

an
intimate life
sex, love,
and my
journey as
a surrogate
partner

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with lorna garano



SOFT SKULL PRESS
AN IMPRINT OF COUNTERPOINT

1.

heavy breathing: mark

Mark O'Brien opened his mouth slightly, making a little silent hiccup. I grabbed the tube that sprouted like a plastic tendril from the portable respirator his aide had clamped to the headboard. As I sat up to bring it to Mark's mouth, my breast grazed against his cheek and we both smiled. Mark squeezed his lips around the flat mouthpiece of the tube and the reassuring hiss of air filled his lungs. He closed his eyes. He luxuriated in oxygen, something most of us took for granted. The machine blinked and made loud ticking noises. He loosened his lips and opened his eyes. I gently removed the tube, leaving it on his pillow, just outside the crescent of sweat that rimmed his head. "How are you feeling?" I asked. "Good, Cheryl. It wasn't as scary as I thought, or it was, but I'm still glad I did it." Then he flashed his sweet, boyish smile.

It was 1986 and I had been a surrogate partner for thirteen years. I had worked with disabled clients before, but none as compromised as Mark. At thirty-six, Mark had lived most of his life in an iron lung

after having contracted polio at age six. He could only breathe on his own for short periods of time and it was only with the help of the respirator that he could meet with me for a couple of hours in the spacious Berkeley cottage he had borrowed for our first session.

The iron lung was essentially a breathing machine. It looked like a wide pipe with levers and dials that encased Mark's whole body, leaving only his head exposed. It worked by creating a partial vacuum every few seconds that lifted his chest so his lungs could fill with oxygen. Because Mark slept in the iron lung, he didn't own a bed. Luckily, he had a supportive friend who was willing to share hers with us.

Except for the ability to wiggle a few fingers and toes and move his mouth and eyes, polio had left Mark paralyzed. It had also contorted his body so that his left hip twisted to the right, jamming his legs together in a way that almost made them look fused. His neck and head were frozen to the right, making him gaze permanently off to the side. He spent his entire life lying flat on his back, except for when he was propped up for an attendant to wash or dress him or a doctor to examine him.

Like all of my clients, Mark was referred to me by his therapist. Like most of them, he was anxious in the first session. "This is a big day for him," Vera, one of Mark's attendants, said when I arrived at the one-bedroom cottage that morning. The friend who owned the cottage was also disabled so the cottage was outfitted with a ramp at the front door and low kitchen cabinets and door handles.

Vera led me past the living room skirted with bookshelves that were low to the ground and down a hallway lined with black-and-white landscape photographs. She knocked on the bedroom door at the end of it. "Mark, Cheryl's here. We're going to come in," she called out before slowly opening the door. She motioned for me to go in first. Mark lay on a broad four-poster bed covered up to his chin with a blue afghan. Sondra, Mark's therapist, had told me that he was slight, only four-foot-seven and around seventy pounds and for a moment I was startled to realize how small that really was. The blanket that covered him was barely raised off the bed. "Hi Mark," I said, "it's so nice

to meet you.” “Nice to meet you, Cheryl,” he said in his gurgly voice. His cornflower blue eyes stared downward.

“Just let me show you how to use the respirator and I’ll leave you two alone,” Vera said. She pointed out the small switch that I would need to flip on to start the flow of oxygen and then she put the breathing tube into Mark’s mouth. “See?” I nodded. Mark took a few little gulps of air and released his lips. “He’ll let you know when he’s done.” She took the tube out of Mark’s mouth and said, “I’ll see you guys a little later.”

From the way he said my name, Cheryl, I could tell that Mark and I had something in common. We were both transplanted New Englanders. I told him I was from Salem, just outside of Boston, and that I had been born into the big French Canadian community there. My maiden name was Theriault (pronounced “Terry-O”). “. . . Or ‘There-ee-alt’ if you were one of the Irish Catholic nuns at my elementary school.”

“You’re Catholic?” he asked.

“I was,” I said, and smiled.

“I still am,” he said. “I need to believe in God so that I have someone to yell at.”

I laughed and Mark’s eyes brightened.

I took off the jacket that I really didn’t need on this warm mid-March day, dragged a chair from the corner of the room, and sat down by the side of the bed. “Let’s talk a little about how we’ll work together,” I said, as if I entirely knew. Like therapists, surrogate partners have a protocol and a repertoire of exercises to help clients effect change in themselves and their lives. These obviously would have to be tailored to Mark’s condition, and I wasn’t entirely sure I knew what that meant. “We’ll work at your pace. What I’d like to do today is learn more about you, and, if you are ready, start with a body awareness exercise,” I said.

I asked Mark to tell me a little about his family and his childhood. He was born in the Dorchester section of Boston and had moved with his family to the Sacramento, California, area when he was sixteen.

He was the oldest of four children. He had some memories of his life before polio. He remembered waking up excited every day to run outside and play. He loved the outdoors and playing with the kids in the neighborhood.

When the disease struck in 1955, Mark was six and he became the focus of the family, especially for his mother. Her dedication to him was unwavering. She cared for him with patience and tenderness throughout his young life.

A few years after falling sick, Mark's sister, Karen, died of pneumonia and since that time an unearned guilt had shadowed him. He believed that his parents, particularly his mother, were so preoccupied with him that they didn't notice that Karen needed help until it was too late. Even though there was no reason to believe this was true, Mark still burned with guilt. He felt guilty about other things too.

Mark sometimes woke up with his crotch sticky with semen. He remembered a flicker of disgust cross his mother's face as she cleaned him one morning when he was around twelve. He could get aroused by having his left leg edged further over to his right so that his penis was sandwiched between his thighs, and a few times he had asked his attendants to position it this way. He discovered this accidentally when an aide had left him like this for a few moments while bathing him.

Even though Mark could hardly be called a traditional Catholic, he still felt shame about his sexuality, which he attributed to his religious upbringing. Like his guilt about his sister's death, it may have been irrational, but to him it seemed as real as the imposing iron lung in which he spent most of his days.

His parents never talked about sex and he received no education about it from the rafts of doctors and therapists who treated him throughout his life. Like many disabled people, Mark's sexuality went unacknowledged. Most people seemed to assume his disability canceled out his need for touch and intimacy.

Despite all of his physical challenges, Mark had earned a bachelor's degree in English from the University of California, Berkeley, and

was a published poet and journalist. He tapped out his work using a mouth stick and a word processor. Mark had started on a master's program in journalism before the effects of post-polio syndrome, a condition that attacks the muscles and causes debilitating fatigue, forced him out of it. He lived near campus and traveled to and from school on a reclining wheelchair that looked like a motorized gurney. He lay flat on it or slightly propped up. His spine was too curved for him to sit up in a standard wheelchair.

Mark had felt alone and alienated for as long as he could remember. Most days he could imagine no end to the loneliness that stretched out before him like a boundless, desolate road. His sexual experience consisted of a few furtive touches from nurses and sudden arousal while his attendants bathed him. Embarrassment always followed. "Sometimes I let myself think that there is someone out there for me, but, really, I think it's hopeless. I feel like I'm outside a fancy restaurant, looking through the window and watching people feasting on all kinds of wonderful food that I'll never be able to taste," he said.

I had been a surrogate and a student of human sexuality long enough to know that attraction involves many factors and you need not have a pop culture-approved body to have a loving relationship and a sizzling sex life. I knew other disabled people who enjoyed both. Still, was he right about not being able to find a partner? I found myself thinking. Even though I had only just met Mark, I felt real affection for him. He was witty, smart, and brave, but could someone this profoundly physically impaired realistically expect to find a partner? Would I date him, or would I be too scared? By training and by temperament I'm inclined to be supportive and encouraging, to see possibilities and potential even in tough situations. I wanted to reassure Mark that there would be someone for him, but I also worried about creating false hope.

"Mark, I can't predict the future, but part of my job as a surrogate is to prepare you to have a loving, happy relationship if you meet the right woman," I said. "Let's talk more about what you want to get out of this process and let's learn more about what your body is capable

of.” I think I said this as much to be honest with Mark as to remind myself of what I could and could not do as a surrogate partner.

“Suppose you began a relationship with someone tomorrow who you thought was just perfect. What would you feel?”

“Well, probably a lot of things. Anxiety, excitement, relief.”

“What would the anxiety be about?”

Mark paused and then asked me to bring the oxygen tube to him. I stood up, the redwood floor of the old cottage creaking as I took the few steps to the respirator. After a few seconds he slackened his lips and I took the breathing tube out of his mouth.

“That it would be obvious that . . . that I’m a virgin and she would want someone more experienced and capable.”

“Okay, so it’s important for you to get some experience. That’s natural. Lots of people worry that they won’t have enough practice to please a partner.”

“I don’t want to live my whole life without having sex.”

“You don’t have to. We can accomplish that together.”

For someone like Mark to be told that what he wanted was achievable and that his fears were not so different from those that many of us confront was reassuring. Even clients who don’t suffer from the kind of physical challenges Mark faced are often relieved to hear that they are not alone in their insecurities and worries. Mark was so accustomed to being an outsider, to being someone who needed special consideration and accommodation that hearing this probably felt akin to a compliment.

Mark and I had talked for close to an hour, and, if he was ready, it was time to begin the physical part of the session.

“How would you feel about doing some physical exploration now?”

“Okay, I mean, yeah, I’d like that.”

It was time for us to get undressed and this would mean me taking off Mark’s clothes and seeing his body for the first time. Suddenly, I was scared. He was so fragile. What if I hurt him? What if I couldn’t maneuver around his body? Go slow, slow, slow, I told myself.

“Mark, if at any time I’m doing something that doesn’t feel good,

let me know. This is important not just for our work together, but for you to learn how to express likes and dislikes to a potential partner. If something feels bad or uncomfortable, just tell me to stop, okay?”

“Okay,” he said, with a slightly worried look on his face.

“Remember, this all happens at your pace, so if you want me to slow down or stop at any time all you have to do is tell me.”

I slowly lifted the blanket that covered him. His frail body was in a red, long-sleeve, button-down shirt and a pair of black sweatpants. Slow and gentle, slow and gentle, I said to myself, like a mantra. “Let’s start with your shirt.” I undid the first button and then worked my way down the column of buttons. When I was finished, I undid the button at the wrist of his left sleeve. Then I folded his shirt over his arm as much as I could. The collar rested off his shoulder. Because he spent so little time outdoors, Mark’s skin was pale. Against the red of the shirt it looked salt-colored. I briskly rubbed my hands together to warm them up and then slid one under his shirt. I carefully brought Mark’s delicate arm toward me while inching the sleeve off of his shoulder. As I continued to peel it away, I moved his arm back down toward the bed. The sleeve was almost completely off when Mark screamed—loudly. Oh my God! Had I hurt him?

“What’s going on?” I said in as calm a voice as I could muster.

“My nail, you caught my nail in the shirt,” he said.

“Okay, okay . . . let me see.” I freed his fingers from the shirt that was now clustered around his hand.

Remember to ask Vera to trim his nails, I told myself.

“Mark, I need to know when something doesn’t feel good, but yelling isn’t sexy. I know we need to be very careful with your body, so don’t ever not tell me if you’re feeling uncomfortable or worried about getting hurt, but try to do it in a calmer voice. Remember, part of what we’re doing here is modeling how you’ll communicate with a partner, and that could really scare someone and kill the mood.” I had goose bumps on my arm that I hoped Mark didn’t notice. “Do you need some oxygen before we go on?” To my surprise, he didn’t. Once I had freed his left side from his shirt, I went to work on the right.

Then it was time to take off his pants. Mark's left hip jutted up and over like a hood of bone and a sliver of his left butt cheek was exposed. At seventy pounds, he was light enough for me to slide the elastic waist of his pants and underwear down past his groin and knees while he stayed pressed flat against the bed. When I got to his feet, I gave the pants a little tug and they came completely off of him. Then I saw his fragile, exposed body in full.