhat familiar with Mom's case, Barnett, who appeared to be about 30, had arrived recently from Michigan, my mother's home state. He listened politely as my father enumerated all of Mom's symptoms, mentioned meningitis as a possible cause, and suggested doing a lumbar puncture, a tap that would yield cerebrospinal fluid for diagnostic purposes.

Dr. Barnett also indulged my father's schmoozing about medicine and his own illustrious career in a ritual that I later dubbed the physician shuffle, a type of medical *pas de deux* without music.

Starved for intellectual stimulation in the Outer Banks, Dad eagerly "shuffled" whenever he met a fellow physician. During this particular exchange, Dad told Dr. Barnett the story of Big Jim Tatum, which was his way of asking the slight-figured, young physician to look beyond the obvious, as Dr. Washburn had not done.

Big Jim Tatum took over the football program at the University of North Carolina at Chapel Hill, Tatum's alma mater (and mine), in 1956, after coaching championship teams at the University of Maryland. He was turning the lowly Tar Heels around when he fell acutely ill and died, much to the puzzlement of doctors at Chapel Hill's esteemed N.C. Memorial Hospital, who suspected a viral infection, but never made

a diagnosis. Tatum's mystery illness? Rocky Mountain spotted fever, which he contracted from the bite of an infected tick.

"I leave you with that story to think about," my emotionally spent father told Barnett before, gratefully, heading for home. The shuffler had exhausted himself. I was on my own.

As soon as my father was out of sight, I delivered my "shell of my mother" speech to Barnett and questioned Dr. Logan's failure to administer antibiotics. To my dismay, Dr. Barnett, like his colleague, didn't want to prescribe anything until he knew what he was treating. He gave me the medical party line about the overuse of antibiotics leading to an increase in resistant bacteria, as if that had anything to do with my mother's critical condition.

I next tried my "rational person, examining the evidence" argument on him and wanted to know his plan of action. Yes, I nodded, agreeing with him that medicine isn't black-and-white: Life isn't black-and-white. But with step-by-step research come results, clues, detection, a diagnosis that makes sense. Certainly, I reasoned, doctors must think like lawyers and journalists do, like all critical thinkers bent on solving a problem.

Please, Dr. Barnett, tell me what's next.

Later on June 4

Dr. Barnett suggested another CT scan (!) and advised me to grab lunch while he studied the records and examined Mom. I went to a nearby supermarket and called Leslie on a cell phone from the parking lot, venting to her about Logan's disappearing act, the breakdown in care, and Barnett's refusal to start antibiotics. I urged her to call the young doc and communicate with him on a medical level. I didn't want to bungle this crisis out of ignorance.

Within 10 minutes, my sister reported back that Barnett had declined her call, having already spoken with "one Sjoerdsma sister." She left her name, number, and R.N. status with a nurse. Despite the stonewall, I felt reinforced, less alone, and was heartened to discover, upon my return to the ED, that Mom was receiving intravenous Rocephin, as a precaution. Dr. Barnett, bless him, had a plan.

Contrary to the results at Beach Medical (from the sample Dad said was impure), the ED urinalysis showed no evidence of infection. Because his earlier blood tests apparently had shed no light, Dr.

Barnett had ordered his own CT scan of Mom's brain, thus contributing to a pattern that I would see often during this crisis: repetitive testing, redundancy. Doctors refused to rely on *any* recent testing done by another doctor in Mom's treatment chain.

Barnett told me that he would be willing to scan Mom's abdomen as well, for a possible uterine abscess, if the family wanted. Mom had wondered recently whether she had a prolapse, which is a descension of the uterus into the vaginal canal. Based on his physical exam, however, Barnett thought that was unlikely. If the CT scan proved negative, he planned to perform a lumbar puncture and have Mom's spinal fluid analyzed, as we had been pushing.

Although I was frustrated by the repetition of tests, I felt encouraged by the emergency doctor's logical approach. I finally had his attention. To keep it, I had to be assertive, but not argumentative with him. With my reportorial and legal skills to draw on, I felt confident I could handle the situation.

Around 2 p.m., Mom had her brain X-rayed; at 3:30 p.m., someone tapped her spine. At 4 p.m., Dr. Barnett updated me: The CT scan showed only the "usual signs of age-related degeneration," and the puncture results would not be ready for another hour or so, by which time Barnett would be gone. Great. Another disruption in care. If the puncture proved negative for infection, Barnett told me, an OB Hospital internist would admit Mom overnight for observation. If it proved positive, Barnett's replacement would transfer her to Albemarle Hospital for treatment. I thanked him sincerely for his follow-through and approachability. He also filled Leslie in.

Dr. Logan, who had disappeared earlier, delivered the results of the cerebrospinal fluid analysis, his panicked look forecasting the bad news. My mother didn't have little-old-lady disease, after all. She had haemophilus influenzae meningitis, a highly infectious and potentially fatal disease.

Logan ordered the recommended antibiotic regimen for "H-flu," which included the toxic drug, gentamicin, and set about arranging a transfer, as soon as possible. He wanted to be sure that the hospital to which he sent Mom had both an infectious-disease specialist and a neurologist available for consultation. Albemarle Hospital in Elizabeth City lacked a neurologist, so Logan turned to Chesapeake General Hospital, 70 miles away in Virginia.

I stayed by my mother's side for nearly nine hours that day,

leaving only during the tests that Dr. Barnett ordered, bathroom breaks, and cell-phone calls to my family. Although tired, febrile, and uncomfortable, my mother remained alert and carried on lucid conversations with me. I assisted with nursing tasks, helping her to the toilet and bringing her iced water and crackers, and I explained all of the medical goings-on, including the diagnosis. She seemed to appreciate its seriousness. I encouraged her to be strong and positive and asked her to promise me that she'd make it. She promised she would.

From the moment I received that promise, I never wavered in my belief that she would survive.

During our long wait for transportation to Chesapeake, a kind nurse named Jodie kept me apprised of what was happening. At last, at 9:30 p.m., I watched a young and energetic duo of male paramedics lift my beautiful mother into an ambulance. She blew kisses at me just before the door closed, and my tears finally came.

I didn't want to let her out of my sight, but I had another patient—my anxious father—waiting in the wings. Nonetheless, I only decided not to join Mom in the ambulance after she assured me she would not be lonely. That was very important to me. I did not want her to feel alone.

Despite the missteps, I still believed that the healthcare system would function as intended, to the patient's benefit. With Mom's paperwork being transported with her, I didn't see that I could lend much to Chesapeake's admissions process. I also would be without a car and personal belongings.

At midnight, I called the Chesapeake Intensive Care Unit, which Jodie said I should feel free to do. An unsympathetic nurse curtly informed me that Mom "was resting comfortably." I braced myself for tomorrow, June 5, the ninth day of my mother's illness.

Wednesday, June 5, to Thursday, June 6

The first thing I noticed about the Chesapeake ICU when Dad and I arrived was the noise. Nurses talked and laughed loudly, without self-consciousness or discretion, as if they were knocking back beers in someone's living room. My mother's nurse called her honey and sweetie and used that damn sing-song voice.

Even more upsetting was Mom's condition. Now in isolation, and

despite nearly three days of IV antibiotics, she looked no better than she had the day before. She was still alert, but sluggish, and very, very tired. Her short-term memory faltered; she asked me about blue meningitis, instead of H-flu. She had managed to eat a little soup. Despite her malaise, no one had thought to catherize her. That she had struggled with a bedpan made me angry. My father and I quickly corrected that.

I had read up on haemophilus influenzae type b meningitis in "The Merck Manual" *(Merck)*, my medical bible, and talked about it with my father. H-flu is an acute bacteria-induced inflammation of the meninges—the surrounding membranes—of the brain and spinal cord. It is the most common cause of meningitis in children.

This seemed a strange diagnosis. Mom hadn't been exposed to children; and while she had experienced the fever and headache that characterize H-flu, she did not have the telltale stiff neck and some of the other symptoms. The progress of her illness only loosely fit with the *Merck* description of meningitis, which did not mention lethargy or profound fatigue. Dad and I eagerly awaited word from the consulting infectious disease (ID) specialist, but none came. Dr. Amble, the "hospitalist" in charge of Mom's case, had not deemed it necessary to bring in an ID expert *or* a neurologist.

We had never heard the term hospitalist before and were unsure of Dr. Amble's status vis-à-vis Mom, but, considering the emphasis Dr. Logan had placed on consultants when he made his referral, as well as the serious threat posed by bacterial meningitis to an older person, we viewed Dr. Amble's no-consult decision as a red flag. After Dad and I spoke with Amble, one of five hospitalists, or staff doctors, employed by Chesapeake General, we had further reason to question her care.

Dr. Amble was personable, but vacuous. Although he had spoken by telephone with Dr. Logan last night and had handled Mom's admission, he lacked familiarity with her case and acknowledged as much. He listened only politely, and with disinterest, I thought, to Dad's rundown of Mom's history. He took no notes; whereas I did. Again, I observed the "shell of my mother" and stressed that Mom had been high-functioning before this illness. Noting that she had elevated liver enzymes, Amble asked us whether she drank much alcohol! She did not and never had. He didn't pursue the issue further. I got the feeling he didn't believe us.

I asked Dr. Amble for a prescription for Rifampin®, which my father knew was a prophylaxis for bacterial meningitis, but Amble

lacked the ability—and his supervisor was unwilling—to prescribe the drug. I didn't understand this. The recommended two-day Rifampin treatment would relieve Dad's and my anxiety over our own possible exposure to H-flu. When I asked him broad questions about Mom's prognosis and the course of her treatment, Amble did the physician shuffle with my father.

"Medicine isn't precise, Ann," they said, frosting me with that exclusive-club attitude unique to doctors. (Lawyers can frost, too, but they seem more like blowhards to me than Dr. Little Lord or Lady Fauntleroys.)

Maybe . . . but as I pointed out emphatically to Dad later, you can learn a lot by asking pointed questions and listening carefully to what is said and not said. You can apply reason; you don't need a medical degree to figure things out. In fact, as I was discovering, M.D.s were more often getting in the way.

In response to my queries, Dr. Amble estimated Mom's IV antibiotic treatment at eight to 10 days and admitted that he had treated only one other case of H-flu in 20 years of practice, and that patient had died.

When my father questioned him about the use of gentamicin, which can be toxic to the kidneys, Amble acknowledged the risk, adding, "It killed my grandmother." This floored me. I could do without such candor, but it provided valuable information about what we could expect at Chesapeake General.

Amble's medical position boiled down to a simple either-or proposition: Either the antibiotics would cure Mom or they wouldn't. Only time would tell. Her brain was fighting a life-threatening infection. She was old. She might die.

So unnerved was I by Amble's lack of authority and confidence that I emailed my younger sister Britt later: "We need to stay on top of her care and make sure no one screws up." Our mother wasn't going to die simply because Dr. Amble's grandmother had.

That night, Dad and I obtained a prescription for Rifampin from a former colleague of his and talked about moving Mom to a university hospital. Only Duke would satisfy my father. I suggested he start calling his influential friends for a referral.

At 11:30 p.m, Dad contacted Dr. Hayes, one of his clinical associates at the National Heart Institute in the 1960s and a former chief of medicine at Vanderbilt. Within an hour, an erstwhile resident

on Dr. Hayes's Vanderbilt service, now an assistant professor at Duke and an infectious disease specialist, called my father. Without such clout, I'm not sure how I would have dealt with my apprehensions, which network I would have tried and how. But I would've done something. I felt certain that my mother's life depended on family intervention.

At 2 a.m. on what was now Thursday, June 6, Dad shared with me the results of his communications with the Duke Hospital transport department: An ICU bed may not be available, *and*, in any case, Mom would have to travel by ground, not air. Also, we would need a physician's referral from Chesapeake. We decided to suspend all talk of a move until 9 a.m. and mercifully got some sleep.

In the morning, Dad informed Dr. Amble by telephone of our intentions. The hospitalist, threatened by our end-run around him, beseeched: "Will you do me this favor? Will you see her before you make your decision? I think you'll find she's improved."

We agreed to hold off on arranging for the transfer until after we'd made the 75-minute drive to Chesapeake to see Mom.

Amble was right. Mom was more energetic and with it. She sat taller in bed and spoke more coherently. She told me that during the night, she had undergone *another* chest X-ray and brain CT scan, and before breakfast a new doctor—who turned out to be the ID specialist, Dr. Taft—had examined her. Dr. Taft decided to take her out of isolation. In fact, nurses told me, Amble was moving Mom out of the ICU, after about 40 hours, and into a private room on a nearby medical floor.

Whether our talk of a transfer to Duke prompted this flurry of activity cannot be determined from Mom's medical records, which I later obtained, because Dr. Amble made no notes. No notes. Not a single jotting. It was as if he didn't exist. But I don't think this transfer was coincidental. (Dr. Taft's report, which I read later, raised no red flags. He thought Mom's condition was consistent with bacterial meningitis.)

I was encouraged, but cautious. Just how sick was Mom? I walked beside her during the gurney transport to her new room and immediately sought out her nurses, filling them in on her illness and its progress. I was determined that Mom would be more than just an anonymous "78-year-old white woman." I placed family photographs on a bulletin board in her room, telling all visitors that Fern Esther MacAllister Sjoerdsma was a vivacious older woman with a full, happy life and many

loved ones.

Soon, though, I learned that Mom would not be receiving consistent nursing care; the R.N.s would be changing shifts too frequently to permit that. Thursday's day nurse would not likely reappear on Friday.

Leslie urged me to assume nursing tasks, cautioning me in particular about the physiological damage that bed rest can cause, especially to elderly people. Reduced to its essence, the human body is made up of functions, the impairment of which can produce ghastly results. Prolonged immobility brings on such impairment.

Leslie drew up a two-page "plan of care," which she emailed to my siblings and me. Among other things, we would ensure that Mom regularly shifted position in bed, in order to guard against breakdowns of her skin (bedsores), and drank enough fluids daily to prevent dehydration. We also would be on the lookout for any new neurological signs indicating a brain infection: weakness of the extremities, drooping of the mouth, seizures.

When I left the hospital that afternoon, Mom was reading the newspaper funnies and planning to watch the evening news. She was still receiving intravenous gentamicin and ceftriaxone, the meningitis antibiotics. Her breathing seemed more rapid to me, but I hopefully assumed that all would soon be well. I put the Duke transport mentally on hold.

The Afternoon of June 7

Throughout the week, I had kept Leslie, Al, and Britt informed by email and telephone of Mom's condition and medical treatment, and they had given me a lot of emotional support. Not knowing what the outcome of her frightening illness might be, each one wanted to see Mom.

Al Jr., a playwright in Ann Arbor, Mich., decided to fly in Friday morning, June 7, and left his return trip open-ended. Dad picked him up. Britt, a television editor in Alexandria, Va., outside of Washington, D.C., planned to drive down late Friday night. I booked a motel room for the two of us near the hospital. Leslie, married and the mother of two young children, checked flights for the weekend and was ready to leave at a moment's notice.

My father still suffered great distress. Although he had come through with the Duke contacts, he seemed to be in a fog. He blamed

himself for not diagnosing Mom's illness and for believing that her mystery virus would simply run its course. Guilt and grief continued to color his thinking and made him vulnerable, especially while driving. I was grateful when Al arrived and could help me to look after Dad. On Friday afternoon, the two Als visited Mom and called me from the hospital parking lot.

Al Jr. was delighted to discover Mom so "with it." He had imagined her locked in an embrace with the grim reaper. Instead, they chatted happily about a variety of common interests. She laughed and teased him.

Al Sr., however, found his wife "unchanged" from Thursday and noted her shortness of breath and swollen feet. He had spoken with Dr. Frank, the Chesapeake General hospitalist who took over from Dr. Amble, about prescribing a diuretic, which would increase her flow of urine and thus reduce the fluid in her body. They also discussed precautions to guard against blood clots. A blood clot "thrown" from the leg to the lungs—at which point it becomes a pulmonary embolus—is a common and potentially lethal hazard of too much bed rest, especially for older patients with damaged circulation.

Dad liked Dr. Frank, who, he said, seemed "to have more on the ball" than Dr. Amble. My brother said Dad told Frank the Big Jim Tatum story in the hallway outside Mom's room.

"What's the Big Jim Tatum story?" Mom had asked about the Carolina football coach who contracted Rocky Mountain spotted fever.

I was concerned about the breathing difficulties that both Dad and I noticed and wondered if Mom should return to the ICU. I decided to assess her condition when I returned to the hospital that night and wished my father and brother a safe trip back to the Outer Banks.

Earlier, I had contacted a hospital lawyer friend of mine whose husband was a neurologist. Dr. Amble had not consulted a neurologist, and I wanted the opinion of a neurologist I could trust. Although Dad later informed me that a neurologist had in fact examined Mom and found nothing inconsistent with the meningitis diagnosis, I emailed my friend that I might call her husband, Dr. Roberts, that night.

I left home at 4:15 p.m., arriving in Mom's room about 5:45 p.m. In a million years, I never could have scripted the evening that lay ahead.

The Interminable Night of Friday, June 7

My mother's appearance stunned me. She had deteriorated markedly in the 24 hours since I'd seen her. What in the world was going on?

Mom lay in bed, moaning and breathing rapidly and laboriously. Her whole body, especially her legs, seemed bloated. She failed to respond coherently to questions I asked and acted irritated by my attempts, scowling at me as she had after the day spent at the Kitty Hawk clinic. She was disoriented and withdrawn, listless, but also fitful. Dad and Al had left just two hours ago. What had happened? Was she having an adverse reaction to some medication? My mind raced. What should I do?

I grabbed the first hospital staffer who walked into the room, a nursing assistant who delivered the dinner tray. She deferred to the nurse, whom I sought, but could not find. I helped Mom drink some cranberry juice and water and tried to assess her condition better. She complained of pain on her side, circling with her hand an area to the right of, but below, her bellybutton. She made little sense, drifting off into incomplete non-sequiturs. Gibberish. I evaluated her as somnolent, but restless.

The nurse arrived, yet another new one, a "hon" sing-songer. I told her of the changes in Mom's condition, but she acted unfazed. She started the next round of IV gentamicin and sodium chloride (for fluid). When I inquired, she advised me that the doctor on duty was not scheduled to visit, but would "pop in"– with no notice. Still reeling, I told her I would like Mom moved on a regular basis, as per Leslie's instructions. She tartly replied that Mom "knows to move."

"Not anymore she doesn't," I said.

The nurse's indifference threw me. Maybe I *was* overreacting. I mentioned the visiting hours, scheduled to end around 9 p.m., and noted that I would like to stay later.

No problem, she chirped. "We're shorthanded tonight. We'd welcome the help. You can stay as long as you want."

My spirit sagged. My mother could be dying, and they're shorthanded tonight.

Cell-phone use was prohibited in the room, and I didn't want to disturb Mom by placing a calling-card call, so I went to the hospital lobby to call Leslie and Dad from a pay phone. Worried that we were

losing Mom, I needed to understand what I was seeing. I needed medical opinions of people I could trust, and I had no faith in Chesapeake General's doctors or nurses.

My sister fired off scary terms like cerebral edema and third spacing, meaning Mom's brain and body had filled with a dangerous amount of watery fluid, and urged her immediate return to the ICU. Because of Mom's altered consciousness, Leslie wanted a neurologist called in, *stat.* I told her about Dr. Roberts, my friend's husband, and asked her to phone him, find out what he thought, and then call me back in the room. We concluded by agreeing that unless I sounded an alarm, Mom would likely be ignored, perhaps with disastrous consequences.

I then phoned my father to put him on stand-by. I might need his expertise in speaking with Dr. Frank. While I could describe Mom's symptoms, I couldn't begin to analyze them diagnostically and know the proper medical questions to ask. Unbeknownst to me, my call triggered my 77-year-old father's emotional collapse. Surely, the death he had feared all along would happen that night. He and Al Jr. grieved together—until I called later to assure them their mourning was premature, and they needed to get a grip.

These phone calls prepared and fortified me. I walked resolutely back to the floor and told the nurse in charge at the front station about my mother's deterioration and my grave concerns. I requested an immediate consultation with the doctor—who, much to my chagrin, turned out to be Dr. Amble, not Dr. Frank—and expressed a desire to transfer Mom to another hospital. I didn't want to threaten anyone, or be obnoxious, but I was determined not to be ignored.

In the 75 minutes that passed between this confrontation and Amble's arrival, a very competent nurse gave Mom a thorough examination, and I worked the phone, talking to Leslie, Dad, and Dr. Roberts. I no longer cared about the cell-phone rule or if my mother heard what I said on the telephone.

Naturally, Roberts was uncomfortable advising me about someone else's patient, sight unseen, so I presented my mother's case as a hypothetical one—a classic legal exercise—and sought only information, not conclusions. Suppose, I asked him, you had a patient with haemophilus influenzae meningitis, and she had shortness of breath and excessive fluid buildup . . . what would you think? What would you do? Roberts suggested that these "peripheral symptoms do not make sense in terms of the meningitis" and might be caused by

another infection. He would consult infectious-disease, pulmonary, and cardiac specialists.

The new competent nurse had recorded a temperature of 100.6 degrees and a pulse of 106. A healthy, resting adult heart beats on average about 72 times per minute. Otherwise, Mom's respiration rate and blood pressure were normal.

"What does the infectious disease specialist think about her fever?" Dr. Roberts asked. I planned to ask Dr. Amble that as soon as I saw him.

Much to my amazement, Amble couldn't—or wouldn't—see the deterioration in Mom that was so evident to me. He described her as having "slight edema" and being more uncommunicative, but not that confused. When he questioned her about pain, she denied having any. I pointed out her stoical habit of minimizing her discomfort, but Amble attributed her fever and rapid breathing to the meningitis infection.

"She's very sick," he concluded. "Her brain is fighting a serious infection."

Yes, but caused by what? H-flu didn't make sense, and the therapy wasn't working. Not only had Mom's physical condition declined, but her personality had altered. A gracious, sweet person, she now snapped at us for making noise.

For the next hour, Amble calmly talked about Mom's worsening condition with me—as well as my father and Leslie, whom I called on the room phone at opportune moments—and resisted all of our suggestions. Under our questioning, he grew defensive. He acknowledged that my father and "his friends are very impressive," but Dr. Amble, too, was not to be lightly dismissed.

Amble adamantly refused my request to transfer Mom back to the ICU. If he did that, he asked me, how could he justify to his supervisor having moved her out just the day before? I didn't give a shit, but I was never anything but courteous with him. My brother, who listened in on Amble's stonewalling conversations with my father, remembers the Chesapeake hospitalist telling them: "She's getting better."

Lest I think he lacked medical muscle, Amble defended his credentials and staff status, telling me of his previous experience at a hospital whose reputation, I now knew, far exceeded Chesapeake's.

He also pointed out: "I know I'm talking to a lawyer."

Doctors don't much like lawyers—really, who does?—so I had made sure that Dr. Amble knew I was one. My opinion on medical malpractice notwithstanding, lawyers can hold doctors accountable. That status gave me leverage. Amble didn't have to know that I had stopped practicing years ago. But, if he actually thought I had a lawsuit even remotely in mind, he was way off-base. Families of critically ill patients don't want litigation after mistakes have been made; they want results while there's still time.

Despite my father's appeal for one, Amble wouldn't summon a pulmonary expert during the night. Any consult could wait until morning, he said. If we wanted to move Mom to Duke then, he'd be more than happy to refer her. I'm sure he thought we were the family from hell, but I wasn't liking him very much either.

Finally, Dr. Amble admitted to me: "I don't know what I'm treating."

But he failed to add what I thought *any* conscientious professional in *any* profession should add: "But I'll find out."

I challenged myself: How could I reach this placid, polite, yet intractable man? How could I convince him to take some action?

I never raised my voice or lost my cool. I searched for an angle, a way to break through to him. Finally, I asked Dr. Amble: "What would you do if you were in my position?" a question I have learned is *the* question to ask an obstructive doctor. I'll never forget his response.

"I'd kiss my mother, tell her I love her, and let the hospital take care of her," he said.

"Well, I can't do that," I replied. "I can't leave." This grandmother wasn't going to die because a doctor didn't know what he was treating.

Earlier, Dr. Amble had noted that the oxygen saturation in Mom's arterial blood was, at 60, a "little low."

"A little low!" Leslie had shrieked on the telephone. "He's crazy. That's dangerously low."

"What's normal?" I now asked Amble, being clueless about what the number measured.

In the 80s and 90s, he said, but elderly people run low.

"As low as 60?" I queried.

"No, usually not that low," he conceded, but he wasn't concerned.

I was horribly ignorant then. Sixty, indeed. A blood-oxygen saturation level below 90 percent is cause for concern.

Knowing that Mom's "PO2," as Dr. Amble called her oxygen saturation, was excessively low, I reached a compromise with him. I would cease and desist if he ordered more tests—of Mom's urine, blood gases, heart, lungs, and liver functioning, etc.—and call me if anything appeared abnormal.

"Would that make you feel more comfortable?" he asked.

"Yes, thank you," I said. "It would."

He agreed.

At 11:45 p.m., six hours after my arrival, I obtained a nametag from the nursing station, enabling me to re-enter the hospital later, and I left. I hadn't yet checked into the motel, and I wanted to be there, if possible, when Britt arrived.

No sooner had my sister entered the motel room, around 1:30 a.m., than Dr. Amble called. Mom's PO2 was now 57; her liver enzymes were "up a little," and she had become more confused. She might have a sepsis condition, an infection caused by pathogens in the blood. He was moving her back to the ICU.

Britt grabbed my nametag and flew out the door.

"Proceed until apprehended," I told her, echoing a phrase Leslie had coined when I expressed doubt about entering certain hospital zones. "Act like you belong."

I then hit the phone. We were transporting Mom to Duke. I only hoped it wouldn't be too late.

Saturday, June 8

Throughout my mother's crisis I had this strong, but not wholly rational feeling that as long as I or another family member watched over her, she wouldn't die. It was a matter of control, I suppose, or connection. Thus, I felt comforted when I managed to reach Britt on a phone in Mom's room and learned that she planned to spend the night in the ICU. My sister's hospital presence freed me to send emails and place phone calls in preparation for tomorrow.

Leslie would be flying in from Florida. Al would be driving up from the Outer Banks. Dad would resume discussions with Duke. Britt would protect Mom, who by now was too far gone to recognize her youngest child. And Mom would hold on.

We finally would get competent help, and answers. But little sleep.

I didn't see Britt again until 10 a.m., when she returned to

the motel to report that the pulmonary specialist, Dr. Kimble, had examined Mom and treated my sister rudely. When Britt tried to fill him in on Mom's condition, especially her mental status, he cut her off.

"I'm talking to her now," he said abruptly. "I want to know what she says, not you." When Britt asked about Mom's breathing, he explained that, because of the meningitis, "her brain is telling her to breathe in a shallow way."

"What can you do to make her better?" Britt wondered.

"Sometimes they don't get better," Kimble answered.

Why were these doctors so prepared for Mom to die? Because she was old? Or were they just irritated by our involvement?

After Kimble left, Britt said, a nurse asked Mom what month it was. She answered June. But she didn't know the year.

The rest of the day unfolded for my family in a series of assigned tasks: motel checkout; breakfast; *Merck* research into sepsis infections (I had my manual with me); a return to the ICU; a trip to the airport, where I met Leslie, who dissolved into tears on the arrival walkway, until I told her our mother was *not* going to die; phone calls to home, to Duke, to doctors at Chesapeake, to friends in Durham, N.C. Eventually, we four siblings converged on the ICU, waiting for the Duke helicopter to arrive. Mom had become delirious and was now receiving oxygen. She happily sang nonsensical songs and talked in a wispy childlike voice. "Whatcha doing over there?" she asked over and over.

That morning, Dr. Frank had taken over from Dr. Amble and been shocked by Mom's decline. He cooperated with the referral to Duke and consulted with doctors there, ordering two new antibiotics for her treatment regimen: doxycycline and Zosyn®, a broad-spectrum penicillin. He also called in a neurologist, who recommended another lumbar puncture and an MRI of Mom's brain. Dad consented to the puncture, but the neurologist couldn't execute the procedure. It was not as easy as Barnett at the Outer Banks Hospital had made it seem.

I never talked to Dr. Frank to find out what he thought was wrong. I just waited for the Duke angels to arrive and airlift Mom to safety. The wait was interminable—nothing happens quickly in a hospital, except disaster—but the angels, clothed in their medical flight suits, were worth it: Confident, efficient, friendly, optimistic. As soon as they took her out, relief washed over me like a refreshing swim. It was about 6 p.m., and Leslie, Al, Britt, and I had a three-and-a-half-hour drive

ahead of us, in three cars, but we all felt euphoric. Almost giddy. Britt was firing off one-liners in her whimsical style, joking about "spending another night in the chair." For all its seriousness and our anxiety, that road trip to Durham felt like a reunion vacation.

Someone else could watch over our beloved mother for a while. Someone we could trust. Or so we hoped.

Midnight, Duke Intensive Care

At midnight on Saturday, June 8, we sat in the darkened waiting room of Duke University Hospital's medical intensive care unit, expecting to meet with Dr. Roddick, whom Leslie had described, after a brief phone chat with him, as likeable and competent. When he arrived, Roddick wanted to know the full history of Mom's illness, from the onset of her "really bad" headache until the respiratory distress of the previous night and that afternoon's delirium. Not just what the tests showed, but what Mom had experienced over the past 11 days.

The young resident listened attentively to my account and then asked me some pointed questions about Mom.

Has she been out of town recently?

—Only to Washington, in April (when she attended Paul McCartney's Freedom concert at the MCI Center).

Has she traveled to Connecticut?

—No.

Does she live or walk in any woods?

—Yes.

Does she have a history of tick bites?

Ticks.

I knew of no recent bites, but I knew that, in walking her dog, Max, Mom would pick up ticks. She regularly checked herself for them. Max, too. The Outer Banks is a haven for ticks.

Roddick strongly suspected that Mom had contracted a *rickettsial* disease from an infected tick, either ehrlichiosis or Rocky Mountain spotted fever. Rickettsia is a genus of bacteria carried as parasites by ticks.

Oh, my God. Big Jim Tatum. Dad was right.

I had never heard of ehrlichiosis, but I certainly knew about RMSF.

"She's not going to die tonight," Roddick told us, but "she's very sick."