

Good Morning—An Ending

benefit of whatever Johnsons are in earshot. Reflexively, I take her question to my heart.

What am I dreaming of? The sweet untouchable man who sent me one red rose this Valentine's Day, who loves me in most of the ways that I love him, who will be happy for me to tell him about this ordinary everyday awakening, who reminds me that there's more to touching and being touched, more to moving and being moved, than what bodies can do for bodies—and, also, yes, without doubt, who agrees with me that what bodies can do for bodies can be very very good.

Geneva brings my breakfast and then gives me a bedpan and then washes me, starting with the nighttime crusts in my eyes, all the way down to the spaces between my toes, and everything in between. If it's not Geneva, it's someone else, someone I've chosen, someone following my instructions. It's a daily necessity, entirely practical and matter-of-fact. I sometimes think how strange it would be to do these morning things in solitude as nondisabled people do, and to regard, as many of them do, a life like mine as a dreadful and unnatural thing. To me it is so natural to feel the touch of washcloth-covered hands on flesh that is glad to be flesh, to rejoice that other hands are here to do what I'd do for myself if I could.

Those hands get me in the clothes I want to wear, get me in my power chair, get me positioned for the day, and set me out. On my own, on the streets and sidewalk in an ordinary morning at home, I roll to the office.

Driving the chair is far more difficult now than in years past. That period of immobility after I fell from my wheelchair left my right hand and arm significantly weaker; it took time to learn to drive again, using my left hand for support. I've lost a lot of flesh with the result that I'm vaguely tottery. As the sidewalk irregularly slant toward the street, as I zoom up and down curb cuts, slam over rough slate, my body strains against the

It is dark when Geneva's hands turn me over. It's dark as night, but my bones tell me it's morning, they are so eager to be moved. I lie curled on my side as hinds of sun push through thick low clouds and then through my window shades and I hear a mourning dove making that coo that every Southern boy learns to make when he's eleven by blowing into his hands. The dove's moaning call provokes a tittering response from his prospective mate. I eavesdrop on the doves' back-and-forth conversation and think of my beloved and of my cooing and of his tittering and of the impossibility of our mating and of his great love of natural beauty—and, perhaps improbably, I smile.

From the next room, there is the unnatural beauty of a domesticated dog snoring and the crackle of Geneva leaning through the *Post and Courier*; as always, I know she's looking to see who died yesterday and what the horoscope promises for those living today. The dog whimpers in her sleep. Geneva speaks, quietly so as not to awaken me if I'm still asleep, but gruffly. "Dog. What you dreaming of?"

When Geneva gets gruff with the dog, it's usually for the

seat belt and the rolled towel underneath it. It's all I can do to keep myself upright. It's all about balance and compensation, resisting gravity and going with the movement. If I'm either too stiff or too relaxed, my head will fall back or my weight-bearing elbow will shift and bounce my hand off the controller. Now driving the chair requires real concentration and skill, and the harder it gets, the more I love doing it. As my limits press closer, I begin to understand what athletes mean when they talk about being in the zone. When driving the chair demanded less from me, I got less from it. It's the same with other hard-won things.

Some days, my morning roll is in some way eventful. There is an encounter with a stranger, a chance meeting with a friend, some unfolding drama that doesn't involve me but provides material for interpretation and narrative. On uneventful days, when nothing is happening, there is the simple delight of movement, of jostling and bouncing and shaking, of controlling what can be controlled, flowing with what can't. I make up little games. Some days the game is No Brakes! The object is to cover as much ground as possible before I have to stop and hear those electronic brakes click on. I look way up the street to gauge the traffic patterns and figure when I need to start creeping, how slowly, to hit the intersection exactly when the walk sign comes on. Some days the game is a simple headlong rush to the destination. I zoom through chaotic swarms of tourists, zip around the raggedy sidewalks I know so well, loop around every inconveniently placed garbage can, with maximum speed and also with style and grace.

At times, the movement is only incidental. What engages me then is being here, in this city. I rarely stray from my standard route, a route where I know the terrain intimately and the local people imagine they know me. My path is constrained but endlessly varied. I watch the sun move up in the morning sky and in and out of clouds, take in the changing light that con-

stantly reinvents the city's classic, composed beauty. I feel the moist air roll over my just-washed skin, breathe in the odors of sea and flowering trees and restaurant grease. Some of the best mornings are the mornings when nothing happens, when there is no story but the continuing relationship of this old city with the ocean that roars just out of sight and with the living jungle that tentatively tolerates our existence here.

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How is it possible that nondisabled people tend to feel sorry for me? It still takes me by surprise. Peter Singer couldn't imagine a disabled child enjoying a day at the beach and he's hardly alone. The widespread assumption that disability means suffering feeds a fear of difference and a social order that doesn't know what to do with us if it can't make us fit its idea of normal. When we seek what we need to live good lives as we are, we come against that wall. Why bother? the thinking runs, all they can do is suffer. When nondisabled people start learning about disability, what seems most startling, most difficult to accept, is the possibility of pleasure.

For decades, little noticed by the larger world, the disability rights movement has been mobilizing people from the back rooms and back wards, along with more privileged people like me, to speak plainly about our needs. We make demands. We litigate. Run for office. Seize the streets. Sit through the meetings. Mark up the drafts. That kind of work has changed the world and we need to continue to do it.

But we need to do something else besides, something that may be difficult but is, I think, vital. We need to confront the life-killing stereotype that says we're all about suffering. We need to bear witness to our pleasures.

I'm talking in part about the pleasures we share with nondisabled people. For me, those include social engagement of all

kinds: swapping stories, arguing hard, getting and giving a listening ear. A challenging professional life. Going to movies, concerts, and exhibits. Wearing a new pair of earrings. Savoring the afternoon hit of Dove dark chocolate. I enjoy those pleasures the same way nondisabled people do. There's no impairment; disability makes no difference.

But I'm also talking about those pleasures that are peculiarly our own, that are so bound up with our disabilities that we wouldn't experience them, or wouldn't experience them the same way, without our disabilities. I'm talking about pleasures that may seem a bit odd.

Let me give some examples.

John Hockenberry rolls across the Brooklyn Bridge self-propelled in a manual wheelchair. As he describes it, it's a high no one but a hotshot para can really know.

A nation within a nation, of Deaf people, capitalizes its name to demand recognition as a language group, equal to any other in dignity and ferocious beauty.

Barry Corbet, a hotshot para now falling apart, is struck in bed for several weeks with a pressure sore. As he lives with one marvelous view, he says life doesn't go away; where would it go? He says life has never been richer or more juicy.

In an essay on smell, Helen Keller wrote that she could never warm up to another person who did not have a distinct and recognizable body odor.

After decades of torment, Professor John Nash recognizes his delusions for what they are and lets voices and visions and mathematical creativity cohabit in a mind unlike any the world has ever known.

My friend Kermit, a quad on a budget, goes out to lobby the legislature and finds a coffee under way. He can't grasp with his hands so he makes a legislator feed him a donut. The last lobbyist out removes his clip-on tie.

At a summer camp, a mentally retarded boy badgers a girl in a wheelchair to teach him to play checkers. He knows he's slow and she's bored, but he won't give up. Then something clicks and her explanations make sense at last and he sees the patterns and wins the game. For the smart girl in the chair—for me—it's a humorous, humbling lesson. For the slow boy, there's joy in pushing his intellectual limits. The peculiar pleasure is unique to each of us, but it's also shared; the sharing makes a bridge across our differences.

Throughout my life, the nondisabled world has told me my pleasures must be only mental, never physical. Thinking to help me, it has said my body is unimportant. I respectfully disagree. For me, the body—imperfect, impermanent, falling apart—is all there is. Through this body that needs the help of hands and machines to move, that is wired to sense and perceive, comes all pleasure, all life. My brain is only one among many body parts, all of which work through one another and cooperate as best they can.

Some people, disabled and otherwise, conceptualize a self distinct and apart from the body. I may at one time have done so. I'm not sure. I know it is somehow possible for me to talk about me and my body as though separate, even though my mind and heart say we are one. At this stage in my life, my body constantly makes its presence known as needed, telling me with an urgent pain to deal with a wrinkle under my seat belt, or reminding me with a tremble or ache or flutter of its desire for food or rest or some other pleasure. Now the body I live in doesn't only affect me. It is me.

The nondisabled world tells disabled people generally that our lot is unavoidably tragic, and if we're smiling, we're smiling through tears and despite suffering. In the face of these powerful social forces, I believe that living our strange and different lives, however we choose and manage to live them, is a contribution to

the struggle. Living our lives openly and without shame is a revolutionary act.

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I might stop there, but before I close I think I owe you an apology. You probably want to know about my Valentine. If you've come this far with me, you're a curious person, and it's a natural thing to be curious about. You want the whole story—who he is, how we met, what happened when, and why I call him untouchable and our mating impossible.

You wonder. Is it a disability thing? Not mine surely! So maybe his or some combination?

You know, or you should know by now, everything's not always about disability. It could be a simple issue of geographical distance. Or any number of other things. A taboo. A hang-up. A code of honor. A fetish. He might be married, in prison, or a monk. He could be in hiding—a fugitive from justice or the spy who loves me. One of us, maybe both, might be gay. All these things happen, right?

Wait. You might be overinterpreting. You might consider whether the untouchability and impossibility might be temporary. You know how I carry on. I could be playing around, pinning my way through a short-term separation. Could he be on a hop out of town, for example, or have a case of the flu?

Maybe, just maybe, we're dwelling on sex when what's important is love.

So what about that, you may ask, this love I mention—is it a sweet safe harbor from life's tempests? Or is it in itself a hurricane, all sturm-und-drangful? Does it give strength or drain energy? Upset equilibrium or restore balance? Are my love and I earnest, deeply serious, or do we joke and tease and flirt? Does he bring out the silly girl in me or draw out something like wisdom?

Mercy! Could it be Abelard and Heloise all over again?

The answer is yes. To some of those questions—certainly not all. Which? I am sorry, but I'm not telling.

The story's not for publication. In truth, there's no story. What they call love stories are actually about conflicts. A story needs some series of obstacles leading to some crisis. This one may be just beginning, in the setup before events play out. If so, I hope the ending is a long way away; these preliminaries are so delightful as to deserve dragging out. Or, better yet, the story might have happened real quick when we weren't paying attention. I dare to hope this is the happily-ever-after that is insufferably boring to everyone but the happy lovers themselves.

Much as I might enjoy relating the details of our billing and cooing, much as I might like to show off each little love token like that law school roommate who taped all those love-ly cards to our dorm room wall, I'll spare you. Be grateful. I'm doing you a kindness. Love, in its real and pleasant form, is best lyrical, not narrative. It's most enjoyed not as a diversion, but woven into the fabric of the routine.

So, lacking a tellable story, withholding the blow by blow, I'll try to give you the benefit of my experience in terms more politic and general. I know a juicy romance might be more fun, but this is what I have to offer you.

My experience so far has taught me that love and sex and intimacy are like so many other things.

The barriers are formidable. The constraints are by definition insurmountable.

No doubt. And yet—

In love as in life, every impossibility opens a door to some surprise. However many things may be entirely foreclosed or more trouble than they're worth, the possibilities that remain are so numerous, so varied, so far beyond the capacity of one

person to experience, so marvelous—that they might just as well be infinite.

At dawn, it's usually impossible to predict whether the day will bring strange events fit for narration or the routine lyricism of life and love. Either way, it's good to meet each morning's sun awakened to all the possibilities.

Author's Note and Acknowledgments

Here, I might be tempted to thank everyone who has made a significant and valuable contribution to my work and life, but I know the list would be unbearably long—even if I were to limit myself to contributions made within the past two or three weeks. This book gives a hint, but only a hint, of how beholden I am, day to day, to friends, family, professional colleagues, movement comrades, paid and volunteer assistants, casual acquaintances, and strangers who help me to do what I do. So I will say a few words on how this book came to be, and leave vast legions unacknowledged.

I learned to tell stories mainly from my mother, Ada Austin Johnson, who happens to have a Ph.D. in comparative literature with an emphasis in short prose narrative, but who acquired storytelling skill from her family and the air we breathe. My writing the way I do owes a great deal to Barry Corber. As editor of *New Mobility*, Barry somehow got me doing, just for fun, a kind of writing I never imagined I'd do; portions or versions of chapters 1, 5, 6, and 7 originally appeared in *New Mobility*, greatly improved by his editing. Since his retirement, he has