

# **POLIO PERSPECTIVE**

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**'Beating' The Tribal Drum: Rejecting disability stereotypes and preventing self-discrimination**

*by Dr. Richard L. Bruno*

The "Tribal Drum." It beats in all societies, warning members of the tribe against the dangers of "the others," those who are not members of the tribe, even those who are different within a society. The Drum's messages result in different tribal behaviors, from religious warfare in Northern Ireland and the Middle East, ethnic cleansing in Yugoslavia and Rwanda, to Neo-Nazi racial purification in Germany and America.

But The Tribal Drum's messages can also be subtle, permeating a society, and producing non-violent -- although no less destructive -- behaviors. The Drum's most subtly destructive effect may be when negative messages about "the others" are accepted by those who are supposed to be immune from such prejudice, those who are supposed to actually help "the others."

One of The Tribal Drum's most ardent, if unconscious, listeners was a physiatrist named Steve. I wish I were as sure of anything as Steve was of everything. He had an expert

opinion about all topics, from medicine to particle physics, and was eager to tell you just where you had "made your mistake." On the spinal cord injury unit, Steve was the local tribal king. He would swoop into new patients' rooms, residents in tow, and opine about one patient's neurogenic bladder or another's lack of vaginal lubrication, never actually talking to or even looking at the person in the bed. After the initial evaluation the patient would typically never see Steve again, since all care was given over to the residents. Not that the patients minded being pawed off. "Hell, I'd rather be treated by an orderly than by him," one patient told me.

But absence made Steve's heart grow fonder. The less he saw a patient, the more opinions he offered about where the residents were "making their mistakes with poor Miss Jones" and the more compassion he would voice. "How will she ever manage, a C3 quad alone, on her own," Steve asked, shaking his head sadly? "Who will ever hire her? Who would ever marry her?"

In contrast to his lack of contact with his SCI patients, Steve frequently volunteered to talk to school and community groups about SCI prevention. He would show the most horrific slides of auto wrecks and physical wrecks. He would show a patient using a sip-n-puff power wheelchair, saying, "This is poor Miss Jones; she wasn't wearing a seat belt! You don't want this to happen to you!" Then he would show a patient with tongs buried in his skull saying, "This is careless Mr. Smith; he dove into the shallow end of a pool. Why would you want to live if you were like him?"

Interestingly, Steve developed a converse alter-ego. As much as he avoided SCI patients, Steve eagerly sought out patients with back pain. A dock worker, who had tried to lift a Land Rover by himself and blew out five discs in his back, came to see Steve. The patient hobbled in, bent at the waist, leaning heavily on a cane.

"What do you think you're doing," Steve yelled as he entered the room? "You don't need that," he said, yanking the cane out of the patient's hand. "Only people who really need canes should use them!"

On another occasion a young man with a ten year history of back pain rolled into Steve's office in a wheelchair. I am told that the sight of the chair so infuriated Steve that his screaming was heard two floors away and that a nurse had to physically remove Steve from the exam room.

"I can't stand these pain patients, limping around looking like helpless cripples," Steve once told me, spraying spittle all over my tie. "Do they expect me to pity them!? Do they think they deserve the same care that I give my patients who are really disabled."

The same care he gave patients who were really disabled? Steve gave no care to his

patients who were "really" disabled. He talked at them or about them and avoided them like the plague. Finally, I saw the problem: Steve could not tolerate disability at all. He couldn't deal with not being able to cure his "poor" SCI patients so he stayed away from them. But in public he heaped pity on them and lectured avidly to prevent others from "making the mistake" of becoming disabled. At the same time, he both hated and sought out back pain patients because he was able to "cure" them by removing the assistive devices that made them look disabled.

Although Steve is an extreme example, he demonstrates the double standard that pervades medicine. How many physiatrists shower new SCI patients with encouragement, even telling some "you will walk again," only to withdraw their attention and become irritated when their skill as healers is insufficient to cure the spinal cord injury? How many physical therapists tell polio survivors to "get rid of that brace" and "start pumping iron" to strengthen weakening muscles, only to become angry when polio survivors actually get weaker with exercise?

Doctors -- even rehabilitation doctors -- are merely products of our society, having grown up listening to The Tribal Drum. "Doctors are Gods, omniscient and omnipotent," is one of The Drum's messages. Despite rehabilitation's focus on quality of life, independent living centers and new assistive technologies are just stop-gaps for the present, until "helpless cripples" are cured by the "Great Healers of Medicine" and are able to stand up and walk. Of course, the message that a life with a disability is a life not worth living had been transmitted for eons by The Tribal Drum. The drum says people with disabilities are helpless cripples who will find neither employers nor spouses, that a life with a disability but is, as one disability insurance company states in their advertisements, "a living death."

But those of us with disabilities have had our own attitudes shaped by The Tribal Drum. Our notion of how we "should" look, shaped by the messages the media pounds into us about normality, certainly does not include a cane, brace, prosthesis or wheelchair. All of us have had the experience of being discriminated against because of our disabilities.

The greatest danger is that we beat ourselves with The Tribal Drum, adopt society's negative stereotypes and discriminate against ourselves because of having a disability. Christopher Reeve may be the most visible example of self-discrimination. Despising his own disability, Reeve said he is disinterested in architectural access or civil rights, spending his time physically preparing for and raising money to find "The Cure" for spinal cord injury. If Chris will be walking within the decade, why won't we all? Why should we be concerned about making the world wheelchair accessible or dealing emotionally with our own disabilities, let alone stopping rehabilitation practitioners from treating us as "helpless cripples" or "the living dead?" As Mr. Reeve says we are only temporarily disabled. "The Cure" is just around the corner. We won't be "the other" for

long!

Both Dr. Steve and Mr. Reeve serve as warnings. We must be assertive, stopping doctors and therapists from beating us with The Tribal Drum, disabling us as people as they treat our physical disabilities. Even more, we must be vigilant to prevent ourselves from accepting The Tribal Drum's negative messages. We must reject society's stereotypes about disability, which rob us of quality of life in the present, even if some of us expect "The Cure" in the near future. We can -- we must -- "beat" The Tribal Drum.

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# 16 Things People With Chronic Pain Wanna Tell You

*by Dianna Labrien*

It's not just in our head. The pain is there and always would be even if there is no apparent reason for it. Our pain is real and will not just go away after we take some pills for a week or two. It would always be there and we have learned to live with it. Here are 16 more things we wish you knew about us!

## 1. We Don't Make a Mountain out of a Molehill

You think you can imagine our pain? Now multiply that amount by 10. No matter how sympathetic you are, studies have proved that people tend to underestimate other people's pain. Chronic pain by default is hard to imagine unless you have experienced it in your life. It's invisible, but it is always there. We urge health care not out of hypochondria or the need for attention, but because of our severe physical state.

## 2. We Need to Balance Actions Carefully

We use the Spoon Theory: We have a limited amount of spoons each day we could use for different actions. Getting up, getting dressed, taking a shower, driving, walking, picking up the phone — each action requires us to use one of our precious spoons. On good days, we finish with a few spoons left, so we can do something fun. On bad days, we borrow spoons from the next day and need extra recovery afterwards. So if we suddenly cancel our plans with you or tell we can't do it now — it's just because we ran out of spoons today. Try to understand this.

## 3. We Struggle to Find a Good Doctor

Sadly, a lot of health care pros lack knowledge in pain management because it is rarely part of their training. We often visit numerous specialists before receiving a proper diagnosis and wait months to years to see a real pain specialist for treatment. Doctors often fall victim to the cognitive error of underestimating another's pain and a small number of doctors are willing to take the legal risks involved in prescribing powerful pain pills.

Same goes with the nurses. Finding a good one who can really understand and help us relieve the pain is hard! Luckily, there are some online schools like Sacred Heart University that are training future nurse leaders to overcome these issues in the future and provide better care for patients.

While you may think it's crazy, we're willing to travel further to find a good nurse with this kind of training and rave about it when we find one.

#### 4. We Are Not Lazy

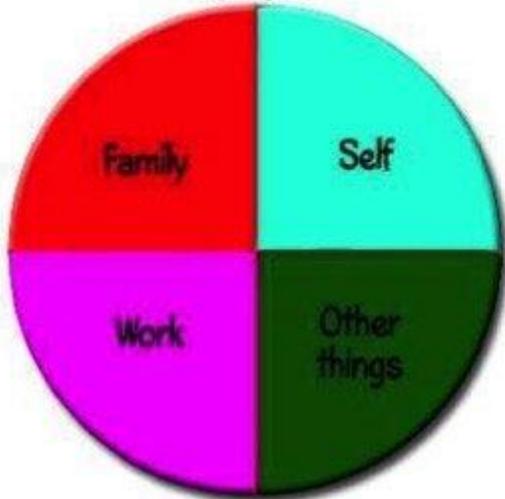
Remember the limited amount of spoons we have? Now add the fact that it takes twice as much effort for us to complete even simple things. We try harder than other folks, yet we still manage to accomplish less.

#### 5. We Try to Look Our Best

"But you don't look sick" is one of the most common phrases you hear if you have invisible disease. Well yes, we try to look our best even on bad days when our body explodes from pain. We dress up carefully to cover up our bruises or swelling, take painkillers at the optimal time, and rest before going out. We would love to pass as normal as much as possible! Even if we feel pain, we would keep it to ourselves until the moment we step into our apartment and just collapse.

#### 6. We Don't Ignore You

### Mind of a healthy person



### Mind of a chronic pain sufferer



www.ThePainReliefFoundation.com

Sometimes our pain occupies too much space in our brains and we simply cannot focus on anything else. Pain can be very distracting and mentally draining, so please forgive us when we can't give all the attention to you.

#### 7. We Know Our Illness Won't Go Away

It's always there. We can't escape. And yes, we have researched all the possible options. If there was a

cure, we would know about it!

## **8. We Are Not Drug Seekers**

Sadly, we need to explain that both to the doctors and folks around. We don't want drugs. We want *anything* to make the pain go away even for a little while. So yes, sometimes our treatment requires taking opioids or medical marijuana. We treat those just like any other remedy. And no, we are not particularly fond of the side effects either.

In fact, as the Cleveland Clinic explains: Addiction appears to be distinctly uncommon in patients without a prior history of addiction. Addiction is a psychological phenomenon that isn't caused by chemical components of the drugs and typically requires a setting different from the one we have. We take our drugs under supervision and come back home to the loving family unlike the street-users.

## **9. We Don't Always Know How to Manage Our Pain**

Just because we have been dealing with it for ages doesn't mean we always know how to tame it. Sometimes, we have very bad days when no previous routines help. We just close our eyes and wish those would pass faster.

## **10. We Get Super Active on Good Days**

Physically feeling good is just about the most exciting feeling we can have! We can do our chores normally, go on a day trip, meet with a bunch of people at a time, and even think of running a marathon. On a good day we are super active and excited with everything, trying to get as much done as possible!

## **11. We Don't Want You to Stop Inviting Us Out**

No matter how many times we have said "no" we still want to be part of the gang and go out when we really can do it.

## **12. We Don't Have a Job for a Reason**

Again, we are not lazy. It's just that we often lack spoons to work on the top of our other activities and daily chores. Besides, most employees refuse to take staff for a few hours per week and tolerate the fact that we can leave at the middle of the day if our pain gets unbearable.

On the bright side though, thanks to technology we can work from home in our own pace, doing various jobs online, selling stuff on eBay or Etsy, learn everything we need from self-help and nursing to design or coding online. If we don't have a regular job, it doesn't mean we can accomplish nothing in life. Multiple sclerosis did not stop Vanessa Heywood from creating an award-winning music company!

## **13. We Don't Want Sympathy, We Want Acceptance**

Instead of making that "I'm so sorry for you" sad face, treat us like equals. It's not that you should completely ignore our condition, but show us you are ok with it and ready to make small adjustments for us.

## **14. We Don't Want Your Medical Advice**

Believe me, we have heard enough already and feel frustrated, as they don't work. Thanks for the thought, but let's just talk of something else. My disease does not define me. I know a lot of other interesting things, I would love to discuss with you instead.

## **15. We Need to Know You Are Here for Us**

No matter how self-sufficient and independent we try to appear, sometimes we just need you to be here with us and hold our hand on a bad day.

## **16. We Appreciate You and Everything You Do for Us**

You should never forget that. We are eternally grateful for supporting us and making us  
feel love

### **LAZY BONES**

*Millie Malone Lill*

Growing up with a German mother, who had nine other kids to care for, I was taught that laziness was The Cardinal Sin. Even my doctors, when I had polio at age four, told my parents not to let me be idle. "Never let her say she can't do something." So I grew up thinking that I could do anything if I simply tried hard enough.

I can't remember ever not being tired. It was as much a part of me as the freckles across my nose or my lop sided gait. I thought everyone was always this exhausted, since I'd never known anything different. Therefore, when I married a farmer and moved from my comfortable home with my parents to the absolute squalor of my first home, I pitched right in. No running water? No problem. Outdoor toilet? I can handle that. Three kids in less than three years? Starting to be a problem, but I can do it.

Eventually the living conditions got better. My home became more modern, but by then my husband was very very ill. My sons helped so much. With two parents, one of whom was often bedfast and the other back in the brace she thought she'd given up for life, they learned to pitch in wherever possible. Then PPS reared its ugly head. Still, I did whatever needed to be done. It wasn't so much that others expected it of me. It was more that I expected it of me. Can't be lazy, that was the only "can't" I allowed in my vocabulary.

When my husband died, my link pin was gone. Suddenly, after so many years of my life revolving around him and his needs, he was gone. I filled my life with even more activities. I took some college courses, learned to use a computer, became very active in my church, traveled, continued to do a lot of what I'd already been doing on the farm. My kids wanted me to move to town where I could take it a little easier, but I resisted. Eventually, the cattle were sold, my old dog died, and I ran out of excuses to stay on the farm. I moved to town. My youngest sister had had a massive stroke and I moved her in with me so I could take care of her. She lived only ten more months, but they were happy and filled with fun and laughter.

I remarried and moved to Canada where life was very hard. Much harder than I was used to, since by

this time I was using a power chair. Nothing was accessible in the tiny village I moved to. My trucker husband was never home, only stopping in for one night every month or two. My vehicle was equipped with a ramp, but finding a spot flat enough to deploy it and load the chair was a monumental task. It had no heater, either, and the temperature stayed at -30 for months on end. Snow, my nemesis, started in October and didn't give up its grip till the middle of May, if then.

Finally, I reached saturation point and moved back to Iowa. I lived with my sister till I found the apartment I now live in. Suddenly, life was easy. What's this? Everything is accessible? I can take my power chair to anyplace in town, only using my van if I need to leave town. When I sprained my knee, I started getting Meals on Wheels. Lazy, you bet. I only do what I want to do. If I want to sleep in, that's OK. Go out to eat? Sure, why not?

I admit it. I am lazy. And I love it! I finally get enough rest, although exhaustion is always just around the corner. But I find I have fewer aches and pains now. I no longer push myself, nor do I allow others to push me. It took me long enough, but I am beginning to think being a Lazy Bones is the best way to handle PPS.

## Web Corner

3-D Printed Pathways Helps Nerve Growth

<http://www.iflscience.com/health-and-medicine/3d-printed-nerve-pathways-help-growth-after-injury>

Disabled man crawls off airplane, airline apologizes

[http://www.news4jax.com/news/us-world-news/disabled-man-crawls-off-plane-airline-apologizes/36044374?utm\\_medium=social&utm\\_source=facebook](http://www.news4jax.com/news/us-world-news/disabled-man-crawls-off-plane-airline-apologizes/36044374?utm_medium=social&utm_source=facebook) WJXT4 The Local Station

What are the secrets to a happy life?

<http://www.dailygood.org/story/1154/what-are-the-secrets-to-a-happy-life-george-e-vailant/>

Ending polio, we are on the verge of making history

<http://edition.cnn.com/2015/10/22/opinions/world-polio-day-ending-polio/>

People can raise pain threshold

<http://www.neuroscientistnews.com/research-news/people-can-raise-pain-threshold-altering-brain-chemistry-study-shows>

Cooking with Disabilities

[http://www.npr.org/sections/thesalt/2015/10/21/448971281/cooking-with-disabilities-an-exercise-in-creative-problem-solving?utm\\_campaign=storyshare&utm\\_source=facebook.com&utm\\_medium=social](http://www.npr.org/sections/thesalt/2015/10/21/448971281/cooking-with-disabilities-an-exercise-in-creative-problem-solving?utm_campaign=storyshare&utm_source=facebook.com&utm_medium=social)

Good and Cheap. A free cookbook you can download

<http://www.leannebrown.com/>

British Polio Fellowship Launch Football Fashion Line to Raise Awareness for PPS

<https://www.youtube.com/watch?v=JrIipBMf9nw>

Failure is success

<https://www.facebook.com/AshrafChaudhrySalesTrainer/videos/855247371177732/>

Using the word Disability

<http://beyondadversity.com/using-the-word-disability/>

### A LITTLE BIT OF HUMOR

**There's a landscaping man who I know**

With a name that is quite apropos.

He loves to cut grass

And thinks it's a gas,

So you probably guessed his name's Moe.



