

Mysterious Malady

Was it all in my mind?



Sadly, the summer was over. Camp in the Catskills had been fabulous — a perfect blend of fun and relaxation. Faigy Kornblitt* had enjoyed the time with friends, reveled in the stimulating atmosphere, and thrown herself wholeheartedly into the enriching camp schedule. At age 14, she was in the prime of her life. That, unfortunately, was about to change.

The Teenage Years

“When I came home from camp, I was exhausted,” Faigy recalls. “Some days I would just sleep and sleep. I remember my mother commenting how the summer camps worked the girls very hard these days.”

After Sukkos, though, Faigy couldn’t even get through the school day, and it became clear that she wasn’t only tired, but unwell. “I started experiencing headaches behind my eyes, and then

one day, I noticed that my left eyelid was swollen and droopy.” My mother took me to an eye doctor, who couldn’t find anything wrong. He referred me to a neurologist, who was concerned that I had a condition called Myasthenia Gravis, a neurological disease that affects the muscles.”

Tests for this came out negative, and she received no diagnosis. Her worried parents schlepped her from doctor to doctor, none of whom could find

anything wrong.

“My teenage years were very difficult, but I pushed through them,” Faigy says. “Every four weeks or so, I would feel a bit better, and then my symptoms would flare up again.” Two years after that summer camp, Faigy was diagnosed with migraine headaches. “My parents were relieved. They reassured themselves that nothing was seriously wrong, and I’d just have to get over it.”



Meanwhile, Faigy continued living with her symptoms. Physically, she was weak, but she excelled in school and was very creative. “When I was 18, I got a job teaching seventh grade. I would go to work, come home, sleep, go back to run the after-school programs, and come home again. I couldn’t understand how my friends had the energy to do other things besides working.”

Newly Married

At 18½ years old, Faigy was engaged; a year later, married. As a *kallah*, her mother couldn’t understand why Faigy sat in the dressing room while she chose her *sheva brachos* outfits, when it was usually the other way round, with the *kallah* picking out the suits and dresses that caught her eye.

“I was so nervous about the wedding,” Faigy recounts. “It sounds funny, but I was afraid that I wouldn’t have the energy to dance, and that fear kept me awake at night. I *davened* hard that I’d find the *koach*, and *baruch Hashem*, I danced the full two hours.”

After her wedding, Faigy continued to teach in the mornings, went home to make her husband lunch, slept a few hours, then returned for the after-school programs from four to six in the evening. Soon, she found herself expecting her first child.

“The pregnancy was hard. My head felt as heavy as a block of cement, and I was in a mental fog. I couldn’t open my eyes properly and had pains in my joints and feet. If a neighbor came to the door, I couldn’t stand there and *schmooze*; I needed to sit down.”

Nine months later, Faigy gave birth to a beautiful, healthy girl. She had felt better by the end of the pregnancy, although she did experience heart palpitations and had trouble falling

asleep. The postpartum period appeared normal; Faigy went back to work, cooked, baked, and took on extra *chessed* projects.

“I was always tired, though, and my husband kept telling me that something was wrong,” Faigy remembers. “Sometimes he’d get frustrated. He’d say that it wasn’t normal for me to sleep so much, that if I’d had a full eight hours, I should be functioning regularly. In general though, my mood was good, even though things were hard. I just thought that everyone with a young baby felt like I did.”

However, Faigy frequently got sick. Every two weeks or so, she had another infection, ranging from pneumonia to double ear infections. There were times when she was too weak to lift up the seltzer bottle at the Shabbos table.

Psychological?

A year and a half later, Faigy had her second baby.

“I couldn’t cope,” she says. “I was only

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teaching twice a week, but my house was a mess. I couldn't clean up and could barely stand on my feet. I kept going to the doctor, who would take the usual tests, but they always came back normal. I went off sugar and saw a nutritionist who prescribed vitamins."

Meanwhile, some of her family members became critical of her. "They started to say it was psychological, that I didn't know how to cope with the stress of running a home and raising children. My husband, thankfully, did believe there was something physically wrong with me, although the family pressure did challenge him."

During Faigy's third pregnancy, her husband had to *daven* at home instead of going to shul because Faigy just couldn't manage without him. "I was so dizzy that whole pregnancy. One day while we were out in the mall, I just sat down on the floor."

There were many complications with the pregnancy, including a blood clot and a high amniotic-fluid level, but the most frightening and dramatic event was when she lost her eyesight one Shabbos.

"Everything went foggy, and I couldn't see. It was terrifying. I went to the hospital, but the doctor said nothing was wrong with my eyes. The following day, I went to another eye doctor who said I had corneal abrasions possibly due to my contact lens solution. *Baruch Hashem*, after a few weeks, my sight returned to normal. A family member told me it was all in the head. I was so hurt!"

After Faigy had her third baby (each of her children were months apart), the general consensus was that she was exhausted due to three pregnancies and births so close together. By this time, though, even she was worried about her situation and was determined to do her *hishtadlus* to find out the cause of her symptoms.

"First I called 'Relief,' an organization that provides mental-health referrals. I decided that if I was suffering from something emotional, I wouldn't

remain in denial about it. I wasn't managing and needed help, and if I needed to take anti-depressants, I was willing to take them. A full evaluation was arranged for me. It showed that I was emotionally healthy!"

Faigy's physical symptoms persisted. Her headaches, in particular, became

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much worse. Medical testing ruled out conditions such as chronic viral infections, thyroid irregularities, and Multiple Sclerosis. She slept overnight at a sleep clinic to test for sleep apnea, the results of which came back negative.

"Once, I was on a bus and felt like I wasn't getting enough oxygen and couldn't breathe. Everyone said it was panic attacks, and even some of my physicians thought it was emotional."

Faigy's new primary-care physician noticed many results slightly out of range in her blood tests. He believed that something was wrong, but didn't know what.

Deterioration

By now, 10 years after that summer camp, Faigy was going downhill fast. Her headaches became excruciating, the weakness debilitating, and she began to experience incapacitating nausea.

"I would sit on the floor and cry from pain," Faigy recalls. "It felt like a bird was eating me up inside my head."

A cycle of hospitalizations began, where Faigy would be tested and receive supportive treatment for her symptoms, but no conclusions were reached. She would then be discharged until the next time, when she endured it all over again.

There were times when Faigy had difficulty in breathing, seizures, stroke-like symptoms, and such extreme muscle spasms that she couldn't move. Her life was filled with never-ending pain and cocktails of injections. In addition, her recurring infections persisted; a particularly nasty one



affected her wisdom teeth.

Eventually she collapsed and was unable to function. After discharge from the hospital, she moved in with her mother. Her husband and children stayed with her in-laws, as they had been doing throughout all the hospitalizations.

"I think the hardest thing for me emotionally was that everyone was critical of me," Faigy says. "One person told me I was lazy because at night I just lay on the couch, while *she* got up and

cleaned her house. No one knew the real me. At least some of my own family and friends remembered how I used to be as a girl. My biggest blessing was my husband! He never pressured me to function, only encouraged me to go to more doctors and find out what was wrong.”

The Diagnosis

About a year after her collapse, Faigy started getting pain in her knee and couldn't walk. The orthopedist she consulted said her knee cap had moved out of place, and he drained the fluid that had built up underneath it.



“My knee was very swollen and painful, and I was convinced it was infected,” Faigy recalls. “The doctor just dismissed my concern, saying I was young and healthy, so why would I have an infection in my knee? He sent me home with a walker!”

The orthopedist was wrong. The next day he called Faigy, hysterically saying her white blood count was very high and the amount of fluid in her knee was excessive. “He sent me urgently to the hospital for surgery to open the knee, drain the fluid, and clean out the infection.”

It was supposed to be a routine operation, but it took much longer than expected. The subsequent hospital stay was also extended because the doctors were not able to get the infection under control and tests for standard infections came back negative.

At one point, the decision was made to consult with an infectious-disease specialist. One of these doctors came to examine Faigy and review her case history. On clinical evidence alone, he was able to reach a diagnosis... Lyme disease, a bacterial infection caused by a tick bite!

Another doctor from the infectious-disease department was an expert on Lyme disease, and he tested Faigy for “co-infections,” meaning for other strains of bacteria in addition to the standard bacteria which causes Lyme disease. She tested positive for multiple co-infections.

After 11 years of untold suffering,

Faigy had been given a diagnosis at last! It had all begun at age 14 back at that summer camp where she'd unknowingly received an insect bite and had been suffering from a bacterial infection ever since.

The Reactions

“I was totally confused!” Faigy recalls. “I'd been given so many incorrect diagnoses in the past, so I was very cautious. I was given the news after the surgery on a Friday. I'd never heard of the disease and didn't understand anything about it.”

Her husband was overjoyed, though, and family members even called to say *mazel tov*.

“My aunt phoned and said, ‘Congratulations! So you really were sick after all!’ I was very overwhelmed and angry that Shabbos. After all, I was just as sick as I had been before; why was everyone finally taking me seriously just because a doctor had made it official?”

“I felt very bitter when I first found out,” Faigy admits. “I began to recall all of the painful comments people had made to me, such as, ‘You must have had a lot of *ayin hara* put on you’ or ‘Did you check your *mezuzos* recently?’ or ‘You must have hurt someone very badly.’ Somehow I never felt I was being punished by Hashem for something I had done. I felt Hashem loved me and was protecting me.

“At first I allowed myself to indulge in my angry feelings, but not for long. Eventually I said ‘Enough! No more pity parties... I've lost too much already.’ I didn't want to live with resentment. I told myself that, *im yirtzeh Hashem*, I had a long life ahead of me, and if I held onto any bitterness, the only one who would suffer would be me. It took me time to look out of my own box and see things from the outside. Had I been in their shoes, I would probably have responded the same way.”

Faigy's husband is not resentful. He says it was all *min haShamayim*. “He's very strong,” Faigy marvels. “He's helped

Lyme Disease

Lyme disease is a multi-systemic illness caused by the bacteria *Borrelia burgdorferi* (Bb), and is transmitted when bitten by an infected tick. If not diagnosed early, if left untreated or not treated adequately, it may cause debilitating arthritic, cardiac, neurological, digestive, or psychiatric conditions. It can cause long-term disability or even be fatal. It is called the “Great Imitator” for it mimics other diseases such as Multiple Sclerosis, Parkinson's disease, ALS, Fibromyalgia, Rheumatoid Arthritis, Chronic Fatigue Syndrome, and an array of mental disorders.

For more information regarding accurate testing for Lyme disease, contact Binah magazine.

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me work through my anger and I have forgiven everyone now!”

Living With Lyme Disease

Since her diagnosis, there have understandably been many ups and downs. Faigy has not suddenly been cured because there is a name to her condition.

“But I have a different life now, and I know what I’m dealing with,” Faigy says. “And I could never have coped without the physical, emotional, and financial support from my family, friends, and community.

“My mother-in-law is very devoted. She even took in my children when they were sick with chicken pox and cared for me like my private nurse when I was in a very serious condition. After the diagnosis, my grandmother would come to my house every morning at seven to get the children off to school. At one point, we all moved in with my parents and my mother looked after the entire family until I regained strength. She literally took care of my every need.”

It was not easy to find a Lyme-disease-literate doctor because there is so much controversy regarding chronic Lyme disease. Now, though, with her new doctor’s multi-protocol treatment method that combines conventional

and alternative medicine, Faigy sees the light at the end of the tunnel. To get rid of the bacterial infection, she receives strong antibiotics on a long-term basis, which isn’t easy.

There was a particularly life-threatening event when her PIC line, used to administer antibiotics intravenously, became infected, and she was so sick that the doctors refused to resume treatment until almost a year after she recovered from the episode.

But overall, on the medication she has a new lease on life. “Yes, I have chronic Lyme disease, but I’m much better than I was... you can’t compare,” Faigy says gratefully. “My family sees a major improvement. Every *simchah* I attend, every Yom Tov that I’m together with my husband and children, is cause for rejoicing.

“Of course, my life revolves around my illness, and sometimes I wonder how it would have been if I’d been healthy. I’m functioning on a much higher level though. Every month I do more than I did in the last. I don’t take a single breath for granted, and I always thank Hashem for all the *chessed* and *nissim* he’s done for me. When things are hard I remind myself where I’m coming from and how much worse I used to feel.”

Upon Reflection

“I think the hardest part for me has been the loss of self. I used to be a sweet, bubbly, creative person. Because my central nervous system was affected by the bacteria, my emotions were affected. I couldn’t cry or *daven* or feel the wind on my face. I couldn’t enjoy the smell of anything, or participate in the pleasures of life. I was in too much pain to enjoy the day. I’m thankful to be getting myself back slowly.”

There are times when Faigy naturally reflects on what could have been, and acceptance has played a major role here.

“It is sometimes hard to accept my life the way it is. For example I could have been a much better wife and mother had I not been sick. If I’ve had a bad day and been unproductive, it’s especially difficult. But I’ve learned to accept that I have to serve Hashem on His terms, not mine. Every single day will be mine for eternity and will not be wasted as long as I’m serving Hashem *besimchah* with the circumstances He gave me. Knowing this empowers and gives me strength.”

Faigy’s goal is to educate the public on the signs and symptoms of Lyme disease so that no one should have to suffer like she did. “If Lyme disease is diagnosed and treated early, it can be cured more easily and doesn’t need to wreak havoc on the body, like it did with mine. For me personally, it’s obvious that my *neshamah* was meant to go through this. These were the amount of years I needed to suffer. Hashem has His master plan, and He never makes mistakes!” **B**

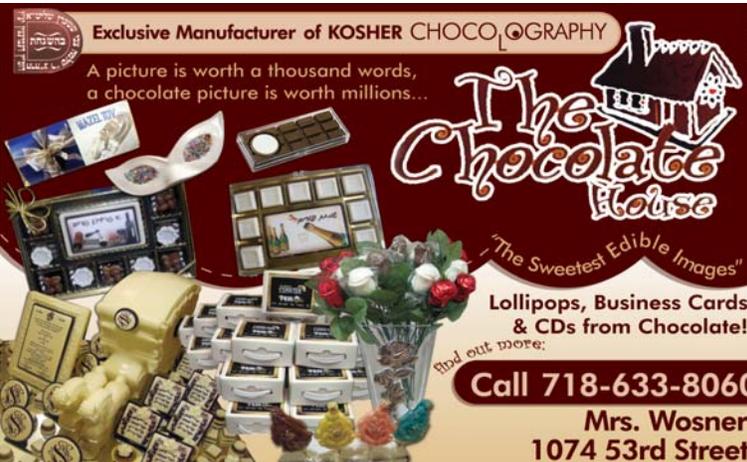


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