

POLIO PERSPECTIVE

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

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 psychiatrist 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 pawned 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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10 Ways To Restore Energy When You're Exhausted Or Burned Out

By Marissa Hakansson

You have the power to cultivate energy within your body in any moment. Even when you're exhausted, burned out and feel like you've got nothing left to give, your body can guide you to a space of greater vitality, inner strength and wellbeing.

Here are some strategies that I've used in my own life to do just that:

1. Rest when your body says rest.

It's important to follow your body's cues on when you need to rest rather than pushing yourself beyond what you can handle and then crashing. If in doubt, rest. When you listen to your body and give yourself the rest you need, you'll rebuild your energy over the long-term.

2. Cultivate stillness within you.

There's an incredible [healing](#) power in stillness. Prioritize creating quiet spaces in your day where you can simply be still. Really allow yourself to feel the stillness around you, letting it soak into your body. Notice that you too, that you also hold a stillness within the core of who you are.

3. Practice whole-body breathing.

Each day, take time out to [breathe consciously](#). Feel your breath inside your body and notice

how far it reaches within you. With each inhalation and exhalation, feel your breath extend further into your body (until it feels like every cell in your whole body is breathing). Then relish that feeling of life within your body.

4. Nourish your body wholeheartedly.

Be conscious and heartfelt in how you nourish your body by choosing foods that feel inherently good for you. Notice which foods provide a sense of restoration and healing in your body. And if you're unsure, ask your innermost self what your body needs in this moment.

5. Explore gentle and restorative movement.

Integrating gentle movement into your day can help you connect more fully with your body and self. Light walking, stretching, restorative [yoga](#), and similar activities can be wholly supportive of you regaining energy in your body and life. Explore various types of movement and see what feels right for your body.

6. Have compassion for your self.

We gain energy from love and [compassion](#). Be gentle with yourself when you're exhausted, and treat yourself kindly. Be kind in your thoughts and feelings towards your self as well as in your actions. Feel love and compassion in your heart and extend that warmth to yourself regularly.

7. Stop doing what drains you.

You'll instantly feel lighter and more alive when you choose to stop doing what drains you. Be aware of how your body responds to various things, people, places and experiences in your life; genuinely consider whether they support and fulfill you, or deplete you of energy.

8. Nurture what inspires you.

The feeling of inspiration is energizing in itself. Get clear on what truly inspires you by checking for that feeling of energy deep in your body. It may show up as a burning desire or

an inner knowledge of your truth, but once you've found it, feed and nurture it through your thoughts, energy, and actions.

9. Be vigilant with your time.

Learn to guard your time like the precious gift that it is. Choose wisely in how you spend it, ensuring that you schedule plenty time and space to care for yourself. Don't be quick to give it away, but when you do, be sure to give it willingly from a place of wholeheartedness.

10. Look for a deeper meaning.

When you can see meaning in your experience of exhaustion or burnout, you'll instantly feel lighter. Get curious about the lesson in this challenging time. When you do, you'll feel a genuine appreciation for your experiences, knowing that you'll grow and evolve as a result, and be able to contribute more fully to this world.

Standing Up For Yourself From a Seated Position By Millie Malone Lill

Probably it's a biological thing, discrimination. You would think that humanity had evolved beyond the kind of thinking that makes the odd colored baby chick get pecked to death by his peers, but apparently not.

I want to go on record as saying that where I live is a wonderful place to live, filled with terrific people who are kind, generous, accepting and fun loving. However, there are those few. You've met them, I know you have, or others just like them.

There's the Glamourous Guy, that good looking guy who wears starched and ironed, crisp white shirts every day and thinks our building needs to be ritzy. He doesn't like my chair, although he has no problems with me personally and if I would just stop being disabled and walk like a normal person, he might consider becoming friends with me. And as soon as he stops being judgmental and uppity, I might consider becoming friends with him. He thinks my chair makes this place look like a nursing home. I think he should have considered the fact that only seniors can live here and often that involves wheelchairs, walkers, canes and such. He'd be better off living with people he considers his peers. I'm thinking somewhere in Hollywood, where reality isn't so prevalent.

And there is the Owner. Since it is a Cooperative, we all own a piece of this building and it's furnishings. She, however, thinks of herself as the Boss of Us All. I'm not supposed to pull out a chair so that I can sit up to the table with my power chair in the Great Room. No, I'm not worthy of sitting up to the table as if I were a Real Person, I

can just sort of crowd into a corner, or better yet, not join the other ladies at coffee at all. The one time I defied her, pulled out a chair and sat up to the table, she slammed down her coffee cup and stomped off to her apartment. She would prefer that we not talk to each other in the halls or on our decks because it might disturb her TV watching. Nothing we have to say could possibly be as important as Survivor or Big Brother! She does not have to pay any attention to the Handbook that explains procedure here, either. She's above all that nonsense.

The rest are Hangers On. They don't really know if they hate my chair or not, but The Owner tells them they do, so they do as they are told. There are not that many, but enough of them to make me spend an entire week in bed with migraines and heart palpitations. It was my own fault for letting them get to me like that. I know that I cannot control anyone else's actions, only my reactions, but when I was told that I cheated to get in here by 'sneaking in' my wheelchair, it was too much. It came from a woman I had not realized was a Hanger On and whom I'd thought was friendly to me. That made it very shocking to me. It was simply the last straw after three solid years of this kind of thing. I'd reached saturation point.

Thus it happened that at a Board Meeting where our Managing Agent explained the Fair Housing Act and passed out booklets that she had made up with more detailed information, I lost it. Yep, level headed, I Can Take It, little old me. I just came right out with it. "What about this chair is bringing down property values?" I asked Glamour Guy. "I am getting tired of being told that the carpet is worth more than I am!" I told The Owner. I'd heard "If you can't walk, you can't live here" too many times. I asked if they would truly kick our oldest resident to the curb if she happened to break her hip. "Would you truly be that heartless" I asked, "to expect a 95 year old woman to have to pack up and move rather than recuperate in her own home?"

Normally, I keep quiet, avoid the bullies, stay out of the way and associate mostly with my polio survivor friends. But this time, I didn't. I felt I was doing this for more than just myself. After all, this building is under the FHA and it is perfectly possible that another wheelchair user might someday move in. I'd already been informed that The Owner had bullied a new resident to the point that this woman was afraid to join us for our monthly activities. That's just not right. No one should have that much power. So I spoke up. I raised my voice. I did not let the bullies win. Not this time. Not ever again. I cannot be evicted. I'm protected by the FHA. And I will continue to advocate for the disabled as I've been doing for over 20 years, even if that disabled person is myself.

WEB CORNER

Polio headed North

<http://www.bloomberg.com/news/2013-09-25/europe-sees-risk-of-polio-re-introduction-from-israel.html>

Twenty-seven things you will only know if you are a wheelchair user:

<http://www.buzzfeed.com/louisebruton/things-youll-know-if-youre-a-wheelchair-user>

No-needle EMG tests:

<http://www.medicalnewstoday.com/releases/266330.php>

Why Are You Questioning My Need for a Wheelchair?

http://www.huffingtonpost.com/beth-griffiths/why-are-you-questioning_b_3916644.html

Home Wireless Network Detects Elderly Tumbles

[http://www.scientificamerican.com/podcast/episode.cfm?id=home-wireless-network-detects-elder-13-09-13&utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A%20ScientificAmerican-Global%20\(Content%3A%20Global\)&utm_content=Google%20Feedfetcher](http://www.scientificamerican.com/podcast/episode.cfm?id=home-wireless-network-detects-elder-13-09-13&utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A%20ScientificAmerican-Global%20(Content%3A%20Global)&utm_content=Google%20Feedfetcher)

Top 5 Benefits of Friendship

http://www.lifescrypt.com/life/relationships/also-in-relationships/top_5_benefits_of_friendship.aspx?utm_campaign=2013-09-13-146198&utm_source=daily-reflections&utm_medium=email&utm_content=todays-inspiration_Top_5_Benefits_of_Fri&VID=146198&FromNL=1&sc_da

Exercise for Post Polio Patients:

<http://postpolioproblemadedisapacidad.blogspot.mx/2012/03/exercise-for-post-polio-patients.html>

THE CAUSE AND TREATMENT OF POST-POLIO FATIGUE.:

<https://www.facebook.com/notes/post-polio-litaff-applac/the-cause-and-treatment-of-post-polio-fatigue/10151643647107895>

Mind-controlled walker:

<http://www.wpxi.com/videos/news/mindwalker-exoskeleton-mind-controlled-walking/v8z3x/>

Polio survivor dance moves:

<http://www.upworthy.com/happens-every-time-watching-this-dude-kill-it-on-the-dance-floor-makes-my-heart-burst-open>

Little Bit of Humor

My Watch is Slow

Three tourists climbed up the tower with London's Big Ben and decided to throw their watches off the top, run down the stairs and try to catch them before they hit the ground. The first tourist threw his watch, but heard it crash before he had taken three steps. The second threw his watch and made only two steps before hearing his watch shatter. The third tourist threw his watch off the tower, went down the stairs, bought a snack at a shop up the street and walked slowly back to Big Ben in time to catch the watch. "How did you do that?" asked one of his friends. "My watch is 20 minutes slow."