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SURVIVAL OF THE UNFITTEST

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Survival of the UNfittest? Because it demonstrates my approach to medical problems, I'll begin with the introduction to my article "Dealing with Breast Cancer" in the Fall 1995 issue of *Polio Network News:*

When I was diagnosed with cancer in my right breast on March 2, 1995, my first thought wasn't, "Am I going to die?" but, "Am I going to be able to type and feed myself?" And on April 3, when the surgeon whom I ultimately chose first examined me and said, "I've looked at your tests and agree that you do have cancer and that it will have to come out," I responded, "No, it doesn't have to come out."

Although I wouldn't have been surprised if he'd asked "Then why are you here?" he listened as I explained the history of my arm and shoulder limitations and watched as I, naked from the waist up, demonstrated my narrow range of arm and hand use, so narrow that I need full-time physical care.

The rest of my article dealt with tests to determine if the cancer had spread; talks with many medical experts, including both my primary-care physician and my polio specialist, as well as the anesthesiologist and his assistant; and a double mastectomy, twice the surgery that I'd started with. Why? The other breast looked as if it might go the same way in a few years; and I feared that leaving one breast would affect my already precarious balance.

After the article appeared, I received comments both praising and condemning my "attitude." If the reader found my attitude positive, the comment was positive; if the reader found it negative, the comment was negative, in the vein of, "Who does she think she is, trying to second-guess doctors?" Actually, I wasn't trying to second-guess anybody: I was first-guessing everybody. And I was taught by a master of the process: Dr. Charles Irwin, Chief Surgeon at the Georgia Warm Springs Foundation, whom I first encountered in 1945.

The doctors in Birmingham had said they wouldn't perform surgery on my feet until I "had my growth," which would've had me endure additional years of pain from the sores on my ankles caused by their rubbing against the inside of my braces. But Dr. Irwin did the surgery then, when I was thirteen. Within months my ankles had healed, and I discarded one leg brace and the hated high-top shoes.

Later, during a checkup at Warm Springs, a young doctor suggested that my right arm would look better fused at the elbow into a palm-down position (following the onset of polio, it had settled into a palm-up position). Dr. Irwin said, "Why don't you ask her how she uses that hand?" The younger doctor asked me, and I demonstrated by hooking the middle finger of my left hand over my bottom teeth, lifting that arm with my head, and setting its elbow down into the up-turned palm of my right hand. I then used the strength of my right arm to maneuver my weaker left arm. The prettying-up surgery fell by the wayside.

Kay Haygood and Ellen Fay Peak

Another time I complained about hurting my left ankle whenever I fell forward. Dr. Irwin examined my braced leg, pushing the foot up and down. Turning to another young doctor, he asked, "What do you suggest?" The other doctor said, "I'd put stops on her shoe." "How many?" Dr. Irwin asked. "Two — a front and a back," he said. Dr. Irwin pointed out that the muscle that pulled my foot up was one of my strongest, and the muscle that pushed my foot down, one of my weakest. Therefore, I needed only the front stop to prevent my foot from being pushed upward in a forward fall; the back stop would impede my walking.

Warm Springs and Dr. Irwin have been significant and positive influences in my life; unfortunately, other influences have been less positive but no less significant, given what I learned from them. For example, I first discovered the dangers in a "public" hospital when I broke the femur of my braced leg in 1973.

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As I lay in the emergency room, an orthopedic doctor whom I'd never seen examined me and announced, "We'll put her in a long-leg cast, waist-high, and send her home." "No," I said. "My mother wouldn't be able to handle me."

He admitted me and put my leg in traction. The next morning, while I was still in a kind of shock, the RN who came to feed me breakfast slung my tray down and announced, "I hope you're a fast eater, because I'm a fast feeder."

A week of traction passed before I realized the doctors were probably using a standard load of weights on my left leg, the one connected to my fragile left hip. When I asked, they x-rayed both hips, saw the difference, and reduced the poundage.

Later, when I asked about inhalation therapy, they ordered it but also suggested I use a monkey bar to exercise. For several days, my mother put my hands up on it, and I did what I could. Then I developed chest pains. When tests found no heart trouble, the monkey bar was removed and the pains stopped.

Another difficulty arose once I was out of traction nearly four months later, the break not yet healed. My doctors assumed opposing positions regarding my brace: one wanted me to wear it through the night, to protect the femur; another wanted me not to wear it through the night, to stress the femur. Their boss sent me home.

Twice a day, my mother hot-packed and stretched my knee. She stood me up every couple of hours.

Although she did not attend public school, **ELLEN FAY PEAK** obtained her GED diploma in 1950, graduated Phi Beta Kappa from Birmingham-Southern College with BA in 1955 (French and Spanish majors) and MA in English in 1963. She was an editorial assistant for *The Progressive Farmer* magazine 1956-63; a teacher of high school English, French, and Spanish, 1963-66; and an instructor of English at Jefferson State Community College 1966-1991, when she retired.

Ellen is a member of the Birmingham (Alabama) Post-Polio Support Group and currently chairs that group's statewide forum coming up May 1-3, 1998. She also volunteers her time as an editorial critic to *Polio Network News*.

Then she and my brother walked me endlessly while supporting me around my waist.

When the orthopedic doctors pronounced me cured, although my leg was too stiff for me to drive and I was unable to move around well enough to return to teaching, I went to Warm Springs.

There I was anxious and defensive, bursting into tears if anyone even suggested that my mother leave my room. As bad as my experience in the public hospital had been, it would've been much worse if she'd not spent much of every day with me, particularly around meal times.

When the charge nurse asked, "What can you do for yourself?" I burst into tears again. "Oh, yes," she said, "You're a quad, so you need total physical care." Not ever having been told I was a quadriplegic, I said, "No, I'm not."

Surprised, she said, "You are. Both your arms and legs are involved, aren't they?" With that, she set up my schedule. My first stop was the doctor's office, where I received prescriptions for a new brace to fit my "new" leg and a glide-about chair I could maneuver with my right foot. The doctor directed my physical therapist to stretch my leg three times a day, walk me three times a day, and do mat work with me at least once a day until my leg was bending to a sitting position, ensuring I could drive again.

When I left Warm Springs two weeks later, I was ready to return to teaching after a nine-month absence — back in a wheelchair, but also "back on my feet," physically and mentally rehabilitated for the second time.

I next discovered the dangers in general rehabilitation hospitals. Because I had learned at Warm Springs about research indicating that "old" polios could wear out their muscles, when I began to experience unusual fatigue in 1978, I consulted one of the new breed of doctors. As I sat dressed and combed before him, he asked if I could tie my shoelaces. I answered, "Probably. But I don't." When he asked, "Why not?" I explained I didn't have enough strength to tie my shoelaces and teach my classes.

Then, I sent a student to the reference library of a local medical school to discover whatever she could about polio, new fatigue, etc. She returned with photocopies of a few articles from *The Lancet,* the only references she could find. Although the term "post-polio syndrome" was not yet used, these articles gave me the earliest concrete examples of what lay ahead.

The shoelace incident was the first time I'd had "to explain myself." In 1979, when my mother, who had tied my shoelaces, started her own decline, I called

several home-health providers, but none opened until eight o'clock, and they all closed on weekends. I applied to several nursing homes for a room and attendant care — I would continue teaching and supporting my mother — but was told I would be a disruptive influence and I couldn't rescue myself if the building caught fire in the middle of the night.

When my mother herself went into a nursing home, a colleague (Jeanne) moved me into her home and took on my physical care while I mulled over what to do next. We had some tense moments: I knew little about instructing another person in dressing me, and she knew even less about taking instruction.

"Just getting my support hose on took forever," I complained to Harriott, another colleague, in my office on the first work day I'd ever started without my mother.

As Jeanne had begun to dress me that morning, though, she'd been anxious to please. But she picked up the wrong hose first. My left leg being smaller than my right, I have shorter and longer hose, a difference we'd discussed the night before, but she'd forgotten it, and we had to start over. When she began to put on my left shoe (left hose/left shoe), she pulled the lace out of its double-laced pattern. By the time we'd gotten my shoelaces tied (snugly but not too), she was gritting her teeth.

Before telling Harriott about the next step, I launched into a defense of myself. Because I am an "upside-down polio," with almost total loss of shoulder and arm function but with some leg function, I can stand while being dressed and undressed. My ability to stand simplifies my dressing because the dresser can "drape" my body instead of pulling and tugging garments on while rolling me back and forth on a bed.

So there I was, standing, waiting for the pulling up of my underpants, the left leg of which, because of the brace on my left leg, tends to twist. When they were at my knees, I told Jeanne they were twisting; through gritted teeth she said, "Wait just a minute, Ellen. I'll fix them." She pulled them all the way up and then tried to straighten them, twisting cotton pants against cotton corset.

At that point, Harriott exclaimed, "The trouble is, Ellen, you want to be dressed perfectly." I shot back, "Is it asking too much to be dressed the way I dress?" and burst into tears.

I did a lot of bursting into tears back then. I don't now because I went into psychotherapy about that time to rid myself of some of the anger and frustration building up during those life changes. I spent hours weeping and wailing to my therapist about how I needed some control over my life, and he spent hours helping me to get it. He watched me move from being a dependent daughter to being an independent woman in her late forties — now I laughingly describe myself as the most dependent Type A personality I know.

Another significant helper in that maturing process was Kay, the young woman whom I chose as my full-time physical caregiver in March 1980. I interviewed her in my campus office toward the end of my second week at Jeanne's house.

I had set up two tests. Since breaking my leg in 1973, I had used on campus the small glide-about chair which I maneuvered with my right leg, in control unless someone decided to "help" me by grasping the hand grips. Thus, as my first test, I would present my back to Kay. If she laid a hand on my chair as we moved to my office, she'd be out.

Next, after a little chit-chat, I would say I needed to go to the bathroom. Again presenting my back, I'd instruct her in the opening and shutting of doors and the positioning of herself in relationship to me — sometimes in front, sometimes behind. Once she, I, and my chair were inside the stall, I would stand up and move to the commode. Facing her, I'd tell her step-by-step how to unbutton the button, unzip the zipper, and pull down first my outer pants and then my underpants.

The second test, a direct result of my experiences with Jeanne, would occur when I had finished with the commode and stood facing her. I would say nothing, but wait for her to retrace the steps in arranging my clothes.

Having come to know Kay in the seventeen years we've lived together, I have often wondered how she knew not to touch me unless the process required it. And because she too likes to be in control, I find remarkable her not taking hold of my wheelchair. She passed my tests beautifully.

As important as these influences have been, without good, long-term medical care, I wouldn't be writing these words. I've had the same primary-care physician since 1977, a physician who expects his patients to communicate with him often and in detail. I never go into his office without a list of items to discuss and a printout of my current medications, including over-the-counter stuff. Before I saw him the first time, he asked that I write up my medical history. I opened by saying, "Both my life and, therefore, my health have been shaped by the fact I've been a polio quad since the age of four in 1937." I closed by saying, "As you may gather, I see a great deal of truth in John Milton's

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notion that 'The mind is its own place, and in itself can make a heaven of hell, and a hell of heaven.'"

I'm sure my doctor finds disconcerting that his patient never gets better, only worse. Through these years of change, however, he's been steadfast in his effort to help me function. He drew my attention to the computer in the early '80s when he sent me an article from the *Wall Street Journal* predicting the importance of computers to the physically limited. He encouraged me to move out onto the Internet to do my own medical research. And he always encourages me to interact with other doctors as I interact with him — asking questions, writing up notes as medical problems develop, following threads as they lead me to decisions I must make, always with his advice.

Now that I'm on the Internet, I have access to more medical information than I ever dreamed of — all without having to lift a book or turn a page. By striking a few keys, I can find a discussion of gallstones, which I have, or a medicine like Plendil, which I take. Information about searching the Internet is widely available: the February 1997 issue of *Consumer Reports* had an in-depth article about Internet sites dealing with medical matters and the July 1996 *Harvard Health Letter* had a Special Supplement containing references both on the Internet and in books for help in answering medical questions. Another of my favorite articles is "Don't Be a Wimp in the Doctor's Office" in the August 1996 *Harvard Health Letter.*

I'm lucky: I have responsive physicians and a strong support system. But my bottom line is that I often create my luck by keeping my eyes and ears open, asking question after question after question, and, above all, trying to first-guess everybody involved in my care — and that includes everybody I know.

Moving???

Please send your old and new addresses to:

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NEW POST-POLIO SERVICES

ALBUQUERQUE

Saint Joseph Rehabilitation Hospital has begun a comprehensive post-polio service in Albuquerque, New Mexico, as of September, 1997, to provide assistance throughout the southwestern United States. Persons with a history of polio can receive a consultation, diagnosis, treatment, and follow-up by a team of physiatrists, physical therapists, psychologists, occupational therapists, speech and language therapists, and nutrition counselors. Saint Joseph has a fully-equipped gym, an activities-for-daily-living center, and a handicapped-accessible therapeutic pool.

Polio survivors may be referred through their primary-care physician, private healthcare physician, or a physiatrist. Self-payers may call directly. Callers will receive information, literature, and, if desired, a call back from a team member providing an opportunity to discuss individual symptoms before visiting the clinic. At the clinic, polio survivors will be referred to appropriate therapies, and a medical team will plan a treatment strategy. Follow-up visits will be made by a nurse case manager at 6- and 12-month intervals, or more frequently if needed. The new post-polio service hotline number is 505/727-4901.

LOUISVILLE

Frazier Rehabilitation Center in Louisville, Kentucky, has established a new interdisciplinary post-polio clinic. It is the result of the combined efforts of Judah L. Skolnick, pulmonologist at the Jewish Hospital Heart and Lung Institute; Frances Brown, Polio Survivors Organization; and Keven S. Hollars, RN, clinic coordinator at Frazier Rehabilitation (affiliated with The Jewish Hospital). A questionnaire was developed to obtain general poliomyelitis history, new problems associated with the late effects of poliomyelitis, and survivors' input on services that would benefit them in a post-polio program. The results were used in developing the clinic program.

The purpose of Frazier's post-polio clinic is to help survivors manage lifestyle changes that maximize long-term health and wellness. Before attending the clinic, survivors are sent an assessment form to assist the clinic team in its two-day evaluation. Day One consists of evaluations by the physiatrist (a physician trained in physical medicine and rehabilitation), clinic coordinator, physical therapist, occupational therapist, and psychologist. Laboratory tests, X-rays, or EMGs are done as indicated by the physiatrist. On Day Two, following the team's recommendations, other consults are made by pulmonary rehabilitation specialists, dietitians, speech therapists, and orthotists. Polio survivors meet with the medical team, try suggested interventions, and receive any additional recommendations.

For more information concerning the clinic or for a copy of the questionnaire and its results, call 502/582-0542 or write to Keven S. Hollars, RN, Clinic Coordinator, Frazier Rehabilitation Center, 220 Abraham Flexner Way, Louisville, Kentucky 40202.

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