

- PROMOTE LANGUAGE ARTS SKILLS •
- RAISE DISABILITY AWARENESS •
- STIMULATE DIALOGUE •

## **Telling Stories**

by Steven E. Brown

I've been creating and telling stories for as long as I can remember. That may have something to do with much of my childhood when I spent days on end lying in bed. I watched hours of television and read many books during these days, but I still found myself with time to fill.

When I was six I started limping on my right leg. I don't have much memory of this. It happened fifty years ago. But I've heard my parents talk about it and I've read doctor's reports.

I lived in Portage, Michigan, a small town next to the bigger city of Kalamazoo. No one in the area knew why I limped. My father's parents also lived in the area and they saw physicians at the Mayo Clinic in Rochester, Minnesota. My mother, grandmother and I boarded a plane to go visit a doctor there.

This was my first plane ride. I was extremely excited to be aboard.

At the Mayo Clinic, the doctors performed biopsies on both of my thighs. I still have the marks of their work. The much longer scar on my right leg indicates they found something. It turned out I was born with a condition called Gaucher Disease (GD). They didn't know a great deal about GD in the late 1950s, but told my mother I had a strain of GD called the adult type, which meant they could expect I would live an average lifespan. They also said GD frequently affected bones and organs like the spleen and liver. In the case of bones they were sometimes weaker than average. With the spleen and liver they often became enlarged. Much later, as an adult, I learned that if my parents had taken me to the University of Michigan in Ann Arbor, another

geographically close place to where we lived, they would have automatically recommended my spleen be immediately removed. The Mayo Clinic, fortunately, had a different approach.

Shortly after returning home from the Mayo Clinic I played football with my friends. I got tackled. I couldn't get up. I lay in my friend's yard wondering why I couldn't move. It turned out my right leg had broken, mainly because it was still weak from the biopsy. I spent time in the hospital. I recollect little from that hospital stay. One vivid memory, though, is of my right leg suspended in air, in traction. Even then, it seems nothing prevented me from rolling over during the night into my usual sleeping position, lying on my left side—something I still do to this day.

It's funny, but in memory, traveling to the Mayo Clinic and fracturing my leg seem like isolated incidents, not connected to the rest of my early childhood experiences with GD. Maybe that's because breaking a bone happened only once before I was about 15, but each Michigan fall and spring I experienced what we now call bone crises. When I was a kid we called them "attacks."

The first bone crisis occurred in my right knee. Eventually they spread to my other knee and then to my hips and ankles. After having lots of bone crises, by the time I was a teenager I knew the signs of their onset. I would begin to feel discomfort and then swelling. Within a day or two, whichever joint was affected became so painful I could put no weight on it. I started hopping, or crawling, around the house. But it was just as excruciating to be off my leg. For about two weeks I was in constant, unbearable pain—except, I did bear it.

Much more is known about GD today than when I was younger. Bone crises, we now know, result from a lack of oxygen to certain areas of the body; in this instance, my right knee. I have written about the acute pain associated with bone crises many times, but that is not the story I want to tell here. I write about it only to share why I spent so much time in bed, as described in the first paragraph. The pain that came with bone crises not only prevented me from going to school and doing anything else connected with my routine, but it also interfered with my sleep. A lot of the reading I did during this

time happened at night while the remainder of my family slumbered. I had lots of time to ponder my situation, my life, the universe, and whatever else came to mind.

I had a bone crisis, as usual, during the fall of my senior year in high school. We had moved the summer before from Michigan to western Illinois. Maybe because I was in a new environment, in a new house, but dealing with a familiar situation, I decided to keep a diary. For the approximately two weeks of this particular bone crisis, I wrote about the experience. Later I published the diary. I called it "Hidden Treasure," because no one I knew in this time, the late 1960s, discussed issues relating to their disability experiences.

Twenty years later, I deliberately began to write and talk about people who have disabilities telling our stories. By this time, I knew that my friends and I had a lot of fascinating stories I thought many people needed to hear. I wanted to do whatever I could so we could share our stories.

I studied history in college. I got all the degrees a student can get and when I got my last degree, a Ph.D. in history, I wanted to work. I looked around and, after a long time, I thought I was really lucky because I talked on the phone with a man whose company told me they would hire me. But when the man I spoke with on the phone learned I used crutches, he decided someone on crutches would not be strong enough to do the research and writing needed to produce a book.

That made me really mad! I started talking with my friends about this, including some new friends who were a part of the disability rights movement. I liked being with them so much that a few months later I started working with them.

One of my new friends in the disability rights movement became my boss at my job at an independent living center. She told me a lot of stories about her life using a wheelchair after she was injured in a car accident. One day she described when she first became a student at college in the 1970s. She had to schedule each of her classes with at least one hour of free time in between each one in case she needed to go to the bathroom. If she did, she had to drive to her home because there were no accessible bathrooms on campus.

I quickly learned all my friends with disabilities had stories about their lives and not very many people knew about them. For a long time no one thought it was too important to hear about the lives of people who used wheelchairs, or who couldn't see, or who had other kinds of disabilities. It seemed like something I could do to tell my own stories and to share those of my friends and coworkers. The narratives of our lives began to find a shape. We learned that even though many of our experiences were not exactly the same, a lot of them were similar. For example, my wife had a really different childhood than I did. She spent a lot of time in hospitals and had a lot of surgeries. I didn't have those experiences, but since I knew what it was like to be home a lot we could both talk about the common feelings we remembered from spending a lot of time away from school and away from our friends and teachers.

All of these stories started to form an idea that some of us gave a name called disability culture. Basically this means we discuss and tell about our lives from the context, or viewpoint, of our disability experiences and how they've shaped us. Some examples of this include art we've created, like paintings, books, songs, movies, and cartoons. My wife and I created a T-shirt a long time ago that had on the front the slogan "promoting disability pride," which we use in our work. Other people have made buttons and posters that say, "label jars, not people," and still other people have made bumper stickers and hats and all kinds of clothes and knick-knacks that reflect disability pride.

After I moved to California to start a new job in the early 1990s, I deliberately sat down and wrote a poem called "Tell Your Story." In this poem I shared three stories. In one story I talked about a friend and coworker who got a chance to march in a protest in Washington, D.C. She had never protested before and she found it gave her great power. When we returned to our home she decided to use more force in getting a local hospital to make some changes to become more accessible to people who didn't hear. A couple of years ago, for a class project I wrote about the history of this poem and the stories in it. The poem and the history about it are both on the Internet. Some of my favorite lines in the poem are "how will our children learn and compare/if we're too timid to dare/to raise the flare/share that we care."

Lots of kids are really happy to listen to music. Musicians can put stories in songs, just like writers do in essays and poems. Many people are doing that these days. In fact, I currently have about 400 songs on my computer written, or sung by, or about people with disabilities. All these songs are in some way connected to the disability experience. Some are in languages other than English. Many different kinds of disability experiences are represented. Beethoven's Nightmare are three people who are deaf and who call themselves the world's only, or sometimes first, deaf rock 'n' roll band. They sing, on the title song from their CD *Turn It Up Louder*.

If you're looking for a good band  
Check us out  
Check us out  
If you're looking for a good band  
Count us in  
If you're looking for a good sound  
Hear us shout  
If you're wondering what we're all about  
We're the only deaf band in the world

Sometimes I listen to this song while I'm writing about disability in essays like this one and in poems like "Tell Your Story." I also write about disability in fiction. The following edited excerpt from a novel I've been working on is based on a real-life situation my wife and I confronted when we lived in New Mexico:

Noise shocked Wishman awake. He shook off cobwebs of sleep and realized a tire blew out. He glanced over at Claire, who concentrated on maneuvering the full-size van to the side of the road. Her van tilted toward the ground on the passenger side lowering Wishman toward the highway's shoulder.

Putting the van in park, Claire looked at him and shuddered. "What'll we do now?" she wondered.

Wishman thought exactly the same thing. When they left the meeting an hour or so ago they anticipated a leisurely drive home where they would then go their separate ways. Now they were stuck in a potential nightmare.

"Don't worry." Wishman stretched for Claire's cellular phone. "I'll call Triple A." He'd already informed her earlier in the journey he neglected to recharge his own cell phone the previous evening, and the battery had expired sometime during the day. He pushed the "on" button, smiling like he had not a care in the world—then frowned, cursed, and placed the phone to Claire's ear. No sound. Nada. Nothing at all.

Wishman looked at the phone again. All the appropriate thingamajigs were punched. He put the phone to his ear once more.

Nothing.

“Look,” she said, “it’s already nine at night. What if no one stops? What if no cops show up?”

“Then I guess we’ll sit here the rest of the night,” Wishman said.

“That’s not funny.”

“I wasn’t trying to be.”

While this is a fictionalized account, my wife and I did spend a night on the side of the highway, waiting for daylight to try and find someone to assist us. We finally got home the next day.

This is only one of many travel stories we can tell. Individuals with disabilities—especially, it seems, those with mobility impairments of one kind or another—are constantly encountering travel nightmares. Looking back, they often become comic adventures, but while in the midst of them, they do not seem funny at all.

I have a picture of a friend in Stockholm, Sweden, from the summer of 2007. We visited a museum. He had been there many times before, but he could not get in, because there was no wheelchair access. He proudly showed me the lift the museum installed for wheelchair access. Unfortunately, at first he couldn’t get on it because visitors had to find a museum employee with a key to operate the lift. His wife did that. My friend entered the lift. I have a picture of him smiling as the lift carries him upward. I also have a picture of him sitting on the lift while all of us wait for a museum employee to unlock the back door to the museum so he can get off the lift and into the building.

This middling kind of access is classic. Less typical is one of the reasons I traveled to Stockholm. I joined thousands of other people for the fifth March for Accessibility, a demonstration in downtown Stockholm asking for a law to recognize the kind of inaccessibility my friend found at the museum as discrimination. When my months-old grandson is older, I can tell him about this demonstration and he’ll learn about some of the disability heroes, like the people I’ve written about in this essay, who are making the world a better place!

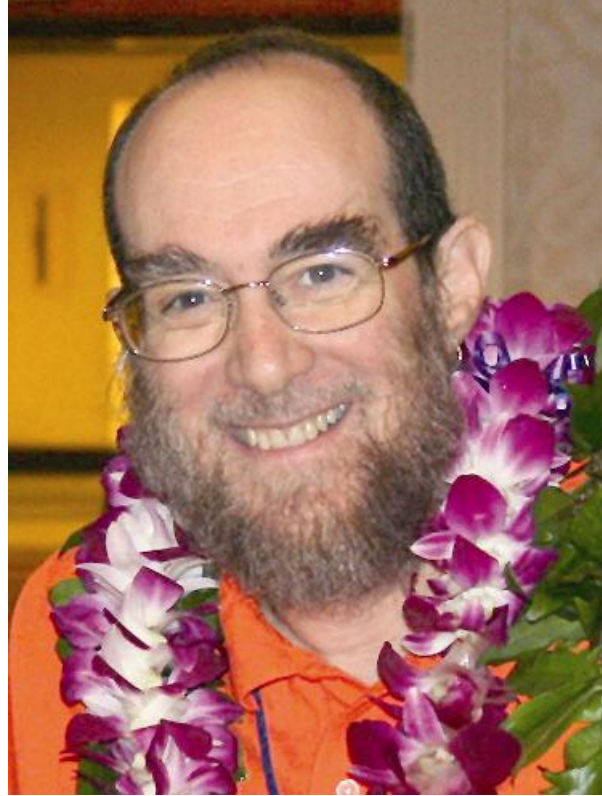
## References

(This is a way to find out more information about something.)

Beethoven's Nightmare, [beethovensnightmare.com](http://beethovensnightmare.com)

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When discrimination because of his disability detoured Brown's academic career in history, he became an advocate. An accomplished author and award-winning poet as well as activist and teacher, Brown has published several books and articles, including *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* (2003); *Love into Forever: A Tribute to Martyrs, Heroes, Friends, and Colleagues* (2002); *Celebrating Passion, Relentlessness, and Vision: The Manifesto Editorials* (2001); and *Dragonflies in Paradise: An Activist's Partial Poetic Autobiography* (2001). He is Coordinator of CDS's Teaching All Students, Reaching All Learners projects and Principal Investigator for My Voice, My Choice, and Media Reviews Editor of the CDS journal, *Review of Disability Studies: An International Journal*.

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