

Twenty-two Books on Disability

Writing on disability is like fine bone china --- it demands a certain delicacy. Many disabled writers (or those who choose to write on our behalf) collapse into fake jollity, or bathos --- or employ a style that is icy, dispossessed, separated from the heart.

A worthy writer must show us the good as well as the ghastlies --- infections, aging, the unexamined hostility of society --- without getting maudlin, without descending into fake heroics, without the chill of unrelieved anger.

Good disabled literature should show the restraint of Ernest Hemingway, the tenderness of Mary F K Fisher, the insights of Virginia Woolf, the descriptive magic of H. G. Wells, and the mordant wit of S. J. Perelman.

Most of the titles below do not turn up in reading lists for Disability Studies, whatever the hell that's supposed to be. In these 22 books one can find the truth of our world: the reality of the body, the wisdom of the soul --- and the occasional rock-bottom despair of it all.

--- L. W. Milam

The Top Ten

- *Don't Worry, He Won't Get Far on Foot*, John Callahan (Vintage Books, 1990). This one should be at the top of all the lists. The reason: Callahan is a kick-in-the-pants --- feisty, cynical, smart. Years ago, he did cartoons for a Portland weekly, entitled "The Lighter Side of Being Paralyzed for Life." Like all funny crips, his writings and cartoons are peppered with the truth of living with a dysfunctional body 24 hours a day. Our bodies don't go away and a writer has to interleave humor with honest grief in what is, after all, our accelerated knowledge of the human condition. My favorite quote: *I felt as if a huge hand had reached down out of the heavens and placed me firmly on my butt in a wheelchair while a voice said, "Just sit there and*

relax for fifty years. Don't get up, ever." The only chance of relief from grief, from anger and from resentment I had was spiritual.

- *The Body Silent*, Robert Murphy (Henry Holt, 1987). Murphy was head of the Anthropology Department at Columbia University when he developed a spinal tumor. Here we have a scientist looking at a brand new world he has been handed along with his drastically changed body. This on rage: "Quadriplegics cannot stalk off in high (or low) dudgeon, nor can they even use body language... They cannot show fear, sorrow, depression, sexuality, or anger, for this disturbs the able-bodied. The unsound of limb are permitted only to laugh."

- *FDR's Splendid Deception*, Hugh Gallagher (Vandamere Press, 1994). Long after FDR died, people viewed him as a "recovered" cripple. The schemes used by him and his associates to disguise the true state of affairs (he was a polio paraplegic) were subtle but effective --- and the public bought into it. Gallagher claims we all paid a price for his pretense, for Roosevelt's last days were spent in deep melancholia which affected the way he ran the country and the decisions he made at the end of WWII.

- *Still Me*, Christopher Reeve (Random House, 1998). I picked this one up to sneer ... and came away convinced of Reeve's honesty and genuineness. The last chapter alone is worth the price of the book: fame and public appearances and world-wide applause mixed with dysreflexia, T.E.D. hoses, pressure sores, picc lines, being dropped during transfers and near suffocations when his breathing tube falls off. He tries magic cures, has out of body experiences, and more than once damn near dies. "I've been told...that as time went by not only would I become more

stable physically, but I would become well adjusted psychologically to my condition," he writes. "I have found the opposite to be true... It's still very difficult to accept the turn my life has taken, simply because of one unlucky moment."

- *The Diving Bell and the Butterfly*, Jean-Dominique Bauby (Knopf, 1997). One day Bauby woke up in a hospital with locked-in syndrome, due to which, according to the *Merck Manual*, "because of motor paralysis in all parts of the body [one] cannot communicate except possibly by coded eye movements." That's how he wrote this book--by blinking his one working eye. "My condition is monstrous, iniquitous, revolting, horrible," he writes. Bauby died several years ago, but this is a worthy gift he left us.

- *Rescuing Jeffrey*, Richard Galli (Algonquin Books of Chapel Hill, 2000). At age 17, Jeff Galli jumped into a friend's swimming pool and broke his spine. His father, an experienced journalist and attorney, asked the doctors to remove his life support. Galli has created a spectacular piece of writing, a cliff-hanging mystery --- one in which we think a murder may be going to happen. Living as a quadriplegic can be a pisser, right? And yet, to kill the kid without his knowledge or permission? It is this rank honesty that sets "Rescuing Jeffrey" apart from most books on disability's effect on the family.

- *Moving Violations*, John Hockenberry (Hyperion, 1995). It's Hockenberry's sometimes angry, always articulate, mostly insightful writing that transforms a specific and personal event into the experience of all of us. "My body had become a puzzle. Solving it was exhilarating beyond the simple imperatives of survival." He claims to have escaped anger, but his description of tearing apart a New York taxi (the driver wouldn't fold up his

wheelchair) implies otherwise. The writing at times rises to high comedy, especially memories of his early days in the hospital.

- *Tumbling After*, Susan Parker (Crown, 2002). Parker's husband Ralph is a C-4 quad --- bicycle accident, Berkeley, 1994. In *Tumbling After*, she manages to convey a fine mix of despair and hilarity and stoicism and soul-cracking honesty --- so much so that when I got done I wanted to call her up just to be sure that everything was still OK, that she's picking Ralph up after he falls and flossing his teeth and watching for bedsores and drying his eyes when he cries. After the accident she found herself in a whole new world, with a new job, and with new people --- her ghetto neighbors --- all of whom she describes lovingly and well.

- *The Boy and The Dog Are Sleeping*, Nasdijj (Ballantine, 2003). Does a book on AIDS belong in this list? Well, AIDS is a degenerative disease operating in overdrive. Nasdijj, a 50-year-old writer, adopts the dying boy Awee, learns to laugh with him, and clean up his shit and vomit, time and time again, and again with such pain, watch him wasting away. This is not only a primer on AIDS, and what the treatment does to destroy the body while saving the body --- but the mad-making world of the medical professionals, especially those who are supposed to deal with the poor, who cannot and will not properly care for those who are at high risk. Sometimes the text is so painful that one must lay it down for awhile, just to give the heart and soul a rest.

- *Learning To Fall*, Philip Simmons (Bantam). Philip Simmons was diagnosed with Lou Gehrig's disease when he was 35 years old. He works hard to find hope in his situation so the book turns into a spiritual treatise, riding on the dual questions: Why would God create such a trauma? And, how can one man

deal with such a trauma without going under? For some of us, *Learning to Fall* has an unfortunate premise--that God sends down bad things to teach us to be good. Despite this Old Testament view, the writing is superb.

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The Runners-Up

- *My Second Twenty Years*, Richard P. Brickner (Basic Books, 1976). This one came out over 25 years ago and was featured on the front page of the "New York Times Book Review." Brickner was one of the first to write about living with disability day in and day out. The book includes a list of ladies he has bedded (which can get tedious) with a studied literary style (which can get tedious). The writing is rich in detail, but there is a strange undercurrent: a proud man's distaste for women, distaste for the lower classes; even a distaste for others with disabilities.
- *Born on the 4th of July*, Ron Kovic (McGraw Hill, 1976). This one appeared the same year as Brickner's autobiography, but the difference between the two is epic. In Kovic's book, rage is transformed into a searing view of his world, complete with stories of his political activism. There is no relief in this steaming brew: not even a bitter humor-in-loss. He writes, "No one wants too many people to know how much of him has really died in the [Vietnam] war."
- *A Whole New Life*, Reynolds Price (Plume, 1994). This author is a darling of the New York Literary Smart Set, so some nondisabled readers may see this as the defining story of disability. Unfortunately, *A Whole New Life* is hack-work at its worst. When the infiltrating tumor of his spine took hold in 1984, Price reported that he was not able to find any books to

help him figure out the course of his new life. In one brief paragraph, he thus kissed off Ron Kovic, Patrick Segal, Richard Brickner, Jonathan Nasaw--not to mention Margaret White, Helen Keller, and even Shakespeare's astonishing Richard III.

- *Under the Eye of the Clock*, Christopher Nolan (St. Martins 1988). Nolan was born with cerebral palsy. His writing is poetic, wry, and gentle. He tells, for example, how at age three he realized that he was different from others: "He showed [his mother] his arms, his legs, his useless body. Beckoning his tears he shook his head. Looking at his mother he blamed her, he damned her, he mouthed his cantankerous why, why, why me?" Nolan likes poetic inversions --- sounding, at times, like James Joyce or Dylan Thomas --- but all the while, his words are fresh and alive.

- *Falling into Life*, Leonard Kriegel (North Point Press, 1991). "And I can't take it, yet I do take it," is his favorite quote, taken from Saul Bellow. Kriegel speaks of "the cripple [his words] who validates his life by creating a sense of selfhood out of physical pain." The general tone of this book is one of self-loathing and fatigue, but it is of historical interest since he was one of the first to write about disability using an intellectual literary style.

- *Broken Vessels*, Andre Dubus (David R. Godine 1991). Autobiographical stories from an ex-Marine and prize-winning author, including the story of the automobile accident that cost him his legs. Dubus was a faithful Catholic, and the book is filled with sin and redemption, sin and redemption. He says that in his life, there is no sadness, only bitterness (he told Susan Stamberg, "I stay angry a lot.") Dubus and Kriegel are members

of what we might think of as the Tough Guy school of disability writing.

- *Plaintext*, Nancy Mairs (U. of Arizona Press, 1986). Mairs has written extensively about living with MS. She was one of the first disabled feminists, and no lightweight feminist either. She believes, for example, that the prejudices and pressures and demands of a male-dominated society have created her depressive attacks. She, like Kriegel, has an aversion to what her body has become: "Because I hate being crippled, I sometimes hate myself for being a cripple. Over the years, I have come to expect --- even accept --- attacks of violent self-loathing."

- *Happy Old Year*, Marcelo Rubens Paiva, David George, translator (Latin American Literary Review, 1991). Marcelo is so full of life and love and heat and passion and being a kid that it becomes quite infectious. Before his diving accident at age 20, he was head of a music group called "The Turds." He regales us with tales of the terrible political world of Brazil and then, a moment later, delights in being able to sit up for the first time in the hospital (he then passes out). He rails, as many of us have, at the lacks of modern medicine: "You mean that science hasn't come up with some goddamn injection to take care of my problem. No operation, nothing? So it's just me and my body? I can't handle this, I'm not mature enough to face this by myself...Please, don't leave me alone."

- *Missing Pieces*, Irving Zola (Temple, 1983). Zola originated the idea that disability is a socially constructed concept. "The very vocabulary we use to describe ourselves," he writes, "is borrowed from that society. We are de-formed, dis-eased, disabled, dis-ordered, ab-normal, and, most telling of all, called an in-valid." As a social scientist, he went to acquaint himself with

Het Dorp, a village in the Netherlands designed to promote "the optimum happiness" of those with severe physical disabilities. Through the author's growing awareness, what began as a sociological study became a socio-autobiography.

- *The Unexpected Minority*, John Gliedman and William Roth (Harcourt Brace, 1980). "Of all America's oppressed groups, only the handicapped have been so fully disenfranchised in the name of health," write the authors. *Unexpected Minority* looks at disability in terms of freedom, politics and history, and it goes back to Plato, through the Christian concepts of sin, and even examines footbinding in China.
- *Still Here: Embracing Aging, Changing, and Dying*, Ram Dass (Riverhead, 2000). Ram Dass--of *Be Here Now* fame --- had a stroke, survived, and is now in a wheelchair. "I've grown to love my wheelchair (I call it my swan boat) and being wheeled about by people who care," he tells us. He also says he "loves suffering." These remarks may irritate many of us, but because of Dass' great popularity, this book will be as influential as any on this list.
- *Rehabilitating America*, by Frank Bowe (Harper & Row, 1981). I am usually bored to death with books about the politics of disability, but Barry Corbet said that if I didn't include *Rehabilitating America* in this list, "the activists among us will feel jilted" (and, presumably, he and his friends will start picketing me and chaining their wheelchairs to my bathroom door). He's right and I did.