**Bringing Back My Real Self With Hormones**

By MARY LOU JEPSEN NOV. 23, 2013

IN my early 30s, for a few months, I altered my body chemistry and hormones so that I was closer to a man in his early 20s. I was blown away by how dramatically my thoughts changed. I was angry almost all the time, thought about sex constantly, and assumed I was the smartest person in the entire world. Over the years I had met guys rather like this.

I was not experimenting with hormone levels out of idle curiosity or in some kind of quirky science experiment. I was on hormone treatments because I’d had a tumor removed along with part of my pituitary gland, which makes key hormones the body needs to function.

This long journey may have started as early as 1978, when I was 13. I spent a summer in intensive care with an unknown disease. After that summer, I never thought I would live a long life. So I wanted to live, to do interesting, fascinating work in the limited time I thought I had left. I took on the math-intensive art form of holography, and in my early 20s traveled the world, living on university fellowships to pursue this esoteric craft. I didn’t date much, really — perhaps because I didn’t have many hormones, though I didn’t know that at the time. I worked as an artist, played in a band, met Andy Warhol, Christo, Lou Reed and David Byrne. I had fun. But the gravity of my illness grew in the 1990s.

The growth that shut down my pituitary gland’s ability to produce hormones did so insidiously over many years. By my early 20s it was, I suspect in retrospect, causing misdiagnosis of symptoms that were most likely caused by lack of hormones like cortisol. No diagnosis was found, despite the efforts of many doctors. I was a doctoral student in electrical engineering at an Ivy League school, but was growing progressively worse. I routinely slept about 20 hours a day, lived with a constant blistering headache and frequent vomiting, and was periodically wheelchair-bound. Large sections of my skin cycled through a rainbow of colors and sores, half of my face wouldn’t move as if Novocain had been applied. I drooled. Worse: I felt stupid. I couldn’t subtract anymore. I couldn’t make a to-do list, let alone accomplish items on one. I recognized that I wasn’t capable of continuing in graduate school. Utterly defeated, I filled out the paperwork to drop out.

Then, in the summer of 1995, my brain tumor was discovered. Diagnosis can often take this long. This might be because of the insidious and chameleonlike nature of this disease. The tumor was not malignant, but it had disrupted my pituitary function. The symptoms are general, confusing, escalate slowly over years and can be easily misinterpreted.

It was great to have a chance at a meaningful life again, but I found it embarrassing to learn firsthand how completely controlled we are by our hormones. I thought it was about the gray matter, but this experience forced me to look differently at how we think. I have had to shape my personality by my hormone doses.

The journey of tuning “me” began by fixing basic things. Everyone focuses on testosterone and estrogen, but these are just a small part of the mix of what is needed to stay alive and healthy. For example, consider the hormone cortisol; it’s a crucial component of the immune system, and you can’t live without it. I don’t make any cortisol. If I don’t take it, I could die.

I had to make a plan to replace the chemicals that the missing parts of my brain used to make. There wasn’t a clear and detailed road map for this. Blood levels of these chemicals vary for people of the same age and sex, and even more between men and women, young and old. More of us may be affected by variant hormone levels than we realize. One systematic review estimated the prevalence of pituitary tumors at nearly 17 percent of the general population.

So, what was the dose for each chemical that made “me” me? And how was I to find out without trying a range?

I started trying different dosages and was amazed by how my thinking, my sense of who I was and my behavior toward others changed with tiny shifts in dosages. I didn’t know who I was anymore, nor who I wanted to be, but I was healthier.

I finished my Ph.D. within months of my surgery to remove the tumor and co-founded my first technology start-up. Yet it took me years to craft a better “me” after my personality was essentially killed by the effects of the tumor and surgery.

This sort of exploration and self-tuning is not easy. Finding a doctor who could help me replace all the chemicals that the missing parts of my brain had made in age- and sex-appropriate combinations was nearly impossible. Doctors told me it would be too expensive, that I was fine and didn’t need to do more.

They were wrong. I gained nearly 60 pounds within a year of surgery on the dosages I was prescribed. I fell down two stairs during this time and broke both ankles, since my bones had been weakened by the absence of hormones. For the next six months I lived in a wheelchair at my start-up because I couldn’t get back up the stairs to my apartment in San Francisco or drive without use of my legs in the stick-shift car I owned. We didn’t have a shower there, so I had to take sponge baths and sleep on a futon in my office. I was not “fine.”

This all changed when I finally found a doctor to work with me to reconstruct my personality and my health by tuning combinations and doses of these powerful chemicals; this physician’s support and patience over 18 months helped bring “me” back to life. I lost about 80 pounds in a year without a program of diet or exercise. I stopped suffering from terrible jet lag during my frequent travels. I felt clever again, and my career began to take off. I started to date.

In my experience it can be difficult to find a doctor to help a patient do this. I believe it is only partly because of the shortage of endocrinologists, doctors who specialize in the hormonal systems. Some doctors seemed not to believe that every hormone mattered. How many other patients like me have failed to find their ideal balance of medications?

There is evidence that careful tuning of these hormones can lead to dramatic personal and professional outcomes. Doctors and patients should consider replacement of every known hormone that is missing. New neurochemicals are identified by researchers every few years and should be studied as possible additions to the mix.

And access to these medications should not be hindered. As it stands today, some of the hormones I need daily to stay alive and to thrive can be, and frequently have been, blocked at the whim or neglect of a doctor’s office, insurance company or pharmacy. And still, 18 years after my surgery and despite great advances in endocrinal science, I need to fight to get them.

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Disputes between organizations on whether prescriptions, test results or proper forms were transmitted or not. Communication breakdowns. A Kafka-esque nightmare of constantly needing another approval. It can take weeks to be notified of a rejection.

I spend an average of 10 hours a month nudging, charming, name-dropping, fulfilling requirements and at times getting angry to try to persuade a chain of people to let me get the neurochemicals that I need at whatever the price. I usually spend between $100 and $1,000 per month on these chemicals, depending on what health insurance I have had at the time. On occasion it has run $5,000 per month. Sometimes health insurance has covered all the cost except a standard co-pay, sometimes very little.

Patients need more control in this process. Any number of people in the chain can keep us from our drugs — the effect is multiplied for me by the dozen meds that I take. The more expensive ones always seem harder to get and involve more steps. Thus more things that can and do go wrong in the perfect chain of dozens of people who need to move my case along for me to get my meds.

A common response is utter disbelief. Most people go the pharmacy and get their prescriptions filled, and the worst indignity is a long line. Their personality won’t go wild. A part of my body has been removed, it will never come back, and I need to take a dozen meds every day or I could get sick or die. Among the drugs I need to take are human growth hormone, hydrocortisone and thyroid hormones. How can we resolve these challenges?

Solutions should focus on allowing patients with a proper diagnosis continuing access to the medications they need. The health care system should make it easier for patients who need vital hormones or medications to actually get them every time. And new technologies should be used to make it easier to get our prescriptions filled and to understand why they are held up. In the past, pharmacies and insurance representatives have denied me access to such information in a timely manner, such as email or even over the phone. Access to online systems would allow patients to track their prescription from the doctor’s office to the pharmacy, and to get information about insurance coverage.

Without the ability to fine-tune my hormones and neurochemicals I believe I would have been trapped as a near-imbecile, wheelchair-bound, in my mother’s basement for an abbreviated and miserable adult life.

But with this ability I have reached the top of my field. Still, the health care system hinders my access to the chemicals I need to live. I am far from alone in this situation. It’s time we changed the system.

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