

1 Telling the Story

It is hard to know how to begin. I have told the story of my illness many times, each telling designed for the conversationally revealed interests of the recipients. I have told the clinical history to physicians—neurologists, immunologists, and internists—but each telling at once searches for things not told before, looks for new angles, and responds specifically to each clinician's inquiry. I have told the story to a Hawaiian *kahuna*, a native healer. Her questions about where I had been in the Pacific Islands and what I had done on each island made me wonder whether my illness was a spiritual retribution for some misdeed on a small Micronesian atoll. (I had spent a summer on Ulithi Atoll in the Caroline Islands.) Her questions about my activities in Micronesia were echoed by my mother-in-law, who thought my first wife had put a curse on me. The *kahuna* also asked me about my activities in the Philippines, where I had traveled widely. I reviewed my life there and even sent a rice god back to the Mountain Province shop where I had purchased it. The statue was cracked and I thought it represented some kind of disequilibrium. It was this state of disorganization in my body and life that had brought on the debilitation of motor neuron disease. Motor neuron disease is also known as Lou Gehrig's disease, or ALS, amyotrophic lateral sclerosis.

I have told the story of my illness to countless acquaintances, friends, colleagues, relatives, and students. Each telling is a little different, designed to fit the perceived

expectations of the recipients and to fit the evolving conversation. My wife, Divina, has heard most of the story's permutations and has collaborated, without having to be told, in fashioning the story to the spot in the conversation and to the listener—priest, neurologist, family internist, fundamentalist Christians who say they are praying for me, *kahuna*, new friends and old friends, neighbors, parents of my children's classmates, each relative according to our history with them, and many more types of people than I have space to name.

I will try to tell the most inclusive version of the history of my illness here, without being boring. But the reader will have to remember that inclusiveness is a recipient-designed phenomenon. Because I do not know my readers, there may be some whose interests I will miss.

It is hard to know when the illness began. Carleton Gajdusek, a 1976 Nobel laureate in medicine, brought to our house by a mutual friend, said that the neuromuscular disease may have been developing for decades. I had told Carleton that I had fasciculation, or twitching, in the legs while in graduate school at UCLA in the 1970s and had them looked at by the school's neurology department. I was told they were benign fasciculations.

When Gajdusek said that the disease could have been, and must have been, developing over a long time, this made me rethink every symptom. Although I hate to admit that I gave a Nobel Prize-winner more creditability than the *kahuna*, I did the same retrospective life evaluation at Gajdusek's behest. But instead of remembering every Pacific island and atoll I had been on, examining my time there for any social offense, for Gajdusek I examined my memory for the onset of every twitch and muscle weakness. This examination went on long after he had left the house, becoming

a constant theme of reflection, reinforcing every ontological doubt about the integrity of my body. I asked myself if my body had been undergoing the motor neurological breakdown all along. Had I been inhabiting a diseased, pathological body all these years? It certainly changed my history, at least when I had occasion to reflect upon it.

My responses to Gajdusek's interrogations and declarations—as well as the conversations with the *kahuna*, my mother-in-law, friends, and clinicians—set off an intense retrospective examination of my life. The search was either for the onset of symptoms or for the suspected cause of my condition. The intensity of these interrogations and my participation in them increased, at least for a while, as I became visibly more disabled and lost muscle mass. After I had become disabled and most friends and colleagues had witnessed my condition for a while, it became old news, at least to my face.

Onset

After my appointment at UCLA with the Department of Neurology in the 1970s to check out muscular twitching in the legs, I thought nothing about a possible neuromuscular disease until the mid-1980s. I started having twitching and cramps in the right upper arm and shoulder. I noticed a loss of strength in my right arm, as well as a hypersensitivity to touch in that arm. I once had trouble holding my briefcase in New York's JFK Airport while on a business trip to Washington, D.C., to look for additional grant money. The trip combined business with pleasure: a short excursion to my home town of Great Neck, Long Island. I merely thought I was tired from a hectic week. My hand muscles cramped up and I had to shift my briefcase

to my left hand constantly as I walked around the airport looking for a flight to Chicago with a connection to Honolulu.

The fasciculations continued in my right arm and shoulder for about six months. At first I had no atrophy of the muscles there. I tried rest, reducing stress, joining a gym, and eating nutritious food. Yet even though I gained strength in the other parts of my body, I continued to experience cramping and gradual loss of strength in my right arm.

I joined the same health club as my brother, and recruited my brother-in-law as well. I started going to the gym three or four times a week. I really enjoyed lifting weights and soaking in the hot Jacuzzi after workouts. I would always go with either my brother or brother-in-law, and often both would accompany me. However, I found it increasingly difficult to do overhead presses. Soon, I had trouble doing bench presses. I would often skip these parts of the workout, even though this would provoke negative comments from my brother.

I would often go to my sister's house after a strenuous session at the health club. I found myself tired, in need of a breather, and I wanted to visit with her and my brother-in-law before driving back to my apartment in Honolulu. Sometimes, after a heavy workout, I would sit down in her house and feel my muscles shake. I would call this to her attention and she would observe the shaking in tiny bundles of muscles in my arms and legs. She encouraged me to see a physician, as did my wife.

I had a friend who was an internist. I had worked with him when I was in the Department of Psychiatry in the medical school at the University of Hawaii. I did not then have a personal physician in the state, having come to the University of Hawaii from Michigan State University's College of

Human Medicine. Until 1985, nothing had happened to me that would prompt me to go to the doctor.

I made and kept an appointment with my friend the internist. He asked me about my life since I had left Michigan for Hawaii. He knew I had been traveling extensively in Micronesia for the College of Medicine for three years. He asked if I were still involved in training mental health workers in Micronesia. I told him I had written several successful grant applications to the National Institute of Mental Health since joining the sociology department. I was still traveling to the islands of Micronesia every three months. These trips would take me out of town and the country for half the year.

The internist had also been involved in Micronesian work for the medical school and knew the "classic" underdeveloped conditions of the islands, as well as the long distances between them. He also knew that I had undergone a lot of stress related to a marital breakup in the early 1980s and an immediate remarriage. Furthermore, we shared a general dissatisfaction with the administration of federal grants at the medical school. His first diagnosis was that I was suffering from stress and overwork. He recommended that I relax by taking off early from work each day and going for a walk with my wife in Ala Moana Beach Park. I did this, thoroughly enjoying the sunsets across the Pacific.

I continued the regimen of working out at the health club, and I especially enjoyed the newly added time with my wife in the park. We would walk, looking at and discussing people. Divina made a conscious effort to talk my numerous anxieties away. As we ambled along she would tell me to relax and make me laugh at the people we saw.

Despite the workouts and walks, I slowly grew weaker. I also began to notice some shrinkage in the muscle mass in

my right shoulder girdle and in my right arm. The fingers of that hand would independently move, which became a source of embarrassment. To keep them out of sight and away from comment, I would hold my hands behind my back. I thought I looked like Prince Philip.

My handwriting began to deteriorate. The muscles in my right hand would suddenly cramp in midsentence. Most often my fingers would extend in a rigid position, requiring some form of massage with my left hand to relax them. This condition affected only my right hand. My left arm and hand remained normal.

The loss of handwriting ability revealed a host of new problems. First, my job as a research professor required signing purchase orders for equipment and supplies, student-workers' time sheets, audits of grants and contracts, and forms when I hired new research assistants. In my other role as a teaching professor, I was even more locked in to writing by hand. I increasingly found I could not make intelligible corrections and comments on student papers. I began to use my computer to write my criticisms, clipping the printouts to the front of each paper. I still could type.

I had students sign my name to forms. This caused some immediate difficulties. I would never have thought a university had signature inspectors. I was wrong. Purchase orders were returned, with notes saying the signature did not match my previous signatures. Fiscal officers came out of the walls, telling me I couldn't do this. I was directed to get a power of attorney for the person signing the forms on my behalf. I considered doing so for one of my student assistants, but immediately realized that, as close as I was to them, they were transitory and soon graduated. My situation would require a regular and expensive renewal of power of attorney. Several colleagues, hearing of my predicament, volunteered

to fill the role. I resisted this kind offer; the flow of paperwork was so intense that I would have to be chasing them around daily, and it was hard enough to get in touch with them in the best of circumstances.

The problem was solved when my wife got a power of attorney for me. She made arrangements with multiple offices on campus to witness that they would know she would be lawfully signing my documents. This took a lot of legwork, and some people still rejected the signature. To clear up this trouble, we deposited notarized copies of the power of attorney with each overview executive, such as the office of the dean and the office of research administration.

Years later, when my disability had spread my fame to almost every corner of the campus, especially after a feature story on the front page of the *Honolulu Star-Bulletin*, the need for a consistent signature and a power of attorney evaporated. I could have any of my student research assistants sign for me. The many divergent signatures—on student-workers' time sheets, purchase orders, grade sheets, change of grade records, and the many graduate student forms—were not questioned.

Philippines

About the time the muscles in my right hand were falling apart, I was named a Fulbright Research Professor. I had applied for this special nonteaching award to be used in the Association of Southeast Asian Nations (then comprising Philippines, Thailand, Indonesia, Singapore, Malaysia, and Brunei) almost a year before. I had planned seven months of research in the Philippines on the organization of community-based health services. Divina had been a faculty member in an innovative training institute in that country

for community-based health care workers. She was my introduction, years before, to the worldwide movement toward low-cost, community-based health care. I visited my wife's former place of employment, the University of the Philippines Institute of Health Sciences in Tacloban, Leyte, both before and after we were married. I met many of her colleagues in community health at Tacloban, at the Western Pacific Office of the World Health Organization in Manila, and at the main campus of the University of the Philippines in Diliman.

Even though we suspected something was wrong with my health, we made preparations to go to Manila for seven or eight months. I decided I wanted to do research at Ateneo de Manila University, a Jesuit school. The priest of the University of Hawaii Newman Center, a Roman Catholic church I attended, was a former professor of sociology at Ateneo, and he wrote a letter of sponsorship for me. With his help, I became a research associate with the Institute of Philippine Culture (IPC) at the Ateneo de Manila University in Quezon City.

We made furious last-minute preparations to pack our entire apartment and put the contents into storage. We were living in a one bedroom apartment on the twenty-second floor, and Divina and I had decided that when we returned from Manila we would move into a house. We had run out of room for our frequent visitors and for my two children from my first marriage. During the mad-dash packing, the muscles in my right arm frequently cramped. Once, my right bicep flexed and then cramped and I could not get it to relax for about half an hour. The episode left signs of torn and bleeding muscles below the skin.

Our first task, once we had reported in at the university, was to find a rental house. The search was exhausting. I

could not decide whether the fatigue stemmed from my apparent illness or from the difficulty of moving around metro Manila in bumper-to-bumper traffic and awful air pollution. But, whatever the cause, my wife and I spent a lot of time sleeping in the hotel operated by the University of the Philippines School of Travel Management. While we were feeling discouraged about finding an appropriate rental, one that would accommodate our many expected visitors, we received a call from a friend who told us that she was willing to vacate her house and rent it to us. Having visited there, we knew the five-bedroom, Spanish-style house built around an inner courtyard would be more than suitable. We moved in the next week.

With a furnished house to call home, Divina and I next searched for a car and for maids to occupy the house while we traveled around the Philippines. We acquired a three-year-old Ford sedan from a Chinese fellow living in Calocan, the town immediately north of Manila. It had a manual transmission. After six months, my right hand had become so weak that shifting was a problem. In heavy traffic, the norm in Manila, my hand would slip off the knob of the floor-mounted gear lever and the car would come to a halt, provoking much honking. My wife suggested we hire a driver. We did.

My mother-in-law arranged for us to hire two maids. We already knew them and felt comfortable with them. They cleaned the big house and cooked the meals, permitting us a life of luxury. The maids were in the house twenty-four hours a day, taking one day off a week. We bought a queen size bed and a Sony television. We were all ready to live in Manila.

I set up an office in the one air-conditioned room of the house. I installed my portable computer and arranged boxes

around the floor to hold the materials I expected to collect. Through a friend of my wife, Jimmy Tan, we made appointments at various church-related and secular non-governmental health organizations. I visited AKAP, a church-related organization that sets up community-based primary care health delivery systems, and an agency concerned with the health of workers in the booming semiconductor industry. Most of the employees were girls and young women from the provinces, who were being put at risk by routine exposure to acids and other toxic substances. I met with members of the National Council of Churches, a Protestant group, which had many community-based primary care organizations in the northern parts of Luzon. I also visited a Catholic group that ran community-based primary care delivery systems in the Visayas and in Mindanao. I frequently heard that the organizations running community-based primary care programs were considered subversive by the Philippine government. I was told it was dangerous to be around persons involved in them and that President Ferdinand Marcos's goons were on patrol for what they considered the leftists running primary care. One time, I was warned that even to be seen visiting an order of nuns that ran community-based primary care services would get me arrested.

I got a bit frustrated about making contact with a Manila-based community health service program. Many of those involved were suspicious that I might be a CIA agent. Of course, these charges must be understood as arising in the hysteria of the last days of the Marcos administration. Men and women were disappearing. Bodies were being found every day. I could see I was not making progress in the Manila programs, and, on Divina's advice, I decided to go south and see if I could find other organizations to study.

Again with the help of Jimmy Tan, I made contact with a church-based primary care program in Tacloban, on the island of Leyte in the central Philippines. We flew south and met with a nun who administered community development programs on Leyte. She recommended that my wife and I visit two primary care programs, one urban and one rural. First, we went to a clinic in a church building in the middle of Tacloban; after it closed for the day, we visited the neighborhood where the patients lived. One week later, we went to see the other program, about sixty miles southwest of Tacloban. It was in the most rural place I have ever been to, with no electricity and no piped water. Yet the thatched huts, made from the nipa palm, were picturesque. It was the most impressive self-supporting community health program I have seen. The villagers backed it with common agricultural goods, mostly rice, which they marketed in Tacloban.

During the flight down to Tacloban and while walking around the town, I suffered many muscle cramps. I did a tremendous amount of walking in the city and in the rural village. I often felt exhausted at night, and went to sleep hoping that the next day I would awake refreshed. However, sunrise brought no refreshment, and the hot and humid weather drained me. I had stayed in Tacloban before and had not been so fatigued. The way my body felt worried me.

Divina and I returned to Manila with lots of material. I was happy we were making progress. I spent two weeks writing up my notes on the computer. After visiting more Manila-based community health organizations, we started to plan a trip to Davao in Mindanao. After a one-hour flight south, we caught the shuttle bus to the Davao Insular Hotel. On the road we had to stop while the Philippine Army cleared a field of Muslim separatist rebels. The driver of the minibus turned off the engine, and I could hear a strange quiet descend on

the line of cars, buses, and trucks. My apprehensiveness soared as I waited for the sound of gunfire. The muscles in my arms began to twitch and my shoulders began to shake.

The danger passed, and we arrived at the hotel. It was a beautiful place, next to Davao Bay. We went swimming in the large hotel pool. After we returned to the room, we called Jimmy Tan, who had come down from Manila about two days before us. Jimmy had been the medical director of the Mindanao Catholic Health Services Program, a community-based primary care organization. It was supported by overseas donors, mainly British Catholics. We wanted to observe two of its programs.

The first of these was outside Davao, about a fifty-minute drive to the west, in a rural barrio. The place had been torn apart by the guerrilla war raging around Davao. There were burnt-out cars and trucks everywhere. I had a hard time concentrating on the health program. My eyes kept going back to the burned homes and vehicles. While we were in the village, a company of Philippine marines patrolled nearby, looking for members of the New People's Army, the Communist insurgency.

Divina and I learned how the barrio program was organized and what services it offered. We met with the local principals in the program and then with the village leaders, mainly the *barangay* captain. We toured the village and observed many public health problems. There was, for example, no running water; the villagers had to walk some distance to an open well, shared by three barrios. Another public health problem was head injuries caused by falling coconuts. The village was next to an operating copra plantation.

The next day we went to Agdao, a slum district of Davao. Much of Agdao, typified by one-room shacks supported by stilts, is built over Davao Bay. I did something there that

would lead me to seek immediate medical attention in Manila. I always prided myself on my sense of physical balance. I think I developed it to an extraordinary degree when I was a boy, standing on deck in big ground swells off the southern coast of Long Island, where my family boated and fished from April to late November.

I tried to walk on the narrow boards that connected the houses in Agdao. I started out from the shore, trying to reach the first of the stilt houses. I began to have a hard time, sweating and trembling. I got only six feet from shore when I fell into the water. Luckily, it was low tide and I landed in shallow water and the underlying mud. It was not so much the falling as it was the trembling and shaking from muscle exhaustion that bothered me. I decided then that we would go to one of my wife's former colleagues, a physician, and ask for an appropriate referral in Manila.

When we eventually returned to our house, we went to see Ed Gonzales and asked him to think about my symptoms and make a referral. He put us in touch with a neurologist in the Manila Medical Center. The neurologist, a woman trained in the United States, told us she suspected I had amyotrophic lateral sclerosis. She did not know for certain and asked to schedule an electromyogram, a test of the electrical conduction of the muscles, at Philippine General Hospital. Then, she added that this was a life-threatening disease and that if I could go to the States for diagnosis and treatment it would be better.

UCLA

When Divina and I returned to our rental house in Teachers' Village, near the University of the Philippines, I jumped on the phone and called Harold Garfinkel. Garfinkel had

chaired my dissertation committee at UCLA. He held a joint appointment in the Department of Psychiatry, housed in the Neuropsychiatric Institute (NPI) in the medical center. I told him what had been happening with my health and asked him to set up a neurological workup at the NPI. He said he would get in touch with Ed Shneidman and ask him to schedule the examination. Garfinkel said he would call back the next afternoon and tell me what had developed.

When I next spoke with Garfinkel, he related that everything had been set up for the next Monday. I then had to arrange for my wife and me to return to Los Angeles. It was summer and every plane was booked. In a feverish attempt to get to Los Angeles, we bought a ticket for Taipei, with a connecting flight to Los Angeles. The next day, China Airlines called us and said the connecting flight had been canceled. We went back to the travel agent to get our money back and to complain. The travel agent came up with an alternative: fly to Hong Kong and wait for eight hours for a Singapore Airlines flight to Los Angeles. The price was a little bit more. We accepted the alternative.

Numbed by having recently been told of a fatal disease, we flew west for two hours on Cathay Pacific Airlines to Hong Kong. Our attention was diverted outward as we made the tricky descent between buildings and approached the city's old airport. Once we got off the plane, we entered the long hall that makes up all of Kai Tak Airport. We would sit and walk about for eight hours while we waited for our flight. The Hong Kong airport is an interesting place to watch people. When the Singapore 747 rolled up and the Los Angeles flight was announced, we felt like we had been saved from an eternity of waiting.

The flight was enjoyable, and we came to understand why Singapore is rated the best international airline; the

service cannot be compared to anything provided by U.S. carriers. I will always remember our cabin attendant, a man from India. After fifteen hours, we landed in Los Angeles and were picked up by my wife's uncle. We drove to a section two miles north of downtown, by Vermont Avenue. We were very tired and went to sleep right away. The next day was Monday, the day of my appointment at UCLA.

By arrangement, we met Garfinkel in his office. We then walked south, across the campus, to the medical center. We arrived at Shneidman's office at the NPI. He treated me like a returning student of his own, expressing great interest in what I was doing in the Philippines and in Micronesia. Between his questions about my studies, he asked many other questions about my condition. After about an hour of conversation, Shneidman got on the phone to the director of the NPI. He related my health complaints, who I was, and that I had just flown in from Manila; he then asked the director who I could see. An appointment was set for the next day.

We drove to UCLA from my wife's uncle's house on Tuesday. We met a friendly, balding, sandy-haired neurologist in his green-tiled laboratory. He took an extensive history and was very interested that I had undergone a neurological workup when I was a graduate student at UCLA. He asked me repeatedly the name of the neurologist I had consulted. I could only describe the appearance of the man. I told this second neurologist that the diagnosis from my earlier exam was benign fasciculations. He told me he would get the microfilm record of my past visit.

After taking the history, the neurologist asked me to sit on a bed. He explained he wanted to examine me and then give me an electromyogram. Afterward, he asked us to sit and talk. He said the clinical picture was unclear and he could not tell what was wrong with me. We asked him if I

had a fatal neurological condition. He assured me I was not going to die. He asked me to have a magnetic resonance imaging (MRI) test. He explained that the MRI unit at UCLA was fully booked and that I would have to go to the Huntington Medical Foundation in Pasadena on Wednesday, the next day. I agreed.

Our appointment was for 7 A.M. We left the house at 5:30. I had only been in Pasadena once before, to buy textbooks for a course at UCLA. We crept along a foggy freeway to arrive at the Huntington Medical Foundation, located in an industrial park, at 6:30. We waited for ten minutes before my appointment and then walked into the building. The staff had just arrived and they were not ready for me. After a half hour, I entered the cylinder of the huge MRI machine, built by General Electric. When I was inside, I felt as though someone were banging a hammer on a steel garbage can. The basics of the sound-wave imaging had already been explained to me by the radiologist. Even though I found the noise irritating, I understood what it was.

Divina and I left the foundation by eight and drove back to her uncle's house. The next day, the UCLA neurologist called and said the MRI had turned up nothing abnormal. He could not tell me what had happened. He asked me to go to the University of Southern California neurology clinic, located in Good Samaritan Hospital, near downtown Los Angeles. That same morning I went to Good Samaritan, where I was directed to the neuromuscular disease clinic. The light there was fluorescent and intense, with attendant noise from the long tubes. The waiting room's temperature was super-air-conditioned, about sixty-five, and I was very uncomfortable. My wife filled out the patient information and medical insurance sheets. I was called into the clinic by a neurology fellow, a Pakistani

man, dressed in strange balloon pants. Every resident and fellow seemed to be Pakistani.

I had bad feelings about the clinic from the start. I never had a high impression of the University of Southern California (USC). Perhaps this attitude derived from having attended UCLA. With the foreign medical graduates, the cramped clinic quarters, the overbright lighting, and the cruel air-conditioning, my impression of USC as a second-choice school was confirmed. When the Pakistani trainee told me he wanted to do a muscle biopsy, I decided it was time to get up and get dressed. He went to the clinic's attending physician, his boss, and told him I was leaving. The attending physician tried to change my mind. I told him I could not understand the trainee's English. He offered to take over my case. I declined. I had an overwhelming urge to leave the clinic and hospital. I entered the waiting room and got my wife and went out to the parking lot. We drove to her uncle's house. I was very upset.

The next day, Friday, I called the friendly UCLA neurologist and related my bad experience at the USC clinic. He apologized and said, "I don't know what to tell you. I cannot figure out what is wrong with you. I am sorry. Maybe you should go to the neuromuscular diseases clinic at the University of California, San Francisco" (UCSF). I asked if I had to go right away or if I could return to the Philippines and finish my work (I had three months left there). He told me I could go back to Manila and finish my work. He urged me to get in touch with UCSF as soon as I finally returned to Hawaii.

We flew to Honolulu, picked up my two children from my first marriage, Adrienne and Terrence, and took them to Manila for three months. I wrapped up my work and gave some seminars in Manila universities. The rest of the time

was occupied with showing the children the Philippines and going on many trips. My health remained an unsettled issue and my body continued to lose muscle mass. I was worried.

Canal House

In mid-August, the four of us returned to Honolulu. The day before our flight, I got some type of flu. I had a fever and started to vomit. I felt miserable as we boarded the plane. When we arrived back in Hawaii, I still had a high fever and terrible congestion. My sister picked us up and drove us to our rental house on a canal leading to the ocean. The home belonged to a chemistry professor and his wife, who had gone on sabbatical in Europe.

The next day my sister and my wife took me to the family practitioner we shared with my sister's family. The physician told me I had pneumonia and admitted me to the local hospital in Kailua. The suspicion was that I had contracted some exotic tropical disease in the Philippines and I was put in an isolation room. I had a tropical medicine consult and many tests.

While I was lying in the hospital bed the most troubling thing was the constant twitching of my muscles. The more I worried about my condition, the more frequent and deep the twitching became. I complained to my family-medicine practitioner about the constant and irritating activity in my muscles. I could not rest. My body could not turn off. I felt. The doctor said he would send me to a neurologist.

I was discharged after a week. I took oral antibiotics. I felt exhausted and spent a week sleeping. When I was rested, I called the physician for the referral to the neurologist. My appointment was at five in the morning, his normal time for seeing patients. The diagnosis was motor neuron disease, or

amyotrophic lateral sclerosis. (My visit to the neurologist is described in full in Chapter 2.)

I went home with the news that I had a fatal disease and could not expect to see the end of 1988. I cried a lot with Divina, always contemplating death and what it would mean to her and to my two children. We would spend hours in the darkest part of the house, crying and talking. After awful periods of sadness and depression, the two of us began to think of reading the research literature on motor neuron disease. My wife suggested we look for a new physician. I left it to her. We found Steven Berman, a decidedly East Coast Jewish internist. He has been my doctor and agent for twelve years.

I feel very comfortable with Berman. It is a matter of area cultural affinity, faith in his medical expertise, and his interactional style, in which he is always my agent and never my moral judge. I grew up in Great Neck, Long Island, an upper-middle-class suburb of New York City. The town was 80 percent Jewish, as were 95 percent of my friends. Although not a Jew, I felt comfortable with the New York Jewish culture, regarding it as my home culture. I was at ease with Berman, even with how he expressed anger. My Filipino wife would sometimes have reservations about my doctor's style and anger, however.

Berman is widely regarded as one of the best communicable diseases specialists in Hawaii. Most of his patients are referrals. He sees them in the morning only. Highly trained, Berman came to the state when the University of Hawaii opened its medical school. He was one of the founding members of the Department of Tropical Medicine. Although no longer a full-time faculty member, he still does research, publishes, attends research meetings, and teaches medical students and residents.

The best things about Berman are his capacity to act as your agent and his ability to make you think you are worth something, no matter how sick and disabled you may be. If you cannot get in to see a specialist, Berman will step in, make the call, and obtain the timely appointment. He will speak directly to the physician you want to see. The greatest of his skills is that having a life-threatening illness makes no difference in how Berman regards you. As Divina has pointed out, when you carry a life-threatening diagnostic label lesser doctors and health workers "see you as a dead man walking."

My favorite story about Berman is one often told by inpatient nurses, who complain about his aggressive treatment of infectious diseases in elderly patients. Many of them have serious degenerative diseases and are perceived as being near the end of life. I smile when I hear these stories, thinking it is the height of conceit for nurses or anyone else to decide to go lightly on therapy, hoping the patient will meet his or her end.

After we found Berman and established a working relationship with him, I decided to go to the University of California, San Francisco, medical center to follow up on the referral of the UCLA neurologist. I also consulted several colleagues from my days in the Department of Pediatrics and Human Development at Michigan State University. My former chairman there, Bill Weil, set up an appointment with the chief of the neuromuscular diseases clinic at UCSF. The chief of the clinic said, upon meeting us, "If I cannot figure out what is wrong with you, no one can." My wife and I were impressed by the self-confidence of this man in his early sixties. When we had a break from the diagnostic tests and examinations, we went to the campus bookstore and discovered our neurologist had just published a standard textbook on neuromuscular diseases.