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Electric Husband

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The neurosurgeon holds a crown of metal above my husband's head. It is slick and gleaming like a futuristic headpiece or medieval torture instrument. *It cost us \$200,000* he says, with pride, smiling. *The hospital owns only two of them.* I watch as he lowers the frame on to my husband's shaved head. Hal looks only at me. A visiting doctor is in the corner, watching, having come all the way from Iran to observe my husband's surgery. We are in the basement of the Jefferson Hospital of Neuroscience, in downtown Philadelphia. In less than an hour Hal will be in the operating room, having a 14 millimeter hole drilled into his skull, and electrodes the size of Tic-Tacs placed into each side of his brain. The electrodes will eventually be hooked up to a neurotransmitter, which will send electrical impulses to the brain and help decrease the symptoms of his advanced Parkinson's disease.

Hal has waited months for this day, with the excitement of beginning a new life in mind, free of the involuntary, spasmodic movements of dyskinesia, and relief from the immobility of his legs and

the clubbing up of his feet. The crown, known as a “stereotactic frame,” is a navigational tool, used by the surgeon to help locate the correct place in the brain to plant the electrodes. “Deep Brain Stimulation,” or “DBS” as it is called, is a long procedure, taking up to three hours for each side of the brain. Approved by the FDA in 2002, DBS is the latest surgery for Parkinson’s patients, invented in France by two professors at the University of Grenoble. We are told that Hal will be able to decrease his medications by 80 percent, the dyskinesia will be eradicated, and he will no longer freeze when walking.

A month before the scheduled surgery date, I looked up DBS on the internet, opening the Wikipedia entry, the first hit. There was a photograph of a man lying on the operating table with the frame around his head and a surgical instrument above him in the glare of bright operating room lights. I clicked out, not able to look at the photograph too closely: I didn’t want to see this man’s brain or to see the details of what will happen to Hal. Perhaps Hal’s *Parkinson’s for Dummies* would be more palatable, less real life. I skimmed through his dog-eared copy. It warned against the possible consequences of DBS: brain hemorrhaging and bleeding, coma, severe depression, and worsened symptoms.

Hal’s neurosurgeon, Dr. Paval, extended a special invitation for me to come early to the hospital on the day of the procedure, to witness the installation of the stereotactic frame. Hal had discouraged me, thinking I should stay home and get sleep, but

I knew I had to be there. It would be a chance to give him a kiss before going into surgery, to fare him well. And it was the only part of the day, of all that would happen to him, where I could be there too, cheering him on.

On the morning of the surgery, I am led through the maze-like corridors of the hospital's basement, to a closed off section with a comfortable lounge, and then to a room where Hal sits on an elevated throne of a hospital chair. An entourage surrounds him. Dr. Paval greets me, excited to have me there to witness this moment. I walk up to Hal, who is wearing a pale blue gown with yellow hospital socks on his feet. He extends his arm out to me and I take his hand and hold it. I watch as two nurses and the doctor lower the frame down to Hal's head. It is lightweight (we are told) but Hal will say later it must have weighed thirty-five pounds. Hal's hand begins to tighten as it is screwed on. We have been warned that this can be even worse than the operation. Some patients don't make it past the installation of the frame, thinking if the measurement tool for surgery is this bad, what will the surgery be like?

Once the frame is screwed into his head, I reach down to his face and he gives me a kiss. I tell him that I love him and he grins painfully back. He is wearing the frame like a king, a huge hat of metal. They raise him up from his seat and move his unmedicated, stiff body to a wheelchair. It takes two male nurses to lift him. Then they wheel him down the corridor, away from the lounge and its smell of burnt coffee, and away from me. A parade of atten-

dants follows: nurses, Dr. Paval, the visiting doctor from Iran, and two residents. I observe the back of Hal's bare, brave, crowned head, as they take him through the double doors to the operating room.

I go to the lobby downstairs and find an empty corner to sit in next to a wall of glass. Hospital employees smoke in the designated smoking area outside. This is ironic to me, seeing them dressed in their green garb, chain-smoking away. The lobby is drafty and I can feel the cold air from outdoors coming in from the huge panes of windows. I pull out the *New York Times*, today's, and the days I'm behind on for that week. I try to start reading but I keep thinking of Hal in the operating room with all of the people surrounding him. They will be listening to music, I am told. They listen to CDs throughout DBS surgery (Dr. Paval's preference, we are told, is country music). They had even invited Hal to bring his own CDs, but he hadn't. It was a funny request to both of us, as if he were choosing music for an aerobics class or a party. What kind of music does one choose for brain surgery?

At 9 a.m., just when surgery is scheduled to start, my father arrives with cups of coffee nestled in a cardboard tray. He hands me a bag. *Sweet rolls*, he says, *nothing beats a sweet roll at a time like this. The sugar helps.* I pull the big whopper of a sweet roll out of the bag. I cannot remember the last time I had a sweet roll. There are swirls of cinnamon and it is covered in white icing. I take a bite, and it is delicious; then I take a swig of coffee to chase the bite down.

And we sit there, reading the *New York Times* together, eating our sweet rolls, drinking our coffee, waiting for the phone calls from the operating room, from a male nurse named Karl, who calls every two hours to give us updates.

First call from Nurse Karl: *Is this Mrs. S? He asks. This is Karl. I'm a nurse working with Dr. Paval's team, calling from the operating room. I'll be calling you every two hours to give you an update on your husband. We are just about to start. We're going to begin with the left side of the brain, and then, if all goes well, we'll continue to the right.*

If all goes well, I think to myself, already beginning to worry. I know from the pre-op discussions that they will start by giving Hal local anesthesia, carving through his skull so that they can enter and begin the journey to place the electrodes. Once they have found the right location for the first electrode, in the left side, they will use that information to place the second electrode in the right side. If the first electrode takes longer than anticipated, or if Hal gets tired and unable to cooperate, they will have to end at the left and continue with the right at another time. They will be in conversation with Hal, to keep him awake and to track his responses. They will listen to the sounds of his brain. Dr. Paval had explained that the Parkinson's brain makes a different sound than a healthy brain. What is it like to listen to a brain? I imagine it is like being underwater—the muted beats, echoes, and vast silences.

I try reading the paper but it is hard to pay attention. I flip through the pages, finding it easier to

focus on advertisements than news. An Easter sale at Tiffany's, caravan tours to the Costa del Sol, Sherry-Lehmann's spring wine selections.

I don't want to think about how my husband is having his skull cut through at this very moment and how dangerous this could possibly be. What if he turns out different? Becomes brain damaged? Loses his sense of humor? Will he be a different Hal? I have to think about how much better his life will be, how he will not waste away from dyskinesia and how he will be able to decrease his meds and have more stamina. This is for Hal to have a new life, I keep telling myself. But what really gives me courage, keeps me from losing it, is Hal. I know from our support groups that many people who have Parkinson's don't have the courage to go through with this operation. He is being brave and I must be brave too.

Second call from Nurse Karl: *We have found the correct place for the electrode on the left side and now we are starting on the right side.*

How's Hal doing? I ask.

He's great. He's entertaining us, making us laugh.

I smile. Only Hal, Hal the performance poet, would be entertaining the operating room team while undergoing brain surgery.

Six months before, on a quarterly visit to Hal's neurologist in the fall, we were told that it was time for Hal to consider DBS. He was getting thin from the dyskinesia—so thin that the shoemaker was no longer able to add new holes to his belts. His pants started hanging on his hips. I'd joke that

he looked like a white rapper. The neurologist told us that he would only get thinner, that he was wasting away.

In the beginning he wouldn't tell anyone about his Parkinson's. He was in the closet about it as many people are with Parkinson's. Of all the people I've met who have PD, about half are in the closet. Not even their close family members know. We are a culture that has become open about coming out of the closet sexually, about personal lives and addictions, but we are still not open about disease. There is shame and fear of judgment. Hal would perform his poetry all over New York City, most people not noticing anything different, but in the years before the DBS, the dyskinesia would give him away: he'd have to hold his hands in his pockets to keep them still. Hal learned, over time, to tell everyone he had Parkinson's before he started reading his poetry. He wrote poems about his illness too, holding a crowd like he never had before. Here was a man with a disease reading a poem about the disease. The audience could see how it had taken him over, how he struggled to express the words that once came so easily.

Third call from Nurse Karl: *We have finished with the right side and your husband was just amazing. He's heading to recovery. Go have some lunch and call Dr. Paval in a couple of hours.*

I thank him and get off the phone. I feel so appreciative of Nurse Karl, my lifeline to the OR, whom I have never met and will never meet. His confident voice helped get me through the six

hours of waiting. The structure of his appointed calls gave me something to hold on to, broke up the waiting period into manageable segments.

Where are you? It is 6:30 a.m. the next day and Hal is on the phone, calling from the hospital. *Come get me out!* I am ecstatic to hear his voice, the Hal voice with the Long Island Jewish accent. He sounds the same! I jump out of bed and run to catch the train downtown.

When I arrive at the hospital, he is in recovery, barely sitting up on the hospital bed. He grins at me from across the room. I am shocked when I see him. He looks like he has been through hell: his head is covered in dry blood and there are big Frankenstein-like stitches across the top of his skull with thin butterfly bandages set across them. He is holding a cup of ice and is hooked up to a beeping machine. He is groggy, drugged-acting, and tries to climb out of the bed.

The nurse explains how to take care of the incisions, giving us gauze and antibacterial cleanser to take home. I help Hal get dressed. I take off the yellow socks and start to throw them away. *No, I want them!* he says. *They will be a souvenir.* I throw them into his suitcase.

My aunt and father wait outside of the hospital to drive us home. In the sunlight Hal looks like he just came out of battle. The sun shines on his bloody head. People walking by stare at him. Did he just get back from Iraq? My aunt acts nervous, no doubt in shock seeing Hal. We carefully load him into the car. I tell her to watch the bumps as we drive up the winding road along the Schuylkill

River, past the boat houses and the Lipchitz sculpture, back up the hill, to our house.

When we arrive home, we are in for a surprise. The dog walker has taken our standard poodle, Bijou, to be washed at Doggie Wash 'n Go. Bijou tries to jump on Hal to greet him but I put her in the crate. Hal is glad to see her but knows that he can't lean over to pet her—for at least a month. We go into the bathroom, where Hal sits on the closed toilet and I begin to clean him up. It takes a full hour to get the blood off of his head. Some of it is dried, hard to remove. I am careful so that I don't accidentally rub off one of the butterfly bandages. I'm glad to have a task, some way to help care for him.

As I clean off the blood, Hal tells me that the worst part of the operation was going off the meds. He says he was in so much pain the night before surgery that he couldn't sleep. Hal had been on those meds for sixteen years, ever since his diagnosis at the age of forty-four. He went cold turkey off of them so that his body wouldn't have dyskinesia for the surgery, so that he would become unmovable. He experienced aches and pains unlike he ever had before. *It made the brain surgery seem like nothing*, he tells me. *I almost walked out of the hospital in the middle of the night. The only thing holding me back was that I wasn't able to walk.* I tell him I wish I could have been there, massaging his cramps and unfolding the bent up feet—as I've done for years in the middle of the night.

Three months later we meet at the neurologist's office with representatives from the neurotransmit-

ter company so they could turn the voltage on, starting at the lowest amount and then working their way up over a period of a few months. We crammed into a small examination room: Hal and I, the neurologist, a nurse, two residents, and the two reps from the transmitter company. After the rep turned it on, using a remote control that he held up to the box in Hal's chest, they asked Hal to get up and walk down the hallway. Hal then walked down the hallway with all of us at the end, watching. There were no signs of PD at all—no shuffling or freezing. We stare in amazement. Hal grins from the end of the hallway, yells out: *I can walk better!* He practically runs back to us. *Don't get too excited yet,* his neurologist warns us. *Sometimes the effects are amazing that first time, when the voltage is first turned on. We have to see over time. It's a long process.* But still, Hal and I have hope. This is our new beginning.

Before we leave they hand me a small box with the remote control in it, to adjust the voltage levels if need be. I joke now that I can control my husband with this remote control—pointing it at him and telling him to wash dishes or give me a kiss.

Having the DBS surgery has given Hal a new life to look forward to. He writes poetry all day now, not just in the mornings, as he did before, when he had more energy. He loves the idea of having the electricity in his brain. He brags about it, opens his shirt and shows off the transmitter box. He claims to feel its buzz. He tells people, *I am the body electric, just like in the Walt Whitman poem. I am the living body electric.*

For me, even though I now have an “electric husband” and more hope, I still worry. Worry hovers over me all the time, like a grey rain cloud floating in a blue sky. I worry more about Hal than he does about himself, and perhaps that’s my role, since he’s the one living with this disease, trying to get through the day. I am there on the sidelines, the cheerer-on, silently thinking about all that could or will go wrong, but also learning to get past my worry and to enjoy my husband as he is now. After all, I still do have Hal and that is what matters most.

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blogs about
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