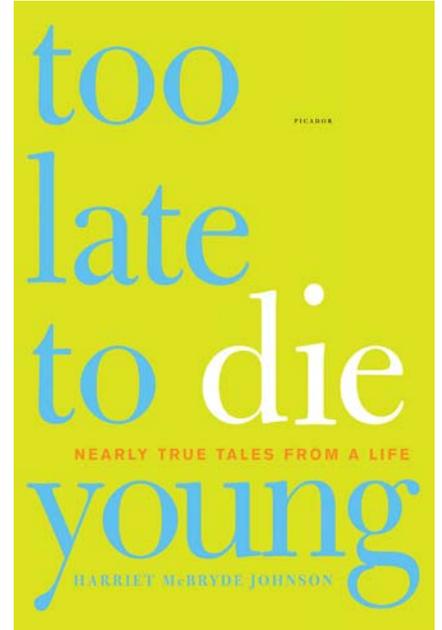


READING GROUP GUIDE

Too Late to Die Young *Nearly True Tales from a Life* by *Harriet McBryde Johnson*

ISBN: 0-312-42571-6



About this Guide

The following author biography and list of questions about *Too Late to Die Young* are intended as resources to aid individual readers and book groups who would like to learn more about the author and this book. We hope that this guide will provide you a starting place for discussion, and suggest a variety of perspectives from which you might approach *Too Late to Die Young*.

About the Book

Harriet McBryde Johnson isn't sure, but she thinks one of her earliest memories was learning that she will die. The message came from a maudlin TV commercial for the Muscular Dystrophy Association that featured a boy who looked a lot like her. Then, as now, Johnson tended to draw her own conclusions. In secret, she carried the knowledge of her mortality with her and tried to sort out what it meant. By the time she realized she wasn't a dying child, she was living a grown-up life, intensely engaged with people, politics, work, struggle, and community.

Due to a congenital neuromuscular disease, Johnson has never been able to walk, dress, or bathe without assistance. With help, however, she manages to take on the world. From the streets of Havana, where she covers an international disability rights conference, to the floor of the Democratic National Convention in Chicago, to an auditorium at Princeton, where she defends

her right to live against philosopher Peter Singer, she lives a life on her own terms. And along the way, she defies and debunks every popular assumption about disability.

This unconventional memoir opens with a lyrical meditation on death and ends with a surprising sermon on pleasure. In between, we get the tales Johnson most enjoys telling from her own life. This is not a book “about disability” but it will surprise anyone who has ever imagined that life with a severe disability is inherently worse than another kind of life.

“There is a small but discrete literature by writers who have experienced personal or family tragedy: William Styron on his depression, Reynolds Price on his paraplegia, Kenzaburō Ōe on his brain-damaged son. . . . To read these stories can deepen everyone’s humanity. *Too Late to Die Young* can proudly take its place among these other important books.”

—*The Washington Post*

“Masterfully paced and structured . . . *Too Late to Die Young* serves as both a memoir and a kind of revolutionary act itself.”

—Mary Johnson, *Ragged Edge Online*

“Johnson’s rich, descriptive writing, humor, and Southern cadence make the book entertaining, thought provoking, and meaningful.”

—*The Post and Courier* (Charleston, South Carolina)

“She insists on being her own complicated person, a Southern lady, for instance, as well as a socialist, an atheist, a lawyer, and a born storyteller with a wicked sense of humor. . . . But her writing is so vibrant, so interesting, and so funny that you can’t help but feel as if you’re in her world, sitting beside her and hearing her story for yourself.”

—*The Tampa Tribune*

“This lady pulls no punches. An entertaining look at an activist who insists on living life her way, disability or no; strongly recommended.”

—*Library Journal*

“A wonderful mix: a keen mind, exuberance, activist politics, along with a special brand of Southern women’s wit.”

—Adrienne Rich

About the Author

Harriet McBryde Johnson has been a lawyer in Charleston, South Carolina, since 1985. Her solo practice emphasizes benefits and civil rights claims for poor and working people with disabilities. For more than twenty-five years, she has been active in the struggle for social justice, especially disability rights. She holds the world endurance record (fourteen years without interruption) for protesting the Jerry Lewis telethon for the Muscular Dystrophy Association. She served the City of Charleston Democratic Party for eleven years, first as secretary and then as chair. She is a frequent contributor to *The New York Times Magazine* and to the disability press.

Discussion Questions

1. As an attorney, Harriet McBryde Johnson has a reputation as a master persuader. Does she build a case in *Too Late to Die Young*? If so, what case? To what new perspectives has she opened your eyes?
2. In broad terms, what were Harriet and Norah fighting for when refusing to vacate their student housing at the request of the Secret Service? What larger issues are reflected in that single incident?
3. Before reading this memoir, what were your impressions of Jerry Lewis's telethon? How might such media events unfold if Johnson were the host instead? How do you answer the picket sign's question: Why must we beg?
4. The trial Johnson litigates for the client with back surgery brings to light important definitions, particularly the distinction between having a disability and being disabled or lacking ability generally. How would you have voted had you served on the jury? How should the Americans with Disabilities Act be interpreted in cases such as these?
5. Johnson's experience in Cuba underscores several universal desires—the desire to be seen for your true self, not as a stereotype; to have basic human needs met, in an environment that doesn't segregate; to live with dignity. Does capitalism support or undermine the individual's right to grow and flourish? What about the right to “contribute to social transformation?” What positive and negative effects does capitalism have on humanity?
6. Johnson's day at Princeton presents an unusual blend of experiences, from unspeakable conversations with Peter Singer to viewing the Christopher Reeve suite at a local hotel. What realities does this trip confirm? What surprises does it bring? Was Johnson right to meet with Singer, even though she agrees with Not Dead Yet that disabled lives should not be subject to debate?
7. Johnson tells us that she comes from a tradition of illustrious storytellers, and that storytelling has allowed her to barter her way out of a few predicaments. How would you describe her storytelling style and her talents as a writer? What is unique about her delivery?
8. What role does Johnson's hometown of Charleston play in this memoir? In what way does the South, as a setting along with its cultural codes, affect the way her memories unfold?
9. What is the effect of ending the book with a love story and with the observation in the next-to-last paragraph that “in love as in life, every impossibility opens a door to some surprise?”
10. Johnson has written that when she tells stories in her van, each telling is a new story because she is influenced by the listener's reactions and questions. If you were listening to Johnson tell her stories, what questions or reactions would you have that might send her in new directions?

11. The book's title and first chapter reflect the author's constant defiance of conventional wisdom. To what do you attribute this ability: family, role models, temperament, life experience, physiology? What separates visionaries from those who resign themselves to accepted norms?
12. The chapters "What the Hell, Why Not?" and "Unconventional Acts" deal in different ways with Democratic Party politics. In one story, Johnson runs for office with no real hope of winning. In the other, she joins in re-nominating a president of whom she is very critical. Was there any point to this activity? How do these stories illuminate Johnson's relationships with the Party, the political process, and community? Is her community represented by Charleston or by the disability community that "seizes the streets" of Chicago at the end of the convention story?
13. In "Trial and Error," a passerby tells Johnson she looks "just like a Doll Baby," intending it as a compliment. Discuss the many quandaries raised by this comment, such as what determines our understanding of beauty, what it takes to be perceived as powerful, and why so many assumptions based on appearance prove to be inaccurate. How does this discussion change when applied to Johnson's experience as an art object, at the hands of *New York Times* photographers? Do you notice other places in the book where Johnson's looks are an issue?
14. What does chapter eight, "Getting Thrown," reveal about the American healthcare system? How do the physicians and hospital workers compare to the personal assistants, friends, and relatives who normally assist Johnson without any medical training? Why is it so important for her that people follow her exact instructions in handling her body? How is Johnson's hospital experience related to the topic of the workshop she helped present in Arizona?

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