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EVERYTHING IS ELIMINATED

THE WAITING ROOM for movement disorders at Mayo Clinic hums with nervous life. A teenager dressed all in pink—from her shoes to her headband—waits in a bricolage motorized wheelchair, yelping every few minutes. I think of Saul Bellow’s definition of boredom: “the shriek of unused capacities.” An elderly man sits with a nurse, shaking his head back and forth, as if emphatically gesturing no, occasionally dispensing outbursts of angry adjectives. An overweight thirtysomething in a camo sweatshirt makes popping noises with his lips.

During the past week, I’ve been thoroughly Mayonazed. Four different MRIs, an EMG, a spinal tap, two clinical exams, and dozens of blood tests. The lumbar MRI sounded like Philip Glass in a barrel. Lumbar Philip Glass. Knock knock. Who’s there? Philip Glass. Knock knock. Who’s there? Philip Glass. Repeat twenty times. Other MRIs were less evocative.

In the wrap-up meeting that just ended, the smart, interested neurologist looked disappointed. No slam dunks.

I’m done at Mayo, but I stay in the waiting room, not waiting for anything really. I could retreat to my hotel room, but I prefer to remain among people, as I mull over my physical decline the past half year.

Beginning in early spring, unusual stiffness in my legs turned into more stiffness, increasing heaviness, and decreasing agility. Each passing day brought more deterioration in my mobility.

Several months after the onset of my symptoms, a long-awaited appointment with a neurologist sent me to the local ALS clinic. Items on the intake form previewed a potential future. *I fall over while walking. I find it difficult to stand up. I find turning and moving in bed difficult.* With five categories of response: Never, Rarely, Sometimes, Often, Always or cannot do at all. At the ALS clinic, I went through my first round of diagnostic tests and medical examinations, with suggestive but inconclusive results.

I started injecting myself with B₁₂ and taking supplements that enhanced functioning of the nervous system. I went to physical therapy,

acupuncture, and sessions with an expert in Feldenkrais—a slow, graceful exercise method for increasing agility and range of motion. But my daily decline continued.

Three friends related stories about loved ones who had suffered many years with dire symptoms and faulty treatment, only to visit Mayo Clinic and have their lives saved. Misdiagnosis for many years, accurate and life-saving diagnosis by Mayo, and a long, improved life. So, in early November, I flew to Rochester, Minnesota, and the miracle clinic. But my story is less newsworthy. I showed symptoms of an incurable, progressive disease, visited Mayo Clinic for a week of interviews and diagnostic testing, and left with symptoms of an incurable, progressive disease.

I stand up and look over the room of waiting people. A planting of mums, an outpouring of bright color, and then, with bowed heads, a fade to brown. Exiting the building through large rotating glass doors, I walk through a gathering of smokers absorbed in the multi-sensory pleasures of tobacco, some in medical scrubs.

I fly home the next day, returning to ominous uncertainty.

ALS IS AN INCURABLE, relentless dying-off of motor neurons in the brain and spinal cord, eventually leading to complete loss of movement—Beckett’s unworsenable worst—and then death. It’s diagnosed by ruling out all other disorders. There is no direct test.

Results from my local clinic and Mayo revealed no tumors, no signs of inflammation, no rheumatoid factors, no stenosis, no vitamin deficiencies, no suspicious antibodies, no connective tissue disease, no lesions on my cervical spine, and no accumulating fluid in my brain. Each negative result—ordinarily expected to bring relief—stepped me closer to a diagnosis of ALS. Meanwhile, my mobility continued to worsen, with weakness spreading throughout my body, bestowing daily loss of function and hope.

Each morning when I awaken, anxiety asserts itself. Coldness pools in my chest and surges into my arms and legs. Muscles twitch in my thighs, my forearms, my face. Taut strings plucked repeatedly, reminding me who’s in charge, reminding me that Nature’s playing my body. Lying in bed, I begin to warm. The bed supports, and the blankets comfort. Soon enough, I need to pee. And suddenly I have purpose.

Each day, the antivirus app on my cellphone tells me, “Everything is OK.” Is it really? My sardines and dried figs have expiration dates that

go beyond my own. I'm my own ministry of silly walks. Dark humor confronts my deterioration, waving its hand in respectful scorn at the awesome force of nature, writ small.

My favorite verb tense was always the future perfect, with its blend of optimism and reflection—thinking ahead about looking back. By four o'clock, I will have completed ten thousand steps. No more. In one year, I will have lost the ability to walk and hold up my head. Not exactly future perfect.

And so much conversation is about the future. Travel, work, learning to dance salsa. When I hear of the future, I grow silent. I'm traveling nowhere. Not Paris, not London, not nearby Chicago, and soon not up the stairs. Today is the best day of the rest of my life. And the worst so far.

A video shows Lou Gehrig standing tall, speaking forcefully to a sold-out Yankee Stadium, proclaiming his thankfulness—the luckiest man on the face of the earth. But we don't see him a year and a half later, on a feeding tube, collapsed in a wheelchair, his motor neurons melted candle wax. Conventional medicine was less regulated back then, and in some ways more humane. I believe (without evidence) that Mr. Gehrig left this earth pharmaceutically assisted.

How to express my decline before my tongue and hands go silent. How to express when only a thin strip separates insight from the obvious. I latch onto appropriate pithiness of geniuses. The onset of my disease, Hemingway's "gradually, then suddenly." My own ending, Aristotle's prescription of "surprising, yet inevitable."

New Yorker cartoons distill my thoughts, illustrating the outsize influence of concision. A doctor talking to a downcast patient in his examination room says, "Sometimes it helps to turn a question around. Why *not* you?"

Popular music transmogrifies. The heartachingly beautiful "Yesterday" is no longer a sweet sad love song, but an ode to progressive disease. "Yesterday, all my troubles seemed so far away. Now it looks as though they're here to stay." And then: "Suddenly, I'm not half the man I used to be. There's a shadow hanging over me."

Sisyphus and Job are conjoined. I push a rock that grows heavier each day. Is this punishment? God extending a ghostly cold hand through my skull and slowly squeezing my motor neurons to death. (And I will not capitalize god, unless it's for grammatical reasons.) No need to be biblical. Nature is cruel enough.

I am less fun at parties. Progressive disability is the most significant, persistent event in my life, but who wants to hear about that? (I'm sorry, dear reader, I guess the answer is you.) Even my subconscious avoids the subject. In my dreams, I'm young and fully able. What is my subconscious working on if not my implacable decline? Perhaps it is. In one dream, I meet a former teacher at a conference. He's surprised I became a professor, saying I was so unexpressive in his seminar. I tell him, people change. You've changed. You're dead now.

So much is spoken and written and sung about death, but almost nothing about disabling. Death is unknown, abstract, absolute (or not, depending on one's beliefs). Disabling is practical. A changing, temperamental collection of mundane questions. Who will bring in my mail? How will my clothes get washed, my nails clipped, my groceries bought and cooked? The simultaneous consideration of actual decline and anticipated decline. But through all the uncertainty and loss, I know one thing. I will do as much as I can, as long as I can.

Walking in my house requires canniness to bump against the walls at the right moment, to position myself with towel racks, to sit supported by weakening arms. The floor feels like the spongy surface of a playground, pushing back against my feet. The flat lawn, a field of troughs and boulders. The historian Tony Judt said ALS imprisoned him in a cell that shrank by six inches every day. Efforts to achieve an awkward dignity are unceasing and insufficient. Walking, losing balance, steady-ing myself—the triathlon of progressive disability.

How are you feeling? friends ask cautiously, with genuine concern. I now give a short answer. The same, except worse.

We don't know how life appears elsewhere in the universe, so the ongoing search for extraterrestrial intelligence is a search for the reversal of entropy—because the only force in the universe that reverses entropy is life. By ingesting and excreting, life organizes the world and fights chaos. Life takes in and life eliminates. We find elimination, and we find life. This I fear. Becoming life that only ingests and excretes.

The diseases we least understand are degenerative disorders of the nervous system. We know the architecture of the brain, the biochemistry of the basic neuron, the many neurotransmitters that operate in our synapses, the way dendrites grow and reach out to other neurons in our creepy-crawly nervous system. We even know how to slow the progression of some diseases for a while. But ultimately, we can do nothing but treat symptoms and provide palliative care. We don't know why these

diseases start, or how. Parkinson's, Alzheimer's, multiple sclerosis, ALS. The eponymous Lou Gehrig played for the 1927 Yankees, and nearly 100 years later, his disease remains a fatal mystery.

Twelve years ago, my wife died from complications of multiple sclerosis. At home in her own bed. Early in the course of her jagged descent, she led an active and mostly healthy life, with occasional exacerbations that sent her to the hospital for steroid treatments. During one extended visit, our ten-month-old daughter learned to walk—holding on to her mother's portable IV stand as we toured the hallways of the hospital.

Much later, I was my wife's caregiver. Grabbing and lifting her from the toilet, hugging her and taking her back to bed. Moving together, face-to-face, the physics of romance without the enchantment. Improvising a pas de deux in a focused effort to get somewhere else. My restrained frustration, her quiet fury.

Deficient imagination blurred my view of her experience, but my own inexorable decline now eliminates the need for imagination. At long last, I understand her losses.

EARLY JUNE. More than a year after my symptoms appeared. I'm in the waiting room of my hometown ALS clinic, a smaller, quieter place than Mayo in November. I distract myself with a paperback copy of *The Great Gatsby*, a book I first read nearly half a century ago.

Every test has been conducted, including the test of time, and my neurologist will give the diagnosis. I've told my family and close friends, and I love the love they show.

My dreams tell me I seek my former self. I believe in the past that day by day recedes before me. Tomorrow I will walk more slowly, stretch out my arms not as far . . . And one fine morning—

So I beat on, my boat against the current, borne back ceaselessly into the future.