

Book Review

Title: *Surprised to be Standing: A Spiritual Journey*

Author: Steven E. Brown

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Reviewer: Janine Bertram Kemp

With *Surprised to be Standing*, Steve Brown is turning over new ground in disability literature. Activists, academics, and advocates might do well to listen up, especially those looking to toss a little wellness or self care into their mix. Brown's book does not point the path for others. His is a deeply personal narrative. He is a writer of integrity and solid disability rights credentials who wades into arenas that could create controversy if his views are misconstrued.

The narrative is divided into three sections: pain, healing, and liberation. The section on pain greatly details the author's experience with Gaucher Disease (GD), which began for him at age 5. GD involved perpetual, excruciating pain and regular experiences with broken bones. Brown managed to work and gain advanced degrees when many might lie in bed and whine, "Just shoot me." The author is affected but yet not beaten down by intense pain. His accounts are matter of fact, no-pity-please: here is how it was and here is how I dealt with it.

At one point Brown notes that for some reason, during the times of body and mind-wrenching pain, he could eat only nuts. And he writes of nuts in poetic prose that made this reader laugh out loud:

"Nuts: cashews have a lovely curve...tender, undulating. Walnuts are like a saw, striated, just enough space for the tongue to lap the salt. Almonds are best whole, yet small. Did nuts feel pain when the nutcracker pierced their tough shells? Brazil nuts are odd – sometimes the flaxy taste one wants, other times, a waxy flavor to avoid. Peanuts, last eaten...." (p. 23)

Reading through seemingly unending descriptions of pain, broken bones and the insults perpetrated by representatives of the medical profession, I wondered how much Brown's inner poetry led to his ability to metaphorically keep dancing.

Yet he had bleak thoughts, like most of us who ride the severe pain train. He describes a particularly desolate episode during the early 1970's when he was attending Southern Illinois University:

“My body responded in a way I had never felt before. It was my worst bone crisis. ...All I could feel was pain...I cursed God. I cried. Suicide began to appeal. Not because I wanted to die, but to do something, anything to escape the pain” (p. 51).

GD weakened Brown’s body, and he began using crutches, a manual wheelchair, and then a power wheelchair. In the book’s first section, the physical aspects of GD are interwoven with matter-of-fact depictions of his life and politics as a student and early spiritual explorations. He becomes active in protesting the Vietnam War, but committed to his hero Gandhi’s principles, and drops back when groups move from non-violence to revolutionary resistance.

Noting his own early psychic abilities, Brown briefly affiliated with Quince, a practitioner who bases his mystical competence on power and fear, rather than knowledge and love. That being the one brush with “the dark side,” the book touches on a number of modalities, including channeling and *A Course in Miracles* that the author’s spiritual travels took him through.

The final portion of the first section “Pain” could almost be in the section on healing. It concerns Brown’s discovery of and joining with the disability rights movement, where with his wife Lillian, he founded the Institute of Disability Culture and, through work and insight, carved out a leading role for himself.

Many parts of Brown’s evolution as a disability rights leader will resonate with others, and some parts are uniquely his. “Overnight Radical,” one of the book’s chapters, tells Steve’s story of finishing graduate school without a job. He had already spent a year as a History Instructor at his university. His department chair called to say he had recommended Steve to a Tulsa-based firm to write the history of the organization. The phone interview went swimmingly, but after the in-person interview, the company representative said they had changed their mind and would not hire Brown because of his disability. They thought someone on crutches could not possibly do the job. “I became radicalized overnight into a disability rights advocate” writes Brown (p.74). Indeed it is a common story for those seeking employment in the 1970’s and 1980’s.

Brown found his way into the independent living movement in Oklahoma, and his first experiences were lessons in the need for consumer, rather than service provider, control. He was part of a group that wrested control of a Center for Independent Living from a provider group run by non-disabled personnel. He became involved in the national disability rights movement and joined people with disabilities all over the country in working for the passage of the Americans with Disabilities Act. Brown moved from Oklahoma to the World Institute on Disability in Oakland, California. He married a co-worker, Lillian Gonzales Brown, whose work as a disability rights advocate is also well known. Together they founded the Institute on Disability Culture.

In his section about healing, Brown describes moving from using crutches to a manual and then a power wheelchair. And finally, after spiritual healing experiences, Brown moves back to walking again. This is a journey that could raise eyebrows among members of the disability community. Faith healers have discounted many of us with disabilities and spiritualists

have viewed cure of our disability, be it physical, cognitive, or emotional, as necessary to recreate us as whole. In our community, “cure” is a dirty word:

“This tension between what any healer – traditional or alternative – offered and our quest to live as people with disabilities, struck at the core of our beliefs. We’d worked for decades to convince society those of us with disabilities lived meaningful, productive, and proud lives despite existing in a society filled with prejudice and discrimination based on disability. A core principle that we didn’t need to change, society did, informed all our thinking. Now this man Lil and I had brought to the conference claimed we didn’t need to hang on to our disabilities if we didn’t want to. How could we merge this kind of thought with being proud of who we were as people with disabilities?” (pp. 154-155)

Brown is not talking about a spiritual cure. He is not stating that a life walking is better than a life riding and he is in no way denying the depth of disability culture and its impact on his own experience. That said, one of my few criticisms of this book is that it would benefit from more exploration of this very point as well as the controversy that engenders the need for it. Few disability rights writers or leaders have had the courage to venture into spiritual realms that many criticize as “woo woo.” Given that the author does not appear to be out to convert readers and that spirituality is a personal, individualized path, it is best to leave skepticism at the door when reading this book.

The healing journey bridges numerous geographies. Brown and Gonzales Brown lived in Las Cruces, New Mexico, traveled to Germany, and moved to Hawai‘i, where they currently reside. In Germany, they met and formed ongoing relationships with two different healers, Otto (no last name cited) and Herwig Schoen, who played key parts in Brown’s odyssey. Otto was a physical therapist and a practitioner of cranial-sacral therapy. Through Otto, Brown met a physician and his wife who used Pulsed Signal Therapy (PST) to treat pain. PST, which seems similar to an Alpha-Stim or TENS unit, uses electrical stimulation to “stimulate the body to rearrange cells to their original non-pain situations” (p. 140). Both Lillian and Steve had several treatments in Germany, which decreased pain enough to lead Brown to a watershed moment. “Lying on the table one day...I remarked, ‘I think I need to focus on healing. I’ve written and talked about pain enough’” (p. 141).

Brown met Schoen at Otto’s wedding and was introduced shortly thereafter to the very new Reconnective Therapy (RCT) that Schoen was developing. It was a life-changing modality for Brown. The therapy is based on the theory that there is a disconnect between our energetic and physical bodies that causes disease and dysfunction. Brown’s RCT experience led to a significant decrease in pain and bone breakage. It also led him to follow his inner wisdom, which kept sending him visions of himself running. Gradually, he reduced pain medication and finally slowed and stopped using a wheelchair. Over time, he became an RCT therapist.

Brown pulls together his stories in the Liberation section of the book. He uses some universal themes like internal focus and connectedness to other people and energies. The author was able to understand liberation through a quintessentially human experience: the deadline crunch. There is so much to do and so little time. Brown writes: “What does the work matter if I lose myself in the process? How can peace be made from this internal war?” (p. 191). The author

stops, balances, reflects and can choose a path of love rather than fear. He sees liberation in his connections to others and the universe and usefulness in the universality of his particular story:

“While this book is my story, the patterns in it – pain, anger, accomplishment, isolation, victimization, disease, connection, healing, and others – aren’t unique to me. Mining my personal experiences is one way to channel and explore universal truths. But fascination with an individual life and becoming mired in its details is when we are most likely to neglect our connections to others, to forget to reach beyond ourselves” (p. 192).

The point is to move beyond individual experience and plum the greater universe.

Brown concludes with noting subtler energies and offering suggestions on paths that lead to them as well as one’s center. This book covers new ground and is a must read. It will prove especially fruitful for anyone who has the honesty and ability to put preconceived ideas and belief systems on hold.

Janine Bertram Kemp is President of the Disability Rights Center (DRC). Bertram Kemp, who has spinal disease and healed a psychiatric disability, is a writer who has worked for over twenty years in the cross-disability world – always with the optimistic goal of the full societal integration of people with disabilities. DRC distributes Tom Olin's disability history photos, completes oral histories, and gives presentations on the history of ADA, where the grassroots met power and triumphed. A member of ADAPT, she is committed to creating inclusive systems change. She lives in Zigzag, Oregon, where she has a spiritual and healing practice and may be contacted at janinebk@mac.com.