

That's It!

By Bonnie Henderson Schell

Strange things were happening to me, and I was scared. I knew that I had developed tardive dyskinesia and torticollis. The skin around my lips was chapped because my tongue hung out of my mouth, making a circle, licking my lips. I drooled all night on my pillow and down the front of my clothes. It was difficult not to walk to the left because lately my neck and body were painfully twisted in that direction so that the necklines of my sweaters and tunics fell off my left shoulder. I had stopped going to lunch with anyone and turned down phone calls using Facetime. I avoided the mirror over the sink.

I had known a woman named Barbara, whom I used to visit weekly in an Institute for Mental Disease. Like me, she had been an English major, but unlike me she had spent many years institutionalized on high doses of Haldol and Mellaril. Barbara's whole tongue hung out on one side making her speech difficult to understand. She could hardly swallow. I never thought that what had happened to her would happen to me. Terrified, I finally called my psychiatrist to describe what was happening.

"The doctor says that you should see your regular doctor," his receptionist informed me on the returned call.

"But my uncontrollable tongue," I said of my ugly, distorted face, "is from the drugs prescribed by psychiatrists."

I placed the call to my primary care physician.

"I'm sorry, but I'm not comfortable treating someone on so many psych drugs," she told me. "I do believe you're best off seeing a neurologist."

When I looked up neurologists, they all seemed to specialize in stroke, athletic injuries, and migraines. I found one, Dr. Anishira Bhati, who had done her residency at Duke University Medical School and completed fellowships in epilepsy, sleep disturbance, and neurophysiology. I went online and was able to make an appointment for the following week.

Dr. Bhati's office was in a building so new that there weren't yet any names lettered on the door or inside next to the elevator. Her office had ergonomic spaceship chairs arranged around her wide stand-up desk that held two red laptops. She looked young, her black hair gathered into a clasp at the back of her neck. At 75, I had a short grey bob.

"You do not need to tell me why you are here, Mrs. Schell," she informed me. "I can see your problem. Stick out your tongue, please."

It writhed in my mouth and the tip curled up.

"I could tell you were a psychiatric patient from your unnecessarily long request for an appointment." I tried to balance on a black swivel stool and had to push my feet hard against the floor so I wouldn't fall off.

"Now," she said, positioning her fingers over her bloodred laptop, as if she were fixing to play a piano concerto, "please name all the psychiatric medications you have ever been on."

"All of them?" I said, thinking I could report them in order because I remembered each one's side effects. "Thorazine was the first," I began. "In 1962 when I was 17, a freshman in college."

"I see," she said, pausing.

My first psychiatrist had a bust of Freud and an antique jade phallus on his desk. He had written down my diagnosis as Incipient Schizophrenia and prescribed Thorazine, little orange pills that were smaller than M & Ms.

“Next, I was on Stelazine,” I remembered. “But I weaned myself off of it because it made my focus blurry and too drowsy to read my assignments.” It had also stopped my periods and caused milk to leak out of my nipples.

“Stelazine poisoning perhaps?” Dr. Bhati queried. “What came next?”

“I didn’t take any drugs until after my first daughter was born in Arizona.” I wiped the spittle from my chin as Dr. Bhati tapped out my account on the keyboard. “During that time, without drugs, I finished my master’s thesis on Women’s Complaint Lyrics from Chaucer to Sexton, *although I have never been able to make my own complaints so that anything ever changes*, I thought to myself.

“Continue, please,” Dr. Bhati said. “The story is not necessary.”

“After we moved to Southern California in 1971, I was sent to a neurologist because the right side of my body felt as if it were on fire. Even my skin felt blistered.”

“And?” she prompted.

“The neurologist sent me to a psychiatrist.”

“And what did he give you?” she asked, sounding impatient.

“Dr. Manebaum gave me Prolixin injections and Artane,” I said, remembering aloud how he had given me the monthly shot in my buttocks, even though he could have put it in my upper arm.

“You must not have been trusted to take your medications as prescribed,” Dr Bhati commented.

“But I wasn’t on anything before I got Prolixin injections. And I hated them.” I could remember how my head would fall forward and jerk back again repeatedly, when I was attending a lecture or a city council meeting. I would forget where I was.

“Perhaps you were sleep deprived,” Dr. Bhati said.

“No. A neurologist decided, after an EEG, that I had narcolepsy, so Dr. Manebaum put me on Adderall and Ritalin. The Ritalin made my breathing and heartbeat so fast that I thought I might die.”

“So, then what?”

“I stopped taking it,” I replied. “After that, we moved to Santa Cruz and I started seeing Dr. Veerman.”

“You were lucky,” she said, continuing to type, “to have had constant psychiatric care.”

“Dr. Veerman changed the Prolixin shots to pills,” I continued, “And added lithium.”

“Both?” she asked to clarify.

“Yes,” I nodded. “Both. I had to talk fast because his monthly appointments were only twenty minutes. There was so much I had to say. I was taking graduate classes, I had children. So maybe I seemed manic to him.”

“Mm hm,” she nodded.

“Well, at first the Lithium made me feel calm, but then it kept me from sleeping at night and it elevated my blood pressure. The GP called it chronic hypertension, and that made Dr. Veerman laugh because he already thought I was hyper too,” I recalled as Dr. Bhati slightly smiled. “Later when I developed tremors in my hands and knees, he prescribed Cogentin.” And I gained 30 pounds. My face looked like a big round buttermilk biscuit. I hid my body with long boyfriend sweaters. “You are not the girl I married,” my husband had told me then.

“What’s next,” she prodded me, wiggling her fingers.

“Let’s see,” I thought of the 2,000 acres of redwood trees on the UC Santa Cruz campus. “I was taking linguistics, the History of Consciousness, and Literature of the Harlem

Renaissance.” I had mastered when to say *hegemony* and *patriarchy* and *speaking truth to power*. But then I began to stutter so that I couldn’t ask or answer questions in class.

“The medications only, Mrs. Schell,” she reminded me.

“My liver enzymes,” I said after a long moment, “were elevated and getting worse, as was my high blood pressure,” so I was sent to a hematologist and a cardiologist who faulted the psych drugs. “Dr. Veerman added Amantadine, because my tremors were growing worse, and Ativan for anxiety.” Dr. Veerman seemed a bit anxious himself about my symptoms, but he did not speculate about the cause or go over the lab results with me.

I lost the ability to distinguish between what I said to someone and what I was thinking. At my husband’s company party, the rumor spread that I was drunk and not friendly. I began to avoid standing because I was losing control of the muscles in my legs. I withdrew from school.

“Next, please.”

“Next,” I told her, “Dr. Veerman doubled my dose of Lithium.”

“And?”

“It made me acutely apprehensive,” I said, “I asked him to call my cardiologist, Dr. Singh, and I asked Dr. Singh to call Dr. Veerman. Why won’t ya’ll talk to each other?” I asked Dr. Bhati.

“I frequently am called in to consult,” she said., “but it is not necessary to meet the patient.”

“Finally, the cardiologist looked closely at my medication list and told me that the Prolixin could cause rapid heartbeat, hypertension, and shortness of breath.”

“Mrs. Schell, are you certain about what you are saying?”

“Yes, I am sure,” I looked at her. “Dr. Bhati, the diuretics and the low salt intake for my high blood pressure also raised the level of lithium in my system.”

“And?” she asked.

“The cardiologist diagnosed me with Lithium Poisoning. I should not have been taking the calcium channel blockers, ACE inhibitors, and ibuprofen with Lithium either. No one told me that. I also developed twitches and uncontrollable eye movements so that reading became impossible.”

“That can happen,” Dr. Bhati responded. “Using any drug your doctor has prescribed means that he or she has judged that the benefit to you is greater than the risk.”

I wondered why I never got to be the judge of that.

“What next, Mrs. Schell?” she asked, sharply.

“Dr. Veerman, who worked a county day job and saw patients in the evening, moved, and I started seeing Dr. Kirby who didn’t sell vacuums but many new pills. Dr. Kirby took me off Prolixin and Lithium and put me on Depakote and Ativan. He increased the dosage until I didn’t hear tunes in my head, which I had not complained about,” I noted. “I tried Tegretol, but it caused the bones in my legs to ache. My head felt like it had a tight band around it.”

“Next,” Dr. Bhati prompted.

“I started on Zoloft, my first SSRI.”

“After the earthquake in 1989,” I said, after a long pause, “I met a group of anti-psychiatry activists in Santa Cruz.”

“Is that so,” she remarked still typing.

“I needed the support and friendship,” I murmured to myself.

“I once went to a conference where 2,000 mental health patients were in charge of the scheduling, talent shows, and speakers describing their innovative programs,” I told Dr. Bhati, who paused in her typing. “In the hall of the Marriott Hotel where it was held, David Oaks handed out slips of paper, asking us to write down our diagnosis. Then he took a match and burned them up. I remembered throwing away my Depakote in the parking lot. You should have seen the look of alarm on the face of Dr. Veerman.”

“Mrs. Schell,” Dr. Veerman had insisted, “it is only our prescriptions that allow you to feel as if you’re doing well,” warning me of the rebound effect that would surely happen. “If you stay off your medications I would likely need to hospitalize you,” he had threatened.

“I hope you had the good sense to go back on your meds.” Dr. Bahti said.

I nodded. “Yes, because after a week, I was more uncoordinated and once more had high blood pressure.” .

“Next, please,” urged Dr. Bhati.

“After that conference I drafted a proposal to the county for a consumer organization and a drop-in center, and I taught creative writing in the County Health buildings.” Dr. Bhati cut me off – “I don’t need to know all these circumstances; just tell me the names of the medications,”

“...before I became Executive Director of the Mental Health Client Action Network and we moved into the basement of a church so we could be open six days a week,” I let the unspoken thought hang in the air.

“Is there more?” she glanced up, with a frown.

“Well, yes,” I replied, moving back towards the medications list. “When I was switched to Depakote, it gave me diarrhea every morning so I needed to get up two hours before work.” I

remembered Dr. Kirby had primly responded, “Perhaps ‘gastric motility’ is a better term than ‘diarrhea.’”

“Then there was Klonopin because Ativan only worked for four to five hours. Calm then jittery, you know. And I took Inderal before poetry readings and county budget meetings.”

“How did you respond to the Klonopin?” Dr. Bhati asked, her fingers hovering.

“Well, the Klonopin was great at first, but I started falling and bruised some ribs on a file cabinet. Dr. Kirby who was on the faculty at Stanford referred me to a psychopharmacologist to taper off Klonopin.”

“And how did that turn out?” she asked as her fingers clicked on the keys.

“Well,” I smiled and shrugged, “six months later I was presented with a triple column list of drugs I should never take as long as I lived. He wrote it by hand and memory.”

“Really,” she said, her typing slowing a bit, and then she asked, “What came next?”

“A new drug called Ambien.”

“That one was in a different class than benzos,” she said. “A real breakthrough.”

“Yes, well, I took Ambien for four years,” I clarified. “But then Dr. Kirby took it himself on a trip and forgot what he was supposed to teach or where his classroom was. He pulled all his patients off of it.

“Next?”

“Prozac came next,” I told her. Dr. Kirby and my husband thought I was suicidal because I was preoccupied, not with my death, but with the self-inflicted death of two friends and a faculty member in Women’s Studies. Prozac was the first SSRI, a selective serotonin reuptake inhibitor, even though psychiatrists didn’t have any way to know what my serotonin level was. I was switched from one SSRI like Zoloft to Paxil and Lexapro as soon as they were introduced to the market. When a new drug hit the market, it was prescribed for me. And if it

made me feel better? Well, that would be proof to the doctor that I had the condition for which it was designed.

“What else?” Dr. Bhati asked.

“Effexor,” I told her and recalled that it was not only an SSRI but also a reuptake inhibitor of norepinephrine. “During the first week on it I really was suicidal.” I became preoccupied with how Japanese warriors knifed out their entrails.

“Just the medications, Mrs. Schell,”

“Dr. Kirby wanted to increase the dose of Effexor, but instead my mood stabilizer was changed to Trileptal for three months.” I stopped to wipe my chin of saliva. “Also, doctor, I took Cardidopa, Levodopa, and Requip for Parkinson’s.” Requip was for Restless Leg Syndrome, I remembered. It felt like spiders crawling on the shin bones under my skin, and was agonizing. Dr. Bhati’s typing continued uninterrupted.

“Please continue with only the psychiatric medications, Mrs. Schell.” It was the psychiatrist who had prescribed those other medications for Parkinson symptoms, but I said nothing more about that.

“Well I took Zyprexa for six years.” The first prescription of Zyprexa had come with a blue rain to play with made out of squishy rubber. Squeezing the miniature brain would distort the brand name. I started Neurontin, Seroquel for sleep, and a new drug that combined Prozac and Zyprexa. “I took Symbyax,” I told Dr. Bahti. Eli Lilly and Company made the combination because their two most popular drugs were losing their patent.

“Next, please.”

“Do you have some Kleenex?” I asked, because all the handkerchiefs I had brought were sopping wet from the drool I had been wiping off my mouth. She handed me the whole box.

“Doctor, I don’t know why but my new doctor after I moved to North Carolina for a new job reduced Symbyax so I could go on Abilify.” I had seen ads in my decorating and recipe magazine for Abilify, which looks like Ability. The person in the ad was not curled up in a ball in a dark room or sitting on a street curb, head in hands, but standing in a stylish suit and heels. Another advertisement said that Abilify would help me “move forward.” It was designed “for the road ahead.” I was eager to try it.

“Is that it?” she asked. Maybe we were both getting tired. I was.

“No. I forgot that I had Lamictal as a mood stabilizer and Seroquel for sleep.” I could go to sleep but not stay asleep. In my dreams I was always struggling with someone trying to kill me.

“The ER doctors thought that I had a stroke when I passed out in a dentist chair and my eyes rolled up.” I spent a week in the hospital. A neurologist said I had memory loss, disorganized thoughts, was paranoid and showed signs of early dementia. She thought that I should find a psychiatrist who would taper me off all psych meds, but no one I asked had heard of such a person.

I was the Director of Mental Health Consumer Affairs. For eight years, I went through the motions of doing everything required. In meetings my head fell forward, then jerked back. At the same time I was too restless to sit through a whole meeting, or by my husband’s hospice bed, or through a board game with my grandson. The Greek word is *Akathesia*. Meditation, prayer, or yoga were impossible. It had been so many years since I had been able to feel pleasure or joy or happiness, even briefly. The Greek word is *Anhedonia*. And, while I could be outraged about immigrant toddlers in cages or bumble bees disappearing, I could not cry or even feel sad

anymore. Everyone was weeping at my husband's memorial service except me. I was stoic, stalwart, and silent. I looked indifferent my neighbor said.

By the time I retired and went on a three-month waiting list at The Promise Institute for Psychotherapy and Education, I no longer cared what psychiatric medicine I was on and neither did the first doctor who told me what a good ballroom dancer she was and then asked what prescriptions I wanted. I switched doctors, tried a Cognitive Behavior Therapist. He sent me back to a psychiatrist. She left the profession and was replaced by a Psychiatric Mental Health Nurse Practitioner who gave me information about everything she prescribed and some choices.

"No- traditional provider?" Dr. Bhati scowled. "I hope she didn't interfere with your regimen."

"No, Right now, I am still on the anti-psychotic Abilify, the tranquillizer Lorazepam, the muscle relaxant Tizanidine, the mood stabilizer Lamictal, and Seroquel, GABA and Melatonin for sleep. I think that's it," I trailed off.

"Sounds like you have at last found the perfect cocktail."

But I haven't been invited to any party, I thought.

Dr. Bhati got up and walked in front of her laptops. She put her hands on her knees and leaned over in my face. "Tell me again. What was your first drug." She demanded.

"Thorazine," I reminded her.

"That's it!" she shouted. "That's it! You are one lucky woman. There is a brand-new drug that I worked on at Teva Pharmaceuticals, called Bravo." She said I couldn't get Bravo at a local pharmacy, but the company handling my treatment would be in touch. In the meantime, she handed me two weeks of slick purple folders with push out 6 mg. capsules. "You'll be titrated up

later. And you will have a call with a nurse every week for 105 weeks to track progress and any minimal side effects.”

“A-okay,” I said, compliantly.

“I am obligated to tell you that the cost of treatment for your condition will run between \$7,600 to \$11,000 a month, but there are foundations that will help out.” She moved toward the door, showing me out. “You will be in good hands, Bonnie,” she said to me, placing her hand lightly on my shoulder.

“Is that it?” I asked, a bit uncertain.

“Yes, that’s it. I won’t need to see you again.”