

Being Disabled — And Female

WITH THE POWER OF EACH BREATH: A Disabled Women's Anthology

Edited by Susan E. Browne, Debra Connors & Nanci Stern
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REVIEWED BY SHEILA KOREN

With the Power of Each Breath" is a challenging and controversial collection of mostly true-life stories, some poems and a few not-very-well-defined-as-such pieces of fiction. Its contributors are all disabled women, representing a wide range of ages, physical and mental conditions, as well as differing geographical and social circumstances.

Editors Susan E. Browne, Debra Connors and Nanci Sterne, all contributors as well, first met as part of a diabetics' support group. While checking blood sugars together they shared stories of their growing up and living with chronic physical illness. Out of their meeting came first a disability workshop that they organized together and then this book by and about disabled women. "Some live with chronic pain," they write, "some with chronic unpredictability and some with chronic stares."

The book's title is derived from its opening poem by Susan Hansell entitled "The Wolf." In it, she describes the terrors of lupus — a condition in which the body devours itself. Without a future to count on, she has learned to appreciate "the power of each breath."

Although a book about disabled women may seem perhaps overly particular in focus at first consideration, it becomes apparent through reading these life histories that disabled women do have some very particular and critically

important issues and concerns to share. Disabled women make only 24 cents to every 59 cents that able-bodied women earn in relation to the average man's dollar. And when you "particularize" that down to black disabled women, the figure is reduced to 12 cents. As Debra Connors points out: "Women patients are much more likely than men to be medically abused." Most rehabilitation and financial assistance programs were developed through male-oriented workman's compensation and veterans' legislation. As medical sociologist Barbara Mandell Altman explains, "Entry to benefits is most commonly associated with the pre-disability role and has created a strong barrier for disabled women because of their non-work force participation prior to disability."

Teacher Anne Finger points out that the "normalization" efforts so much in vogue these days — moving developmentally disabled people into the community — often involve instructing clients that "normal" women are supposed to "curl their hair, wear make-up and dresses, giggle and sleep with men."

Unlike classic and corny disability literature, doctors are by no means the heroes of this book. They are portrayed throughout as largely cruel, insensitive and arrogant, often exacerbating already troublesome conditions. Mary Ambo, who has cerebral palsy as well as her own apartment and a staff of 11 various helpers, writes that "When I go into a doctor's office, instead of talking directly to me, the doctor asks the person I'm with why I'm there."

Local activist Jill Sager's differing leg lengths were

made more so by physicians who got her permission to do experimental surgery by asking if she wanted to wear high heels to her high school graduation. Such outrageous assaults are equalled by disrespectful and humiliating school systems that put disabled students into special "health classes." "Every week," describes Sager, "we walked to assembly in single file in front of the rest of the school while they stared and we tried not to feel different."

Undoubtedly the most controversial issue raised in "With the Power of Each Breath" concerns abortion. Although no contributor seems opposed to the pro-choice position, several were clearly offended that detection of a disabled fetus is seen by many as good reason to abort it, when they themselves feel quite happy to be alive. Debra Connors writes: "Prenatal diagnosis, which early eugenicists sought to discover, has been praised as a miracle of modern medicine, one that has made it all too clear that only children who might some day be permitted to be 'productive' are welcomed into the world."

Many contributors to "With the Power of Each Breath" write constructively about how they envision better, more respectful treatment in the family, the workplace and the women's community. Some pieces, however, like Emily Levy's description of her environmental illness, create confusing double binds for others. She wants friends to appreciate her ever-varying reactions to presences like smoke, animals and perfume, but also wants them to second-guess and plan for her as well.

Mostly, however, contributions to "With the Power of Each Breath," whether dealing with obesity, deafness or quadriplegia, are non-complaining assertions of self-love, sincerity and social responsibility. What might have been just an angry collection of self-pitying documents about how oppressive it is to be double-whammied with both disabled and female status in this society, is instead a highly creative and analytical effort that contains invaluable insights and information not available anywhere else. ■

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