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April Fool's Day

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This account is based on real life. Names and localities are not mentioned for reasons of privacy.

HE

The room is soaked in the grayish powdered light of a fading moon. By rolling my left eye from one side in an arc upwards and then back downwards I decipher the objects around me. I repeat this tiny oblong circle several times, delighting in the ability to move around in this room by moving my eye, the only part of my body that follows my will and intention.

Every night I wake at about this hour: four o'clock in green electric numbers that colour the desk at the foot of my bed. The moon shadow of the pole with intravenous dripper reaches like a clumsy finger towards the blue-rimmed bedpan and "diapers," and then it crawls slowly along the plastic tray where the medications are stacked according to colours, starting with a mustard yellow at the bottom and stepping upwards through sage

green, tomato red and plum purple, bland white sits on top. Black is missing. Nobody colours medications or their containers black, as it is associated with death. I'm not dead yet, I want to live. I want to live. My body is mostly unresponsive, but all of my senses are alert: I smell, taste, touch, hear and see. I perceive the scent of food and spices and the sweet sweating skin of the woman who sleeps beside me. I taste my own saliva before it oozes out between my open lips. I feel the sleepy touch of the woman's hand on my skin. When she follows the contours and folds of my body with her hands, like this night, she knows how to restore the celebration of this man I am, or was, before the radical stroke. The French call it *maladie de l'emmuré vivant*, or the walled-in-alive-disease. It is a condition in which I am fully aware and awake, but cannot move or communicate due to complete paralysis of nearly all voluntary muscles, except for my eyes.

I can think clearly. I am alive, my SELF still exists but it is held imprisoned inside my own body.

The moon shadow of the pole has crawled toward the wheelchair. I don't want to call it "my wheelchair," I reject identifying with this machine, I refuse to admit that it is part of my body. My wheelchair, *my* medications, *my* stroke, *my* imprisonment. I am caught in this *I* and *I* and *my* and *my*. This is solitary confinement.

I am so cared for from morning to late, that I spitefully imagine, during these gray hours of the night, that I might wake up one day and be abandoned, neglected, and forgotten, and thus be free of "help" and compassion. I despise compassion it

hangs around me like curtains made of rotten sails, stained by the mold and trauma of disaster. I exude the musty stench of dependence. During the light of the day I ignite irritation and compassion in visitors, they are shy and often clumsy; they turn towards me as an object of their concern and then they turn away because I am *the freak*; I trigger their curiosity and fear, they are glad not to live in my carcass. During the days we keep the sense of dignity alive; *we* are a triangle; my lover, my nurse, and me. Dignity is expected from patient and caregiver. But the night is mine: I dream of being untamed, wild, unkind, rejecting and sticky with decay and repulsive odors. I feel tired of behaving well, of being grateful, tamed and appropriate. During these hidden, uncanny hours of the vanishing night I want to embody and admit the horror of my state and allow it to reveal its suffocating grip around the throat of the powerful person I was and still am. During the night I catch a glimpse of God; I see Him disappear just out of the reach of my inner eye. He's letting me know his presence. We sealed an uncanny contract, a bond that fills me with ecstasy and glee.

Death has been waiting patiently for many years. I linger, ecstatic to live in both worlds, Death allows me to choose the day when I am ready to pull the other foot across the line. I never cared much for this body of mine. I used and misused it as a source of pleasure but felt bored and annoyed when having to maintain it; the dread of daily upkeep was bothersome. That task has been taken on by my devoted nurse of seventeen years

and by my lover. I celebrate being relieved and freed from that habitual assignment of civilization.

The woman at my side moves. Her loving hands masterfully shape the landscape of my pleasure and draw the map of my body so that I remember myself. I don't know how she weaves all the strands of our romance into a whole story. She creates and untangles the fabric of this bond like Penelope waiting for her beloved Odysseus.

She moves and my groin tingles as I remember the texture of her hair. Wherever our skin touches and rubs there is *outside*, there is sensual freedom. Our sex is clumsy and thrilling, absurd and frivolous. Her weight on top of me gives meaning to the unmovable bulk of my body. Oh, I feel how her heavy leg crosses and then slides away from mine; she is flesh and I am wood, she is woman and I am tree. Now she puffs feathery snores out of her slightly open lips. Those snores accumulate in the air and gather in piles in the corners of the room and between the objects. I am unable to produce any word or sound; my breathing and my vocal cords don't synchronize. I am a musician, but my Muse is strangled.

The puffs of the woman's snores delight me and turn me on. They take on the shape of wriggling creatures; they interact and move like dancers on a stage. Now they stumble and fall, get entangled and plummet to the ground. If I were able to, I would burst into laughter.

SHE

With eyes still full of night, I strain to lift the lids. Every morning I wake up from the dream that he is still alive, my husband and companion of thirty years, my beloved and friend. Those thirty years of marriage left his imprint in my flesh, in my thoughts, my voice and breath. Thirty years of shared life were abruptly altered that morning, three years ago, when we sat together at the breakfast table. He suddenly gurgled and screeched and then he fell backwards, pierced by the calamity of an inexplicable stroke of fate. That moment was followed by nine months of grim wrestling with decay and death. Nine months of my desperate attempts to reach inside the flesh-and-blood cage where he, the man and companion, was still present. After nine months his ability to fight was exhausted, he died.

I reach to my left and touch the chest of the man beside me. And then I remember this new man in my life the stranger whom I befriended and learned to love. I slid into our bond with force, moved by destiny, like a salmon swimming upstream to familiar waters; in this case they are the waters of disease, struggle and grief. Inside the walls of his diseased body this outstanding man is vibrant, creative, lustful and demanding. I am outside trying to connect, reminded of my dead husband and partner. In my heart the two men merge.

How did I get caught in this room and in his life? How did I slip into my old role as caretaker with a new man? How did I get ignited by this

new love story? How will I untangle myself from the cosmic loneliness in the inner space that enfolds this man, who attracts me and lures me into his cave? We are talking about marriage.

When I encountered him for the second time, he signalled to me: “Kiss me!” and so I did, because I was attracted. He sends me flowers and poetry. He dictates it slowly with help of his nurse, a letter-board and the blinking of his left eye when she points to the right letter.

My hand touches his hip, and I am amazed how much excitement such an ordinary gesture holds when experienced from the place of knowing physical impairment. When I wipe the saliva from his chin or rub his shoulder with my cheeks, I live for both of us. When I wash his penis or chest with a soft sponge, I feel his pleasure in my own body. The hundreds of daily burdensome or delightful procedures I am able to do for him every day seem like a dance of grace to me after I have witnessed the restrictions of the disease, that strangled the two men I love. Nothing is the same; I am changed through these encounters with disability. My own window to the world was opened as I observe this extreme human limitation.

WE

I demand that they stay inside the reach of my eye. The two women, my lover, and my nurse of seventeen years, move from kitchen to bathroom and back, and I require that one of them be always in

the room with me. I don't trust them. I don't trust this woman and the nurse. The dark shadow of doubt brushes and whips the inside of my skull like a wolf's tail. Suspicion and distrust are the opposites of love or they might be part of it? This love has lasted for two years; it is a love that makes me greedy and ravenously hungry for her attention. I am squirming under my own terrifying attacks of envy and jealousy.

I observe the two women together: how they lean shoulder to shoulder when they turn me over and straighten the linens. How they exchange glances without words. They have secrets. Their secrets exclude me. I am excluded from life outside my walled-in place and cannot tolerate being banned from their intimacy. I feel screeching panic when they move into corners where I cannot control them, beyond the reach of my left eye. Their mutual focus on me bonds them intimately; they are joined into one fluid ballet of caring. They circle around me and I am stuck in the centre. They indulge in each other's warmth, loyalty and womanliness. Their concern for me weaves a net around them, a fabric of charged feminine mystery.

Oh, my demons! They whisper in my brain: "Did you see how their hands brushed against each other? Did you observe their hips touch and halt for a second in intimate closeness? When they prepare the bed for your lovemaking, their cheeks flush with excitement. See how they gasp for air and close their eyes with delight." "It's better to be alone," says my demon, "than to be witness to this intimate, vibrant, radiant feminine bond."

Exclusion from their intimacy will suffocate you like hot ashes in your throat, but solitude is cool, quiet and peaceful.”

I usually get what I want. I am a force of destiny, I demand and I am entitled. But I have become weak and nimble. Caught in the net of these women’s attraction for each other. I am lost and knotted into a spider’s web of resentment and rage. The flow of the energy currents in this room has changed. The engulfing stream of these women’s attention towards me is dwindling; they now fold their loving around each other. Their passion for each other drains my pool. That loss of energy tears holes in the fragile fabric of my life. I begin to sink and shrink, the lacy edges and ribbons of death and decay are encircling my prison house.

I am caught in my obsessions, imagining how the two women undress and stroke each other’s bodies, touch skin to skin, suck each other’s fluids and lick the sweat on their temples, rubbing and sliding along the curves of each other’s flesh. I luxuriate in my ravenous fantasies.

If I cannot get what I want, I will construct what will destroy me. I will free myself from the fire of suspicion that clouds my brain. And so I take the last painful but liberating stance in my life: I fire the nurse who cared for me for more than seventeen years. I force her out of my room and out of my life. She bonded me to my physical existence by accepting me in all my royal and disgusting ways of being a powerful man in a dilapidated body. I cut her loose; I rip her out of my

existence. She is the one to whom I dictate my letter that terminates her services.

And I let the lover go, the beloved woman and companion. The woman, whose hair covered my face when she mounted me. The beloved, who kissed my distorted salivating mouth. The partner, who massaged my crippled feet and fingers. I take command, and I take revenge. I free both women from the grip of compassion that bonded them to me.

And now, I sit in my room that is saturated with cool solitude, stillness, and loneliness. Death crouches patiently near the window and watches the fading moon. I have fooled him with lovesickness, wilfulness, and genius, and in turn he showed compassion for me. But I don't accept meekness; I would rather have grandeur and humour. Today is April Fool's Day. I give Death a sign: looking at him with my left eye, I blink once, signalling, "Yes!" He scuttles from the window towards my bed, and I step into the moonlight on the floor without casting any shadow.

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