Tethered to the Body

Jane Kokernak

A $6,000 insulin pump with an on-board computer chip is not alluring. Neither is the white mesh adhesive patch on my naked abdomen or the length of nylon tubing that connects the patch to the pump. There is only illness, and there is no way to make that sexy. After several years as a medical device wearer, I know.

Negligees and nudity are impractical, because neither provides much to clip the device to. Clothes and pajamas, on the other hand, have waistbands or pockets, which keep the pump steady during the prelude of kissing and touching. The pump can even be negotiated during the impatient slithering of fingers into nightclothes. If my husband and I lie on our sides, front-to-front, I can clip my pump against my hip. If I’m on my back and Jimmy wants to lay his full length on top of me, I adjust the pump along my waistband toward my back, so the hard case doesn’t press into his abdomen.

At some point, somehow, the clothes need to come off. We are cautious around the pump and its accoutrements. I am the more adept at this task. Most of the time Jimmy’s hands know to work around the white adhesive patch and hard plastic connector button that marks the tender insertion site, but sometimes they stutter and miss and fingers drag at it, reminding me. Although we are both aroused, I cannot be completely caught up in the moment, because I’m calculating what to do with the pump and when. I can remove the device for up to sixty minutes without bringing harm to myself, but then I have to remember to stay awake or get Jimmy to function as a human alarm clock and remind me, if I doze off, to reconnect. If I’m tired and know that I’ll want to finish soon and then fall into a long stretch of sleep, I might leave the pump connected during sex, the device tucked under a pillow near my head, leashed to me by the tubing. Perhaps we are leashed to it: If we try to roll away from the pump, its weight seems to tug me, and therefore us, back into place. My body knows how to move, though, and Jimmy’s, and we arrive eventually at relief and pleasure.

I want these moments to last longer than just minutes. I want to lose myself in them. But that kind of loss, which promises liberation, seems out of reach for me. Instead, I tug my bottoms back on, reattach or adjust the pump, and turn onto my side, listening to my husband’s breathing relax into sleep.
Five years ago, I went from being a person with Type 1 diabetes who injected insulin the old-fashioned way—with syringes, by hand, four times a day—to one who wore a computerized pump that, under my control, delivered insulin to me around the clock. Although the pump offered me better health and the hope of fewer long-term complications from diabetes, wearing it made me feel fragile and also inexplicably obsessed with doubts about myself as a woman.

Mike, the sales rep, sold me on the pump. On an overcast June day, we had rendezvoused at a crowded, four-table café that was midway between his location and mine. I ordered coffee and he a scone. Before the food arrived, he checked his blood sugar level with the glucose meter that everyone with diabetes carries, and then he unclipped his pump from his belt and showed me how he calculated and programmed the dose of insulin that would cover the estimated carbohydrate grams in his scone. With him I felt at ease. People who have the same affliction, and reveal it to each other, experience an instant closeness. He told me about his life: childhood, his history with diabetes, his wife, their new baby daughter. I told him about mine.

As if we were on a date, I imagined him in bed. Not with me, though. I imagined him naked, with some faceless woman whom I placed in the "wife" position. I saw him on top of her, moving vigorously, the blankets falling away. I tried to insert the medical device, the one he had just demonstrated to me, into my mental movie of him and this woman I didn’t know. Was it attached to him, bouncing on the mattress next to their bodies? Did he keep his shirt on and the device clipped to the breast pocket? Just like we were on a date, I avoided asking him the very question I wanted to ask, the one that kept bubbling up as we were talking about insurance reimbursement forms: "What do you do with the pump during sex?"

Later, during an appointment with a nurse educator at the Joslin Diabetes Center, it occurred to me that this was exactly the kind of issue I was supposed to bring up with a health professional. Sex: that’s the body, right? She and I did talk at length about another difficult subject: death. In the lead-up to getting a pump, patients must consider the enormous implications of being constantly attached to a machine that could fail and require immediate human intervention. You can’t ignore a malfunctioning pump the same way you can a broken wristwatch. Insulin doesn’t only control blood sugar levels; insulin is a hormone essential to life. It was easier, however, to talk with her about a threat to my life than it was to talk about a damper on desire. Sex and death make good bedfellows only in art.

During the weeks before I switched to the pump, I thought more about sex on an hourly basis than I had since I was a young adult. Although I wanted a direct answer for what would sex be like, I wasn’t bold enough to directly ask a nurse, doctor, or even another person with diabetes my questions. The few books on insulin pumps that I found, and even the official literature from manufacturers of the device, shied away from or minimized the topic. There were no nearby friends, no other women with insulin-dependent diabetes, to interrogate. Who was there to ask? I turned, of course, to Google.

I typed “sex and insulin pump” into the search box and mostly found pages from manufacturers of various pumps that all relied on opaque language about “intimate evenings.” I read a few blogs by pump users that unhelpfully pushed a vague “sense of humor” strategy. How exactly would this humor manifest itself? As jokes? Innuendo? I conjured a vision of two winking lovers and pictured one saying to the other, “Hey, baby, why don’t you come over here and show me your device?” I winced.

Changing my query, I asked Google for “sex and medical device.” There was plenty, mostly written by nurses and physicians, on sex for people with pacemakers (“ask your doctor first,” and “take it easy”) and devices for people with sexual dysfunction, like the penis vacuum pump that is used by men with diabetes who experience poor blood flow to a penis damaged by years of high blood sugar. There were even a few articles on the use of medical devices as sex toys, but these, I noticed, were not written by clinicians.

I broadened the search and found a surplus of information on “sex and disability.” While I didn’t find the answer to my particular worries, I did hit upon two illuminating topics: scholarship on disability and sexuality, and disability erotica and pornography.

In the first topic, there was practical advice for people in wheelchairs, people with partial or total paralysis, people in the early stages of multiple sclerosis, people with sexual disability. There were psychological self-esteem messages for every sexual anxiety; “communication between partners and with the healthcare team” was encouraged repeatedly. There were also advocacy groups that sought to normalize the sexual lives of chronically ill and disabled people. There were inspirational messages to “forget loss and pursue possibility.” All of this matter-of-fact, explicit, and psychosexual information—“frank talk”—was what I thought I was looking for. To find it, though, actually made me sadder, reminding me that I was stuck in the loss that I was being exhorted to gloss over.
What buoyed my mood, strangely, was an archive of erotic fiction written by a wheelchair-bound man, paralyzed from the waist down. Wheelchairs and paralysis seemed to have nothing to do with my particular situation, diabetes, but as a reader I was drawn into the iteration of the writer’s sexual fantasies, which he used as material for his self-published stories.

In each of them, the scenario always began with the date preparations: shaving, dressing, lighting candles, assembling dinner ingredients, and selecting music. The protagonist scoots around the apartment in his wheelchair as he creates a romantic setting. The woman arrives, beautifully dressed in gauzy layers, and the date begins. Romance ensues. Sexual excitement takes over, and the narrator’s physical potency seems to accumulate as he and his date kiss, touch, and make love. Meanwhile, the wheelchair disappears gradually from the text; desire lifts the man out of his chair, so to speak, into a kind of sexual heroism. He is muscular, powerful. She responds. The scene fades on sated lovers embracing with healthy arms and murmuring to each other. The wheelchair never returns to the scene. In ecstasy, this paraplegic man doesn’t just transcend himself, he becomes himself—the self of possibility that he imagines.

These stories turned me on, and the transformation affected me every time, even though I got to know this writer’s work well enough to know what was coming. Although his work offered readers no advice for dealing with the ill or disabled body during sex, the stories did help me understand what it was about the insulin pump that was making me obsess about sexual losses. Don’t many of us—healthy or ailing, able or disabled, unassisted or assisted, young or mature—locate our ideal selves in the sexual? When we kiss, we close our eyes. Desire and sensation airbrush the outward signs of our lesser selves: stretch marks, missing toes, breast scars, purple veins, bruises, or sagging flesh. This kind of nakedness, however, the one our imagination creates, is a disguise. Nakedness becomes an idealized performance of our selves, and sex the context in which we express and communicate it. None of us wants to be that other kind of naked, the entirely bodily kind that exposes the undefended self: the one in the wheelchair, the one with two hearing aids, the one wearing prosthetics, the one mourning her pre-pregnancy fitness, the undefended self: the one in the wheelchair, the one with two hearing aids, the one who wrenched his middle-aged knee. That self requires sympathy, acceptance, and often help.

Late one night, I heard the pump’s alarm while Jimmy and I were having sex. The three-beep melody is a quieter, more lilting version of the electronic pulse that a garbage truck backing up makes. Jimmy heard it, too, and paused inside of me; I decided that I could ignore it for the moment. “It’s okay,” I said, and we finished. Then I checked the alarm: Low battery. I sighed heavily then got dressed. To the darkened bedroom, to a groggy husband, I muttered, “I need a new battery.”

In the kitchen I peered into the crowded cabinet where I stash alcohol wipes, lancets, a glucose meter and test strips, insulin reservoirs, Ketostix, and backup syringes. It’s a little pharmacy in there. What was missing was the miscellaneous: AAA batteries.

Standing in the laboratory-bright light, I cursed. How could I have let my battery supply run out? I rummaged in the bottom of my satchel. Then I stomped down to the basement where we keep tools and light bulbs. Jimmy came downstairs and searched the backs of drawers; he found plenty of batteries, just none the right size. I pried open all the remote control devices in the house, fished out their batteries, and slid them hopefully into my pump. But each time I tried one of those half-used batteries, the alarm melody played and the same error message appeared. The pump would only drink fresh juice. After a few tries, the pump shut itself off according to its internal program. My real pancreas had stopped working more than a decade earlier; now the replacement one was giving up.

By then it was almost 2:00 a.m. Though weary, I felt the flutter of will inside of me. It might have been automatic, or it might have been a decision; nevertheless, it helped me focus on the immediate task—getting new batteries. Jimmy offered to look for a 24-hour store. He put on clothes and a jacket, grabbed the car keys, and went out.

I climbed back in bed to keep warm, stay calm, and consider a back-up plan. Minutes later Jimmy called me from his cell phone. “Star Market, closed,” he said. “Any ideas?” We decided he should head to a Boston neighborhood where plenty of university students live, then out to Walgreen’s in Newton. As I lay there, I thought about ditching the pump altogether and going back to my old program of four to five injections of insulin each day. It didn’t occur to me to not take my insulin, as it never had in my then twelve years of living with diabetes. I am a pragmatist when it comes to illness. As I considered reverting to injections, I realized that I had come far enough with the pump that I wanted to stick with its advantages. That meant sticking with its drawbacks, too. I would live with them.

Jimmy called again. “Everything is closed, can you believe it?”

“Try a gas station,” I suggested. He did.
The Head is a Canvas

Dana Koster

These are the things we keep hidden: our bodies when we cannot bear them. Our lenient stomachs. Our shame. We are gifted bearers.

Last night, you exposed your scalp: no hair to hide behind, black whorls on the skin. The head is a canvas, you said, your teeth bared.

I held so many nothings on my tongue. I wanted to say: How much the hair has changed you. How much we refuse to bare.

You thought these were your choices: red wig or brown. Thick hips or cocaine. We falter in this climate. We lose our bearings.

Even when the sky is heat-muted cornflower. Even when nectarines plump and languish on the branch, we search for bareness.