

Preview

I begin, in the morning, by casing my joints. I spot-check my ankles on the stairs, flex my fingers at the kitchen counter, hope to peel an orange or open a jar, give up trying. Too stiff today.

These same joints used to glide through my rooms from morning to midnight, tossing off letters or scooping out chocolate ripple. I was still young, in my twenties, at the time they suddenly turned old. Then from one day to the next my life got thrown out of joint. An ailment called rheumatoid arthritis took hold of me, along with two million other people, mostly women. It felt like fire and ice, making my joints flare and congeal. It pinioned the moving parts and wrecked the bones' soft cushions. It demanded tablets and shots, baths to soak in, helpers to lean on, until no other remedy—please, no suggestions—seemed worth trying. My goal was to last it out, nothing more.

Of the countless people bearing daylong, lifelong ailments, a surprising portion live with a hundred kinds of arthritis. Some of them hardly move till midday, their pain's that bad. Others gulp down pills and take the side effects. Some have surgeons scrape their bones or replace joints. Others quit their jobs or bring home a fraction of what they'd earn if their joints worked right. Some feel jolted out of time, young but old. Others watch their lives coming apart at any age. Some whine and moan. Others are struck dumb. Most go without saying much about it. And at one time or another all these people were me.

For thirty years I kept my life-with-arthritis under wraps. The reason, I'm ashamed to say, was shame. I was embarrassed to ask for favors on the job, chagrined at moving slower than full stride, humbled by looking tired and antique. What's worse, I judged my slowness as a fault, marking myself tardy every day, behind the curve.

Before this disease I'd always sped forward, pushed by desire, will, and pride (I never thought of joints) through college and halfway

through grad school, heading toward history teaching, raising a baby too. I'd jumped into the women's movement and helped create a feminist icon—the invincible, independent woman—that I couldn't imitate after arthritis set in. I still held to my former desires and aims, just chewed myself out for falling short of them.

Waking with arthritis and going to sleep with it, for decades, I learned to shrink before that icon. Even now, with great drugs, I'm tired, pained, slower than anyone realizes. Producing a meal, a memo, let alone an actual paragraph, means measuring out every move. I'm OK to hike, but short on velocity or traction. Fine to make sandwiches, but bad with grip, with twist tops. Good for an hour of gabbing, but hopeless with handwriting or typing.

During the early years I tried pretty hard to learn nothing about my disease, certainly not why it came to me in the first place. Grasping at causes seemed so fruitless I hit on only one insight: it wasn't going to go away. In fact I barely said the name *rheumatoid arthritis* out loud.

For others too the varied experience of arthritis—stiffening, harrowing, immense—remains privately told or more likely untold. Oddly absent from public space is any sustained personal story (one I needed but never could find). This story belongs to millions of Americans with connective-tissue diseases like rheumatoid arthritis, osteoarthritis, fibromyalgia, some of them pesky and persistent, some exceedingly painful, some more treatable than many think, some more shameful than they should be, all unpublicized at best by those who live inside them. Now that arthritis drugs get pushed onto and whipped off the market, more publicly than ever before, we know enough to ask (for the first time in history) how bad arthritis is and what should be done, at what cost, for its sufferers. But no answers will come unless we have someone's full personal disclosure about the disease.

If arthritis sufferers still find it tough to confess, that's because their condition has stayed obscured from view. For most of my years few news stories covered the extent of arthritis, few fresh drugs alleviated its pains, few new doctors specialized in treating it. Meanwhile long inattention made the condition worse than it needed to be.

Few people, even now, realize that one in three Americans have arthritis, upward of seventy million adults (most with osteoarthritis, a disease wearing down cartilage between bones), plus three hun-

dred thousand children. Arthritis isn't known for what it is, our nation's most common disease, more hurtful and impairing, more costly (eighty-two billion dollars in annual impact), more rampant than anyone admits.

I'm forced to ask: how has it become possible to treat a national curse like a private mishap and a personal shame?

If I want this question on the table along with everything else, I have to change my mind about joints. By medical lights mine present a case of common degeneration. Even drugs that work are basically flame retardants, slowing damage but never stopping it. In chronic terms I have nothing to look forward to but a steady downward spiral. Yet slowly I'm arriving at another view, a view that harm is done, over time, by leaving illnesses unspoken and that good might come of knowing the ingenuity it takes to deal with them.

The upshot is, I'm trying to heal by delving into history. Not that visiting the past erases the pain of having lived there: it doesn't equal cure and isn't promoted by the AMA. Yet tracing a private timeline, and splicing it into a public one, has been the single best discovery of my chronic years, a way of enduring that's more like a way of moving ahead.

With a long illness there's time to do the thing historians do: sleuth around, go back to the sources, dig up old diaries stashed in the attic, recall the years before the disease hit, scan medical files kept under lock and key, pick through pieces of the past, reclaim a body that could have been ditched. Anyone can do it—pry open medical secrets, forgotten life events, and memories that witness the times. It's never too late to lift the limbs an inch or two by breathing the past back into them.

In the afternoon I swear, "I can take this, damn it," punching a two-hundred-dollar syringe, a wonder drug, into my thigh. I can take this weekly shot, the sequel of all-over hives, the future side effects—anything to push back the pain. Anything to climb the hills behind my house so a light wind can brush my skin.

Climbing today I can see the liberty I'm all for, and up against, as joggers and striders, sports bras and stretch pants, speed past me and my somewhat hidden handicap. Of course *handicap* isn't the proper

word anymore: it sounds accusing, like faulting people themselves instead of the barriers that get in their way. But it also sounds refreshing, seeming to level unearned advantages, offer slower people a head start, faster ones a little responsibility. For years I've been imagining an arbiter called the Angel of Anatomy, who'll balance everyone's chances, worsen an ailment here or grant a remission there. I've even made a bizarre bargain with this Angel: in exchange for hushed-up arthritis on my part, nothing dreadful can happen to my family.

Recently I've been granted a breather, released from stiffness by way of drugs. This remission arrived like new grass over last year's straw, a temporary state (who knows what's next?) where people like me hope to live out a lifetime. After years of dragging up these paths, now my joints are pretty much striding along. And I'm stunned by how much effort—medical and social, as well as personal—it's taken to get them moving.

Now's a good time to recall which efforts, over the years, managed to get my joints through the trials of being a parent, a teacher, a writer, a walker. From the start I relied on the empathy of family and friends. Then I tried research, learning where arthritis attacks the body, what causes inflammation, stiffness, fatigue, and danger. Eventually I got more daring, plunging into self-help and feminism, struggling with technology and alternative treatments, risking new remedies. Finally I've come far enough to track this long transformation.

Under an old familiar oak, an Endurance Tree, straining for straightness as if an unseen water table feeds its branches, I look on my bent joints with new curiosity. Which treatments and attitudes fed into them? Which beliefs kept blaming sickness on inborn defects or self-made faults? Why did silence take hold of this illness, and why is it beginning to expire? What changed recently so that "The Coming Epidemic of Arthritis" now rates cover stories in *Time* and *Newsweek*? What is forcing my ailment, and myself with it, into the open? What leaps in technology, what drives for remedies or profits, and above all what movements for rights have started to turn my shame upside down?

Only by incorporating all these changes—how much it took to get me to this place on this day—can the ankles and knees and toes and shoulders and elbows and hips and hands and neck and back and wrists and knuckles make their way toward healing.

Healing by history calls for an experiment. It has to do with binding together the pieces I've picked from my past, the same way joints connect the bones. If I think of others whose bodies keep backsliding, if my own questions can help them view illness in fresh ways, then I'll keep asking about my past: what did it set me up for? And about prospects: what happened to everything I expected? What changed my lot—new drugs, new rights? What about family? Did it prop me up, or did I drag it down? And pain: how much could I take? And the choices I made: any lucky ones? And despair: could I draw any good out of it?

In this experiment I hope to link my own moving parts with motions in public life and become, after years of silence, someone who speaks up about bodies in trouble, who changes the way trouble is privatized. Because my joints can't do what they used to, they might get me going this new way.

As evening sun lights the hilltop, I come on a flock of blackbirds roosting. A moment later, startled by wind, they burst into breakaway flight, and I feel lifted among them. I turn and head across a ridge, the wind catching me too, pasting my T-shirt around my ribs, moving my heavy feet along. I'm about to take a flyer, about to take a chance on the worst that's happened making the best sense of my life.

To lay open that life, I could begin anywhere, from my birth in a health-filled family to the deaths of all but me. But a juncture at midpoint is where I'll start off, thinking back to one late-night moment, in 1969.

There I am, in my twenties and sound asleep, when a first warning of pain like a sudden storm comes rolling in on me.