

A person who experiences a terrible personal tragedy and chooses to write about it faces a daunting challenge. Though every detail of the sad and difficult journey is searingly meaningful to the afflicted writer, will anyone else care? Or will the distant reader think the misfortune is merely repellent and shrink away, relieved that so awful a fate did not afflict him?

In *Too Late to Die Young*, Harriet McBryde Johnson has overcome this problem with her essential wit, humanity and pluck. This is a transporting tale about a determined and attractive woman with congenital neuromuscular disease, who has never walked, who expected to die young and yet who has gone on to a distinguished career in the law, an often fun-filled life as a brassy activist for the handicapped and a rich existence with friends and colleagues in the mossy insouciance of Charleston, S.C.

This is a book full of surprises. Johnson puts us on notice at the outset that she has a wry eye for the "natural" world. She rejects the "formulaic narratives" that we have constructed featuring handicapped people as "stock figures" to be pitied and at the same time praised for their courage and inspiration to others. Though her spine may be horribly twisted, though a simple tumble from a wheelchair may turn into a life crisis, she argues for her humanity in the fullest and most equal sense. She is prickly and feisty. She is not to be trifled with.

And yet there is great value in knowing what the life of a fragile figure, imprisoned in a wheelchair and unable to swallow solid food, is like in modern America, especially the America that has been considerably improved by the Americans With Disabilities Act of 1990. The logistics are formidable: the need for caregivers, the navigation of streets and buildings, the simple acts of getting into bed or going to the bathroom, the desperate risks that may lurk around any corner. Life for the handicapped is pretty elemental.

Johnson escorts us into what she calls "cripworld" or "cripdom" with bubbly good cheer, almost daring us to feel sorry for her. No authority, no impediment seems to stymie her. As an undergraduate at the University of South Carolina, she took on the Secret Service and Ronald Reagan when the police invaded her private space and tried to shut down her protest of the president's visit to her campus. Eight years later when she was assistant city attorney in Charleston, she became a leading figure in a protest against Jerry Lewis and his pity-inspiring commercial telethons.

"We don't want pity," she quotes a fellow protester against the Lewis bathos as saying, "Pity gets in our way when we are looking for jobs and a place in the community."

She fought for her dignity and her space as a delegate to the 1996 Democratic National Convention when she was alternately trampled and then shut in by a cordon of buttocks. "Keep your butt out of my face," she demanded. She deplored the way that Christopher Reeve was used at the convention. "There he is, Charlie McCarthy," she writes. And in 2002 at Princeton, in a quite fascinating debate, she confronted animal-rights philosopher Peter Singer and his genocidal argument that society would be better off if disabled people like her did not exist. The essence of the interchange was the question of whether the life of a disabled person is inherently less happy and valuable. She won.

Her tales are generally told in a chatty style. This works for the most part, though I wish the Southern lady, in turning the tables on all those Yankee writers who have tried to reproduce Southern dialect, had not tried to reproduce the speech of the New York cabdriver. "I take you to Foity-foive Foity-sixth, and if that dun't woik, we can troy something else."

Her foray into elective politics in the form of a run for the Charleston seat on the County Council is hilarious and unforgettable. She ran a contest for a campaign slogan and eventually came up with: "Vote Harriet. What the hell, why not?" Who could resist voting for such a candidate? "Our politics can be ceremonial and stately," she writes about courtly Charleston, "but no one would call them pretty -- even when the azaleas are in bloom." Try putting into that mix a wheelchair atheist with dangly earrings and a platform of gun control, abortion rights and the right to burn the flag. She lost.

When she turns to her role in a court case involving the Americans With Disabilities Act, and later to her debate with Singer, the serious person beneath the chat is fully on display, along with the seriousness of the issues and the discrimination that handicapped people in America face. To make the abstract issues of the courtroom real and immediate, she follows with a chapter on a wheelchair accident that she once suffered at a conference in Tucson. This is a terrifying story. Every movement by emergency personnel had to be just right, with dire consequences for the wrong move, and the medication at the hospital had to be exact for a unique patient. In a curious twist, it was Johnson herself who directed every move, despite being crumpled in a ball on the ground and in terrible pain. She was the one in charge.

There is a small but discrete growing literature by writers who have experienced personal or family tragedy: William Styron on his depression, Reynolds Price on his paraplegia, Kenzaburo Oe on his brain-damaged son, Morton Kondracke on the Parkinson's disease of his wife, Milly. Though the specific nature of the difficulty varies in these books, they all touch on common themes: fear, pity, anger, depression, shame, risk, relation to the outside world. To read these stories can deepen everyone's humanity. But they are also especially useful to the millions who quietly endure the same or worse situations and are desperate for some small insight into how to cope. Toward the end of Johnson's fine book, she is upset that someone has complained about her being a difficult person.

"Oh, no," her father replies. "You're easy to deal with. As long as you get exactly what you want." Brava.

Too Late to Die Young can proudly take its place among these other important books.

Reviewed by James Reston Jr.

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