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THE WAY WE LIVE NOW: 3-16-03: BODY CHECK

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By Austin Bunn

Eleven-year-old Elizabeth Hughes was, in retrospect, the ideal patient: bright, obedient, uncomplaining and wholly unprepared to die. Born in 1907 in the New York State governor's mansion, Elizabeth was the daughter of Charles Evans Hughes, who later became a justice on the Supreme Court, ran against Woodrow Wilson in 1916 and served as secretary of state under Harding.

Elizabeth had a perfectly normal, aristocratic youth until she seemed to become allergic to childhood. She would come home from friends' birthday parties with an insatiable thirst, drinking almost two quarts of water at a sitting. By winter, she had become thin, constantly hungry and exhausted. Her body turned into a sieve: no matter how much water she drank, she was always thirsty.

In early 1919, Elizabeth's parents took her to a mansion in Morristown, N.J., recently christened the Physiatrie Institute and run by Dr. Frederick Allen. A severe, debt-ridden clinician with a pockmarked résumé, Allen had written the authoritative account on treating her condition. He prolonged hundreds of lives and was the girl's best chance. Allen examined Elizabeth and diagnosed diabetes -- her body was not properly processing her food into fuel -- and told her parents what they would never tell their daughter: that her life expectancy was one year, three at the outside. Even that was a magnificent extension of previous fatality rates. "The diagnosis was like knowing a death sentence had been passed," wrote one historian. Then Dr. Allen did what many doctors at the time would have done for Elizabeth, except that this doctor was exceptionally good, if not the finest in the world, at it. He began to starve her.

The history of medicine "is like the night sky," says the historian Roy Porter in his book "The Greatest Benefit to Mankind: A Medical History of Humanity." "We see a few stars and group them into mythic constellations. What is chiefly visible is the darkness."

Diabetes doesn't come from simply eating too much sugar; nor is it cured, as was once thought, by a little horseback riding. It is not the result of a failing kidney, overactive liver or phlegmy disposition, though these were the authoritative answers for centuries. Diabetes happens when the blood becomes saturated with glucose, the body's main energy source, which is normally absorbed

by the cells -- which is to say that the pathology of diabetes is subtle and invisible, so much so that a third of the people who have it don't even know it. Until the prohibition against autopsies was gradually lifted (by 1482, the pope had informally sanctioned it), what we knew of human anatomy came through the tiny window of war wounds and calamitous gashes -- and even then it took centuries for doctors to decide just what the long, lumpy organ called the pancreas actually did or, in the case of diabetes, didn't do. We like to think surgically about the history of medicine, that it moved purposefully from insight to insight, angling closer to cure. But that is only the luxury of contemporary life. Looked at over time, medicine doesn't advance as much as grope forward, with remedies -- like bloodletting, quicksilver ointments and simple, unendurable hunger -- that blurred the line between treatment and torture.

Diabetes was first diagnosed by the Greek physician Aretaeus of Cappadocia, who deemed it a "wonderful affection . . . being a melting down of the flesh and limbs into urine." For the afflicted, "life is disgusting and painful; thirst unquenchable . . . and one cannot stop them from drinking or making water." Since the classical period forbade dissection, Porter notes, "hidden workings had to be deduced largely from what went in and what came out." An early diagnostic test was to swill urine, and to the name diabetes, meaning "siphon," was eventually added "mellitus," meaning "sweetened with honey." Healers could often diagnose diabetes without the taste test. Black ants were attracted to the urine of those wasting away, drawn by the sugar content. Generations later, doctors would make a similar deduction by spotting dried white sugar spots on the shoes or pants of diabetic men with bad aim.

For the Greeks, to separate disease symptoms from individual pain while isolating them from magical causes was itself an enormous intellectual leap. "We should be really impressed with Aretaeus," says Dr. Chris Feudtner, author of the coming "Bittersweet: Diabetes, Insulin and the Transformation of Illness." "He was able to spot the pattern of diabetes in a dense thicket of illness and suffering."

But for centuries, this increasing precision in disease recognition was not followed by any effective treatment -- more details didn't make physicians any less helpless. At the time, they were unknowingly confusing two kinds of diabetes: Type 1, known until recently as "juvenile diabetes," which is more extreme but less common than Type 2, or "adult onset," which seems to be related to obesity and overeating. With Type 1 (what Elizabeth Hughes had), the pancreas stops secreting insulin, a hormone that instructs the body to use the sugar in the blood for energy. With Type 2, the pancreas produces insulin (at least initially), but the tissues of the body stop responding appropriately. By 1776, doctors were still just boiling the urine of diabetics to conclusively determine that they were passing sugar, only to watch their patients fall into hyperglycemic comas and die.

If dangerous levels of glucose were pumping out of diabetics, one idea was obvious: stop it from going in. That demanded a more sophisticated understanding of food itself. In the long tradition of grotesque scientific experimentation, an insight came through a lucky break: a gaping stomach wound. In 1822, William Beaumont, a surgeon in the U.S. Army, went to the Canadian border to

treat a 19-year-old trapper hit by a shotgun. The boy recovered, but he was left with a hole in his abdomen. According to Porter, Beaumont "took advantage of his patient's unique window" and dropped food in on a string. The seasoned beef took the longest to digest. Stale bread broke down the quickest. The digestion process clearly worked differently depending on what was eaten. Then during the 1871 siege of Paris by the Germans, a French doctor named Apollinaire Bouchardat noticed that, though hundreds were starving to death, his diabetic patients strangely improved. This became the basis for a new standard of treatment. *Mangez le moins possible*, he advised them. Eat as little as possible.

In the spring of 1919, when Elizabeth Hughes came under Dr. Allen's care, she weighed 75 pounds and was nearly 5 feet tall. For one week, he fasted her. Then he put her on an extremely low-calorie diet to eradicate sugar from her urine. If the normal caloric intake for a girl her age is between 2,200 and 2,400 calories daily, Elizabeth took in 400 to 600 calories a day for several weeks, including one day of fasting each week. Her weight, not surprisingly, plummeted. As Michael Bliss notes in his book "The Discovery of Insulin," the Hughes family brought in a nurse to help weigh and supervise every gram of food that she ate. Desserts and bread were verboten. "She lived on lean meat, eggs, lettuce, milk, a few fruits, tasteless bran rusks and tasteless vegetables (boiled three times to make them almost totally carbohydrate-free)," Bliss writes. Instead of a birthday cake, she had to settle for "a hat box covered in pink and white paper with candles on it. On picnics in the summertime she had her own little frying pan to cook her omelet in while the others had chops, fresh fish, corn on the cob and watermelon."

You could say that Elizabeth Hughes was on a twisted precursor of the Zone diet: her menu relied on proteins and fats, with the abolishment of carbohydrates like bread and pasta. In fact, Allen's maniacal scrutiny of his patients' nutrition -- fasting them, weighing each meal, counting calories -- was one of the first "diets" in the modern sense. At the time Elizabeth entered the clinic, being well fed was a sign of good health. But the new science of nutrition fostered the idea of weight reduction as a standard of health and not illness.

Allen's "starvation diet" was a particular cruelty. Patients came to him complaining of hunger and rapid weight loss, and Allen demanded further restrictions, further weight loss. "Yes, the method was severe; yes, many patients could not or would not follow it," writes Bliss. "But what was the alternative?" Over the years, doctors recommended opium, even heaps of sugar (which only accelerated death, but since nothing else worked, why not enjoy the moment?). But nobody had a better way than Allen to extend lives. If the fasting wasn't working and symptoms got worse, Allen insisted on more rigorous undernourishment. In his campaigns to master their disease, Allen took his patients right to the edge of death, but he justified this by pointing out that patients faced a stark choice: die of diabetes or risk "inanition," which Allen explained as "starvation due to inability to acquire tolerance for any living diet." The Physiatrie Institute became a famine ward.

Some of Allen's patients survived levels of inanition not thought possible, Bliss writes. One 12-year-old patient, blind from diabetes when he was admitted, still occasionally showed sugar in his urine. The clinic became convinced that the kid -- so weak he could barely get out of bed -- was somehow

stealing food. "It turned out that his supposed helplessness was the very thing that gave him opportunities which other persons lacked," Allen later wrote in his book, "Total Dietary Regulation in the Treatment of Diabetes." "Among unusual things eaten were toothpaste and birdseed, the latter being obtained from the cage of a canary which he had asked for." The staff, thinking he was pilfering food, cut his diet back and further back. The boy weighed less than 40 pounds when he died from starvation.

No one explained to Elizabeth Hughes why the friends she made at Allen's clinic stopped writing her letters. Death was kept hidden, though it must have been obvious from the halls of the clinic, where rows of gaunt children stared from their beds. "It would have been unendurable if only there had not been so many others," one Allen nurse wrote. Dutifully, Elizabeth -- strong enough just to read and sew -- hardly ever showed sugar. Her attendant punished her severely the one time she caught her stealing turkey skin from the kitchen after Thanksgiving. Still, she was wasting away. By April 1921, 13 years old and two years into her treatment, Elizabeth was down to 52 pounds and averaged 405 calories a day. In letters to her parents, she talked about getting married and what she would do on her 21st birthday. Reading the letters "must have been heartbreaking," writes Bliss. "Elizabeth was a semi-invalid."

In the history of illness, there are countless medicines, over time and across cultures, with varying degrees of suffering and success. There is only one kind of cure -- the one that invariably, irrefutably works. Insulin is not a cure. It is a treatment, but it changed everything. In the summer of 1922, two young clinicians in Toronto named Frederick Banting and Charles Best surgically removed the pancreases from dozens of dogs, causing the dogs to "get" diabetes. They found that by injecting the dogs with a filtered solution of macerated pancreas (either the dogs' own or from calf fetuses), the glucose level in the dogs' blood dropped to normal. The researchers had discovered insulin.

But in August 1922, Dr. Frederick Allen had patients who could not wait, like Elizabeth. Allen left for Toronto to secure insulin. While he was gone, word leaked through his clinic about the breakthrough. Patients "who had not been out of bed for weeks began to trail weakly about, clinging to walls and furniture," wrote one nurse. "Big stomachs, skin-and-bone necks, skull-like faces . . . they looked like an old Flemish painter's depiction of a resurrection after famine. It was a resurrection, a crawling stirring, as of some vague springtime."

On the night Allen returned to the clinic, he found his patients -- "silent as the bloated ghosts they looked like" -- waiting in the hallway for him, wrote the nurse. "When he appeared through the open doorway, he caught the full beseeching of a hundred pair of eyes. It stopped him dead. Even now I am sure it was minutes before he spoke to them. . . . 'I think,' he said. 'I think we have something for you.' "

He did, but not nearly enough. Though the results were striking -- with the insulin, sugar vanished from the urine of "some of the most hopelessly severe cases of diabetes I have ever seen," wrote Allen -- he did not have enough extract to treat all his patients, including Elizabeth. So her parents

got her to Toronto. When Banting saw Elizabeth, she was three days away from her 15th birthday. She weighed 45 pounds. He wrote: "Patient extremely emaciated . . . hair brittle and thin . . . muscles extremely wasted. . . . She was scarcely able to walk."

He started her insulin treatment immediately. The first injections cleared the sugar from her urine, and by the end of the first week, she was up to 1,220 calories a day, still without sugar. By the next, she was at 2,200 calories. Banting advised her to eat bread and potatoes, but she was incredulous. It had been three and a half years since she had them. That fall, she was one of several hundred North American diabetics pulled back from the edge. By November, she went home to her parents in Washington, and by January, she weighed 105 pounds. The same year, the 31-year-old Banting won the Nobel Prize. Meanwhile, Dr. Allen, proprietor of an expensive clinic whose patients no longer needed him, went broke. Insulin was a miracle drug, resurrecting diabetics from comas and putting flesh on skeletons and, since it needed to be administered at least twice daily, it was a miracle that would be performed over and over. The era of chronic medical care had begun.

That may be the most poignant part of the history of Allen's clinic. The end of the famine of Elizabeth Hughes is really the start of another hunger: for the drugs that will keep us well for the rest of our lives. Elizabeth went to Barnard, reared three children, drank and smoked but kept her diabetes a secret almost her entire life. She died of a heart attack in 1981, more than 43,000 injections of insulin later. But if the discovery of insulin took away the terror of diabetes, it replaced the miraculous with the routine. Healing lost one major ingredient: awe. "To think that I'll be leading a normal, healthy existence is beyond all comprehension," Elizabeth wrote to her mother, days after her first injection, in 1922. "It is simply too wonderful for words."

Photos: Charles Evans Hughes with his daughter, Elizabeth, two years before she developed diabetes. (Underwood and Underwood, collection of The Supreme Court of The United States archive); In 1919, Dr. Frederick Allen was a diabetic's best hope. His treatment: near starvation. (Joslin Diabetes Center); Before insulin was discovered in 1922, diabetes was a death sentence. (Eli Lilly and Company archives)