

My First Fifty Years as a Diabetic

by

Dr. Richard Bernstein

I developed diabetes in 1946 at the age of 12, and for more than two decades I was an "ordinary" diabetic, dutifully following the doctor's orders and leading the most normal life I could, given the limitations of my disease. Over the years, the complications from my diabetes became worse and worse, and like many diabetics in similar circumstances, I faced a very early death. I was still alive, but the *quality* of my life wasn't particularly good. I have what is known as Type I, or insulin-dependent, diabetes, which usually begins in childhood (it's also called "juvenile-onset diabetes"). Type I diabetics must take daily insulin injections just to stay alive.

Back in the 1940's, which were very much the "Dark Ages" of diabetes treatment, I had to sterilize my needles and glass syringes by boiling them every day, and use a test tube to test my urine for sugar. Many of the tools the diabetic can take for granted today were scarcely dreamed of back then. There was no such thing as a rapid, finger-stick blood sugar measuring device, nor disposable syringes. Still, even today, parents of Type I diabetics live with the same fear my parents lived with: any morning they could try to wake up their child and discover him dead. For any parent of a Type I diabetic, this is still a real and constant possibility. Because of my chronologically elevated blood sugar levels, and the inability to control them, my growth was stunted, as it is for many juvenile-onset diabetics, even to this day. Back then, the medical community had just learned about the relationship between high blood cholesterol and blood vessel and heart disease. It was then widely believed that the cause of high blood cholesterol was consumption of large amounts of fat. Since many diabetics, even children, have high cholesterol levels, some physicians assumed that the vascular complications of diabetes (heart disease, kidney failure, blindness, etc.) were caused by the fat that diabetics were eating. As a result, I was put on a low-fat, high carbohydrate diet before such diets were advocated by the American Diabetes Association or the American Heart Association.

Because carbohydrates raise blood sugar, I had to compensate with very large doses of insulin, which I injected with a 10 c.c. "horse" syringe. These injections were slow and painful, and eventually they destroyed all the fatty tissue under the skin of my thighs. In spite of the low-fat diet, my blood cholesterol remained very high. I developed visible signs of this state: fatty growths on my eyelids, and gray deposits around the iris of each eye.

During my twenties and thirties, the prime of life for most people, many of my body's systems began to deteriorate. I had excruciatingly painful kidney stones, a stone in a salivary duct, "frozen" shoulders, a progressive deformity of my feet with impaired sensation, and more. I would point these out to my diabetologist, but I was told "Don't worry. It has nothing to do with your diabetes. [!!!- Ellis] You're doing fine!"

But I wasn't doing fine. I know now that most of these problems are commonplace among those whose diabetes is poorly controlled, but then I was forced to accept my condition as "normal". By this time I was married. I had gone to college and trained as an engineer. I had small children, and even though I was not much more than a kid myself, I felt like an old man. I had lost the hair on the lower parts of my legs, a sign that I had developed peripheral vascular disease, a complication of diabetes that can eventually lead to amputation.

During a routine exercise stress test, I was diagnosed with cardiomyopathy, which is a replacement of muscle tissue in the heart with fibrous (scar) tissue. This is a common cause of heart failure and death among those with Type I diabetes.

Just as the disease had taken its toll on my parents, it also took its toll on my wife and children. Even though I was "doing fine" according to my doctor, I suffered a host of other complications. My vision deteriorated; I suffered night blindness, microaneurysms (ballooning of blood vessels in my eyes)[note: when this is occurring in the eyes, it is probably also occurring in capillaries in the brain, and kidneys. This could cause tiny "strokes" and a sudden loss of cognitive functions, advanced kidney disease, etc. - Ellis] I suffered macular edema (swelling of the central portion of my retina) and early cataracts. Just lying in bed caused pain in my thighs, due to a common diabetic complication called "ilio-tibial band/tensor fascia lata syndrome." Putting on a T-shirt was agonizing because of my frozen shoulders.

I had begun testing my urine for protein and found substantial amounts of it proteinuria. This is a sign of advanced kidney disease. In those days (mid and late 1960's) the average life expectancy of a Type I diabetic with proteinuria was five years. A classmate had told me how his sister had died of kidney disease. Before her death she had ballooned with retained water. After I discovered my own proteinuria, I began to have nightmares of blowing up like a balloon.

By 1967 I had these and other diabetic complications and clearly appeared chronically ill and prematurely aged. I had three small children, the oldest only six years old. I was certain, with good reason, that I wouldn't live to see them grown.

At my father's suggestion, I started working out daily at a local gym. My father thought that if I were to engage in vigorous exercise, I might feel better. Perhaps exercise would help my body help itself. While I did feel less depressed about my condition, I couldn't build muscles or get much stronger. After two years of pumping iron, I remained a 115-pound weakling, no matter how strenuously I worked out. It was about this time that my wife, a physician, pointed out to me that I had spent much of my life going into, experiencing, or recovering from hypoglycemia. Hypoglycemia is a state of excessively LOW blood sugar. It is usually

accompanied by fatigue and headaches. During these episodes, I became confused and unruly and snapped at people. The strain on my family was clearly becoming untenable. Then, suddenly, in October 1969 my life turned around completely! I had been the research director of a company that made equipment for hospital laboratories. I received trade journals from my field. One day I opened the latest issue of a publication with an advertisement for a new device to help hospital emergency rooms distinguish between unconscious diabetics and unconscious drunks at night, when laboratories were closed. Knowing that an unconscious person was a diabetic and not drunk could easily help hospital personnel save his life. What I stumbled on was an ad for a blood sugar meter that could give a reading in 1 minute, using a single drop of blood. Since I'd been experiencing low blood sugar, and since the tests I had been performing on my urine were wholly inadequate because sugar that showed up in the urine is already on its way out of the bloodstream, I figured that if I knew what my blood sugar levels were, perhaps I could catch and correct my hypoglycemic episodes before they made me disoriented and irrational.

I marvelled over the instrument. It had a 4-inch galvanometer with a jeweled bearing, weighed 3 pounds, and cost \$650, which in those days could have been a month's salary. I tried to order one, but the manufacturer wouldn't sell it to patients - only to doctors and hospitals. Fortunately, my wife was a physician, so I ordered one in her name. I started to measure my blood sugar levels about 5 times each day, and soon I saw that they seemed to be on a roller coaster. What I learned from my frequent testing was that my own blood sugar levels swung from lows of under 40 mg/dl to highs of over 400 mg/dl about twice per day. A normal blood sugar level is about 85 mg/dl. Small wonder I was subject to such vast mood swings! In an effort to balance my blood sugar levels, I began to adjust my insulin regimen. I went from one to two injections per day. I made some experimental modifications in my diet, cutting down on my carbohydrates to take less insulin. The very high, and very low sugar levels became less frequent, but few were normal, yet.

Three years after I started measuring my blood sugar levels, my diabetic complications were still progressing, and I was still a 115-pound weakling. My sense of gaining insight into the workings of my diabetes had diminished, so I ordered a computer search of the scientific literature to see if exercise could prevent diabetic complications. In those days, computer searches were not the simple, almost instant searches that they are today. In 1972, you made your request to your local medical library, which mailed it to Washington, D.C. where it was processed. It took about two weeks for my \$75 dollar printout to arrive. There were quite a few entries of interest, and I ordered copies of the original articles. For the most part, these were from little known journals that dealt with animal experiments. The information I had hoped to find didn't exist. I didn't find a single article pertaining to the prevention of diabetic complications by exercise in humans. What I did find was that such complications had been repeatedly prevented, *and even reversed* in animals not through exercise, *but by normalizing blood sugars!* To me this was a total surprise. All of my diabetes treatment was heavily focused in other directions, such as low-fat diets, preventing hypoglycemia, or preventing high blood sugar. It had not occurred to me that keeping blood sugar levels as close to normal as possible for as long as possible would make a difference.

Excited by my discovery, I showed these reports to my physician. He was not impressed. "Animals aren't humans," he said, "and besides, it's impossible to normalize blood sugars." Since I had been trained as an engineer, not as a physician, I knew nothing of such impossibilities. And since I was desperate, I had no choice but to pretend I am an animal. I spent the next year checking my blood sugars 5 to 8 times each day. Every few days, I'd make a small, experimental change in my diet or insulin regimen to see what the effect would be on my blood sugar. If a change brought an improvement, I'd retain it. If it made the blood

s orse, I would discard it. I discovered that 1 gram of carbohydrate raised my blood sugar by 5 mg/dl, and 1/2 unit of the old beef/pork insulin lowered it by 15 mg/dl.

Within a year, I had refined my insulin and diet regimen to the point that I had essentially normal blood sugar levels around the clock. After years of chronic fatigue and debilitating complications, almost overnight I was no longer continually tired or "washed out." After years of sky-high readings, my serum cholesterol and triglyceride levels had now not only dropped, but they were at the low end of normal ranges! I started to gain weight, and at last I was able to build muscle as readily as a non-diabetic. My insulin requirements dropped by about two-thirds of what they had been one year earlier.

With the subsequent development of [recombinant - Ellis] human insulin, my dosage dropped to one-fifth of the original. The painful slow-healing lumps the injections of large doses of insulin left under my skin disappeared. The fatty growths on my eyelids vanished. My digestive problems (chronic burning in my chest and belching after meals) and the proteinuria that had so worried me eventually vanished. Today, my results are all normal. My deformed feet, the calcified walls of arteries in my legs, and the cystoid macular edema of my eyes are not reversible, and still remain.

I had a new sensation of being the boss of my own metabolic state, and began to feel the same sense of accomplishment and reward that I had when I solved a difficult engineering problem. I had taught myself how to make my blood sugar levels whatever I wanted them to be, and I was no longer on the roller coaster. ***At last, my blood glucose levels were under my control!***

Back in 1973, I felt quite exhilarated with my success, and I felt that I was on to something big. Since getting the results of my computer search, I had been a subscriber to all of the English language diabetes journals, and none of them had mentioned the need for normalizing blood sugar in humans. In fact, every few months I'd read another article saying that blood sugar normalization wasn't even remotely possible. How was it possible that I, an engineer, had figured out how to do what was impossible for medical professionals?

I was deeply grateful for the fortuitous combination of events that had turned my life, my health, and my family around and put me on the right path. At the very least, I felt, I was obliged to share my new found knowledge with others. There were no doubt millions of "ordinary" diabetics like me suffering needlessly.

I was sure that all physicians treating diabetics would be thrilled to learn how to prevent and possibly reverse the grave complications of this disease. I hoped that if I could tell the world about the techniques I had stumbled upon, physicians would adopt them for their patients. So I wrote an article detailing my discoveries. I sent a copy to Charles Suther, who was then in charge of marketing diabetes products for Ames Division of Miles Laboratories, the company that made my blood glucose meter. ***He gave me the only encouragement I received in this new venture***, and he arranged for one of his company's medical writers to edit the article for me.

I submitted it and its revisions to many medical journals over a period of years. I was continually improving in health, and continually proving to myself and to my family, if to no one else, that my methods were correct. ***The rejection letters I received are testimony that people tend to ignore the obvious if it conflicts with the orthodoxy of their early training.***

Typical rejection letters read in part:

New England Journal of Medicine: "Studies are not unanimous in demonstrating a need for 'fine control'. . ."

Journal of the American Medical Association: "How many patients would use the electric device for measurement of glucose, insulin, urine, etc.?"

As a matter of fact, since 1980 when these "electric devices" were finally made available to patients, the worldwide market for blood glucose self-monitoring supplies has come to exceed 3 billion dollars annually. Look at the array of blood glucose meters in any pharmacy, and you can get an idea of just how many patients would use, and do use, the "electric device." Trying to cover several routes simultaneously, I joined a few lay diabetes organizations, in the hope of moving up the ranks, where I could meet physicians and researchers specializing in the disease. I attended conventions, worked on committees, and met many diabetologists. This met with mediocre success. In this country, only *three* physicians who were willing to offer their patients the opportunity to put these new methods to the test.

Meanwhile, Charlie Suther was travelling around the country to university research centers with copies of my unpublished article. *The rejection by doctors of the concept of blood sugar selfmonitoring was so intense, however, that the management of his company had to turn down the idea of making meters available to patients until many years later.* The backlash from the medical establishment prevented it on a number of counts. It was *unthinkable* for patients to be allowed to "doctor" themselves. They knew nothing of medicine. *And if patients could take care of themselves, how would doctors earn a living?*

In those days, patients visited their doctors once a month to "get a blood sugar." If the patients could do this at home for 25 cents, why pay a physician? Besides, almost nobody believed there was any value to having normal blood sugar anyway. Blood sugar selfmonitoring was and remains a serious threat to the incomes of physicians who specialize in the treatment of the *symptoms* of diabetes and not the disease itself. Drop into your neighborhood ophthalmologist's office and you will find the waiting room three-quarters filled with diabetics, many of whom are waiting for expensive fluorescein angiography or laser treatment.

With Suther's backing in the form of free supplies, by 1977 I was able to get the first of two university-sponsored studies started in the New York City area. Both of these studies succeeded in reversing early complications in diabetic patients. As a result of our successes, the two universities separately sponsored the world's first symposiums on blood glucose selfmonitoring.

By this time, I was being invited to speak at international diabetes conferences, but rarely at meetings in the United States. Curiously, more physicians *outside the United States* seemed interested in controlling blood sugar than did their American colleagues. Some of the earliest converts to blood glucose self-monitoring were from Israel and England. By 1978, perhaps as a result of Charlie Suther's efforts, a few additional American investigators were trying our regimen or variations of it. Finally, in 1980, manufacturers began to release blood glucose meters for use by patients. The "progress" was entirely too slow for my liking. I knew that while the medical establishment had opposed the introduction of these meters there were diabetics dying whose lives could have been saved. I knew also that there were millions of diabetics whose quality of life could be vastly improved, so in 1977 I decided to give up my job and become a doctor. I couldn't beat them, so I would join them. This way, with an "M.D." after my name, my writings might be published, and I could pass on what I had learned about controlling blood sugar.

After a year of premed courses and another year of waiting, I entered the Albert Einstein College of Medicine in 1979. I was forty-five years old. During my first year of medical school I wrote my first book "Diabetes: the Glucograf Method for Normalizing Blood Sugar" Here I enumerated the full details of my treatment for Type I, or insulin dependent, diabetes.

I 1983 I finally opened my own medical practice. By that time I had well outlived the life expectancy of a Type I diabetic. Now, by sharing my simple observations, I was convinced I was in a position to help both Type I and Type II diabetics who still had the best years of their lives ahead of them. I could help others to take control of their diabetes as I had mine, and live long, healthy, fruitful lives.

The goal of this book is to share the techniques and treatments I have taught my patients and used on myself, including the very latest developments. If you or your loved ones suffer from diabetes, I hope my book will give you the tools to turn your life around, as I did mine.

- Dr. Richard K. Bernstein,
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