

if you are in the bottom 3 percent of the population that scores 70 or lower, your actual I.Q. number will mean a great deal. Scores in that range will most likely lead to a diagnosis of mental retardation, and that diagnosis will entail many things, starting with mandated special education. Since last June, across the United States, it has also entailed exemption from capital punishment. And so, for someone who has committed a capital crime, an I.Q. score can mean the difference, quite literally, between life and death. It can mean, if we want to be blunt about it, that there is such a thing as being too dumb to die, at least at the hands of the state.

Source: Talbot, Margaret. 2003, July 29. "The Executioner's I.Q. Test." *New York Times Magazine*. Available at: <http://www.newamerica.net/index.cfm?sec=Documents&pg=article&DocID=1275&T2=Article>

### ▣ Andrea Dworkin, "Through the Pain Barrier" (2005)

*This is the last piece written by Andrea Dworkin, composed just a month before she died. Few knew that she had suffered from an agonizing bone disease for several years. She describes with grim humor her worst moments and why she felt she was starting to heal.*

The doctor who knows me best says that osteoarthritis begins long before it cripples—in my case, possibly from homelessness, or sexual abuse, or beatings on my legs, or my weight.

John, my partner, blames *Scapegoat*, a study of Jewish identity and women's liberation that took me nine years to write; it is, he says, the book that stole my health. I blame the drug-rape that I experienced in 1999 in Paris. I returned from Paris and finished *Scapegoat* over a period of months while caring for my dying father. Shortly after he died I was in hospital, delirious from a high fever, with infection and blood clots in my legs. I was there for a month. John had been told that I was dying. I forgot that in hospitals when one is dying, nurses abrogate the rules. John was allowed in after visiting hours; nurses would pull the curtain around my bed and let him lie with me. This was my happiness. Doctors tell me that there is no medical truth to my notion that the rape caused this sickness or what happened after it. I believe I am right: it was the rape. They don't know because they have never looked.

A few months after I got out of the hospital, my knees began to change. They lost their flexibility. Slowly they stiffened. As they stiffened they became sore. They started to hurt terribly—as if injured but not visibly injured. I got a cellphone—this was before they were ubiquitous—so that if I couldn't walk any more I could call a car. I had given up on New York City subways: my knees could no longer bend enough to use them.

I went to an orthopaedic surgeon. I was diagnosed with osteoarthritis in my knees. I was treated with the anti-inflammatory Celebrex and, when that didn't work, its stronger cousin, Vioxx. Vioxx was recently taken off the market by its makers because of a risk of heart attacks or strokes; I was on it for three years. I had cortisone shots in my knees, followed by prednisone. The cortisone shots, which are painful, worked only once. Then I could walk without pain; in joy I sat on my front steps and talked with my neighbour—inconsequential chat. When I tried to stand up, my knees were rigid and excruciating. I managed to stand and swivel around; I took the remaining two steps up to my front door and used the door to drag me inside. I had had an hour-and-a-half of freedom.

My mobility lessened as the pain increased. Eventually I found myself housebound. I could walk only a few steps at a time, intimidated by the pain and the refusal of my knees to bend. John and I lived in a three-floor house. I could barely make my way up or down the steps. I'd crawl up the steps on hands and feet. I'd try to go down on my butt, step by step. The kitchen was on the first floor; the toilet on the second; my desk, books and shower on the third. My physical world became tiny and pain-racked. I stayed in my bed when I could. John brought me up food. I'd go out only to the doctors.

The orthopaedist started giving me narcotics, most of which contained acetaminophen, a common, nonprescription analgesic. My pharmacist persuaded the doctor that the liver damage caused by too much acetaminophen was more dangerous to me than stronger drugs. Through her advocacy I got a drug normally given only to cancer patients. It was a little yellow lollipop and when in pain one was supposed to lick. I licked a lot. I was told that I had to have my knees replaced. The prostheses are made out of titanium and plastic. I had both knees replaced at once, a normal practice now but unusual even a few years ago. My surgeon would later tell me that if I had had one done, I would never have returned for the second. He got that right.



*"Bodies in Commotion." Dancers at the annual Society for Disability Studies Dance, 2003.*

Source: Photo by Sharon Snyder.

I still don't know what he did to me but I came to the conclusion that the operation was barbaric, involving as it did the sawing out of the arthritis, which meant sawing through bones. It was like being kneecapped, twice, or having one's knees and bones hammered and broken into bits. After the operation I was in a nightmare of narcotics and untouchable pain. There were morphine shots. I asked for them and got them often. Even morphine shots in the upper arm hurt.

I had a hallucination but it is still real as rain to me. I was in Virginia Woolf's house and I was happy. But "they" wanted me to go down the stairs. I can't, I begged, I can't. My hospital bed was at the top of the stairs and I was afraid that they were going to push me down. I saw the steep decline of the steps. I couldn't get over my visceral fear of falling or being pushed or being turned over from the bed down the flight of steps. I kept experiencing my bed as being on the edge of a precipice.

One day, I remember, a nurses' aide braided my hair and I felt cooler, cleaner. I was on the bedpan, but raising myself up to use it—knees—was so fiercely painful that I would rather lie in my piss.

Then the day came when I had to walk. There was a vinyl chair next to my hospital bed. The physical therapist's name was Carl. He was like a tree trunk, big and

solid. You can do it, he said. I'll help you; we'll just go over to the chair. It was impossible, outside the realm of the imaginable. Carl let me hold on to him in a desperate, tight embrace as he carried me over to the chair. My legs dangled, my knees twisted, I sweated, I screamed. See, you could do that, he said, without a shred of irony. I had to sit there for two hours, which meant knees bent but not weight-bearing. Nurses came by and gave verbal approval: good dog, good dog. Eventually Carl carried me back to bed.

Pain is a four-letter word. There is no way to recreate it through memory. It is not like the flashback arising from traumatic events such as rape or battery. The flashback is as if it is happening now, in the present, even if it is from decades ago. Pain can be recent yet inaccessible to immediate experience. Torturers

know that people can't die from pain. The consequences of pain—for instance a heart attack—yes, but not from pain itself, however intense. The horror is that no one dies from pain. This means that suffering can be immeasurable, enduring, without respite. So it would be for me for the next two years.

I was taken to an institute for physical rehabilitation. A nurses' aide took me to shower in a wheelchair. I used a walker from the cot on which I slept to the wheelchair, maybe two miserable steps. I had two responsibilities—take my pain medications (Vicodin or Percocet) and show up at the right room at the right time for the scheduled rehabilitative class. I was not allowed to go to class if I did not take the painkillers. In fact, the pain was unrelenting. I lived for the next pill.

Physical therapy is based on tiny movements, increments of change that almost defy detection; it is built on the repetition of the minuscule. Yet to the hurt person these motions or movements or minute steps are hard. The first time is daunting and the 10th is like climbing Mount Everest. I sit in a big room, my wheelchair in a big circle of wheelchairs. Big is good because it means that my turn does not come often. I stand up by holding on to a walker and take a step. Then I step back and sit down. The cycle is hideous. The steps with the walker increase to two, then three. After several weeks I am assigned a means of locomotion: crutches.

Rehabilitation also includes so-called occupational therapy: throw a ball around in a circle; put round pegs in round holes; stand up, arms on a table, and read a page of a magazine; water a plant; play checkers or cards; and the *pièce de résistance*, cook and serve a simple meal. I am guided in the intricacies of shopping while crippled; I learn how to use a “grabber” to latch on to things I have dropped or cannot reach; I am taught again how to put on shoes and socks and tie shoelaces.

I also have to meet the institution’s psychologist once. I keep getting called back.

When I ask why, I am told that I am “interesting.” Well, yes, I think, I used to be. The narcotics help me deal with the psychologist but the physical pain simply marches on. It does not lessen or change or stop.

I learn three rules in my occupational therapy classes: never hold on to anything that moves; if it rains or snows, stay inside, even if that means cancelling doctors’ appointments (to those medicalised this is nearly profane); and kick the cat—if a cat curls up in front of your feet, kick it away. I learned to use my crutch to kick the cat. I will go to hell for this.

On discharge, social services are provided. My male partner is not expected to be a care-giver. I am sent an itinerant nurse, a young, poorly paid and badly trained social aide to help me with baths and to do light housework, and a freelance physical therapist who will do the drill: stand up, take steps, bend your knees, and—the killer—stand on your toes.

And on discharge a wreck like me is sent to a “pain management centre.” Despite my small successes at physical rehabilitation I am in agony. I spend almost all my time in bed, a bed of nails, all through the knees. The pain management centre is run by Curly, Larry and Moe. First there is a 10-page questionnaire. Rate from 1 to 10 your pain (I modestly assert an 8; my social conscience, atavistic as it is, tells me that there are others in more pain). Rate from 1 to 10: is your mother dead; how many people in your family have died of cancer; how is your sex life; how many times a week do you have sex?

They want me to undress so they can examine me. This is absurd. I refuse. There is a table they want me to lie on that they claim lessens pain. The bottom line is that New York State regulates narcotics to such an extent that regular doctors are reluctant to write prescriptions for painkillers; and so Curly, Larry and Moe at pain management put you through whatever rigmarole and then write prescriptions, none of which,

according to state law, can be refilled. So one is in a cycle of coming back for new prescriptions and new indignities every 30 days.

Curly eventually puts me on Percocet, fentanyl patches and methadone. I am on these drugs for nearly two years. I become slightly indifferent to the awful pain. My speech slurs and my memory is impaired. It is during this time that I write my memoir *Heartbreak*. I want to remember some good things in my life. I work for one hour a day. The narcotics do not make me Coleridge; but I hold my own.

One day I wake up and the pain is gone from my right knee—as if God had intervened. The pain in the left one is the same. I begin to go outside on my crutches. I can walk half a block to my local Starbucks. One day I sit there, still on my meds, and I see the ballet going on outside. The sidewalk is heavy with pedestrian traffic. They are so unselfconscious, these normal walkers. They have different gaits; they move effortlessly; each dances without knowing it. I used to be one of them. I want to be again.

The anti-drama of small gesticulations continues, this time in physical therapy several blocks from where I live. My left knee is still rotten. After another year of physical therapy they give me a cane. I put away all the crutches and other signs of what I call “disability chic.” I can sort of walk. The cane means victory. The pain in my left knee keeps me on my meds. Over the course of another year, that pain lessens. It’s a whisper, a shadow—it goes. I give up the pills, though I go through a nasty withdrawal from methadone.

Alas, there is no happy ending. John and I move to Washington so that he can take a job as managing editor of a large-circulation magazine. We live in an apartment without steps. I am on the cane. I go into physical therapy because, unable to stand up straight, I hunch over the cane. A few days later I am at the kitchen table reading a magazine. I stand up to get something and my right knee cannot bear any weight, none. I can’t use it because I can’t step on it. I have no pain; I have had no warning. I get to my crutches, which are in a closet. I need both of them in order to move. My right knee remains useless. The physical therapist determines that the quadriceps above the knee has stopped working, because imperceptible pain occasions the quad muscle to give out. Then my knee buckles and I fall. It is dangerous to fall. I see the physical therapist twice a week.

The orthopaedic surgeon (“a genius with knees,” says my internist) puts me in a restrictive brace that allows



*"Disabled and Proud" wheelchair lovers hug each other during the Chicago Disability Pride Parade, 2004.*

my knee to bend only so far. That way, if my knee fails, I am unlikely to fall. After nearly a year of physical therapy my quad muscle is not much stronger and my knee still buckles. The surgeon sends me to a rehabilitation hospital where they make me a new brace, specifically fitted to my leg. This brace works on the opposite principle to the first one: it immobilises the knee so that no buckling is possible, thus, no fall is possible.

It takes months for artisans to make the brace. It goes from beneath my calf to the top of my thigh. It is made of a black space-age material created to go to Mars or Saturn. Nothing makes it bend or stretch or break. It is completely unforgiving. I call it Darth Vader. It is the principle of evil incarnate. The straps that attach front to back are Velcro. I am supposed to lock it when I walk and unlock it when I want to sit. The brace is worn under my pants leg so no one can see it. Each manipulation is distinct: in public locking

it makes me look as if I am masturbating, and unlocking it makes me look as if I am fondling my thigh. The brace must be very tight and positioned perfectly to work. It takes me nearly two months to learn how to put it on and use it. I lose my balance in efforts to lock it. Once I flip backward, magically landing on a chair.

Self-respect demands that I clean up the faecal mess that my cat has made. It is the immobilized knee that makes bending down to the floor fraught with peril. I start falling and know that I must not hit the floor. I fight against gravity, my fingernails clawing at the walls and my hand grasping for the door frame. I know that if I fall I probably will not be able to get up. Somehow I raise myself.

I was slow with the first brace. I had to remind myself to be patient. With Darth I make the turtle look like the hare. The landscape is one of hazard. Anything can reach up and bite me: a break in the sidewalk; leaves; sand; mud; a sudden slope up or down; a stone; some pebbles. Anything threatening balance is dangerous: first the brace itself; then wind, people running or bicycling or being too close or too many; a fast car; a step; a curb; a puddle; heavy doors; slick surfaces. Crowds are impossible and so are stairs.

I want to be able to carry a cup along with a plate to the kitchen sink in one trip. I don't want to have to make two trips. The cup slips and breaks. This happens several times. Is it a small thing? I can't bear it or accept it. I reject the extent of my disability. I find myself in a silent rage that stretches over weeks. I am utterly exhausted by my incapacity. I am worn out from walking. I am sick of physical therapy.

There are little humiliations. I keynote a conference on the Holocaust. The organiser picks me up. She is driving a truck. I try to climb up into it. She physically pushes me under my ass without permission, all the while talking to me in baby talk, put your tooshie there, keep your cute little fanny there. I turn to her and say, I am disabled, not stupid. A friend throws a party for me in Washington. I ask how many steps there are to the apartment. He doesn't know. I assume he will get back to me. John and I go to the party. There are three flights of steps. I can't get to the party being given for me. We could have given it in another venue, the friend says the next day. It cuts. I go to a bar and need to use the rest room. The men's is filthy, the bartender says; the women's is two flights up. I use the dirty one. I go to a new movie theatre that has elevators and disability bathrooms but the polished

stone of the floor is so slick that my crutches cannot safely navigate it. I am walking with a friend who suddenly looks at my crutches and says, you don't want to be this way the rest of your life, do you? Her repulsion is barely masked. I feel unutterably alone.

Each disabled person has a story, often including pain, impairment, disorientation and loss of control. Each disabled person lives always on the threshold of separation, exile and involuntary otherness. Only a determined policy of public access can help to mitigate the loneliness. One needs to be able to enter buildings; have a cup of coffee; go to a restaurant, the theatre, cinema or a concert; attend school; go to lectures or readings; use public transport, bathrooms, hotel showers; go to museums and sporting events and political rallies. One needs equal opportunity in employment. One needs to be integrated into the world, not separated from it; yet one has special needs, ones that able-bodied people rarely consider. The low consciousness of the able-bodied increases alienation.

For mobility problems, one needs a new geography: kerb ramps; ramps in addition to steps; handrails; grab bars; high toilets; light doors; wheelchairs; room for wheelchairs in public bathrooms and hotel rooms; elevators; safety in floor surfaces including carpeting; entry and egress from public transport as well as acceptable seating; and a host of other considerations. Other disabilities require other remedies. In 1990 Congress passed the landmark Americans with Disabilities Act, which articulated in great detail the requirements for making the world available to disabled people. This is a civil rights law that recognises the exclusion of disabled people from the larger community as outright discrimination.

The law had its impact because disabled people found aggressive trial lawyers to sue commercial and private venues for noncompliance. The plaintiffs went after big-money damages for violating the civil rights mandated by the ADA. Eventually it became clear that compliance would be cheaper than continuing litigation. Losing money does put the fear of God into Americans.

I have to say that the ADA increases the quality of my life, Darth notwithstanding. I get through airports in a wheelchair provided by the airline; John takes me to the zoo a few blocks from where we live [and] the zoo provides a wheelchair; local coffee houses to which I gravitate have disability-standard bathrooms; there are special seats for me in cinemas and theatres and in rock venues; there are kerb ramps at pedestrian crossings and ramps or elevators in addition to steps and escalators in most public accommodations. In my neighbourhood I see many other disabled people outside all the time. We are not rare or invisible, because we are not hidden as if in shame.

And bless those nasty trial lawyers, whom George W Bush and the Republicans hate so much. Without them the ADA would be a useless pile of paper.

For myself—despite physical therapy, the breaking cups, and my immobilised knee—in the middle of the night, worn down, I listen to Yo-Yo Ma playing Bach or Loretta Lynn's Van Lear Rose; and I am, I think, healing. Surely music must be more powerful than bad luck.

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