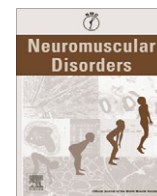




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# Neuromuscular Disorders

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Patient's forum

## Not waiting to live, not living to wait....

P.T. Moeschen

Woodbury Middle School, Salem, NH 03079, United States

Recently, I presented the following points for discussion at the Parent Project Muscular Dystrophy conference in Denver, Colorado. I truly believe that all disabled adults (as well as growing kids!) have the capability to enlighten society as to how we are viewed, versus how we perceive ourselves. The main differences lie between two models when it comes to thinking about disability: medical and social.

### Medical model

The medical model of disability locates impairment in the body. Disability arises from the neurons that do not fire correctly, the muscle tissue that does not grow, or from the corrupted DNA. It is the job of medicine, science, and technology to issue correctives in the form of cure, rehabilitation, or artificial enhancements (i.e. hearing aids, wheel chairs, eye glasses). As a result, the individual becomes a passive entity, "waiting" for scientific, medical, and even philanthropic institutions to manufacture these various devices or accoutrements as a means to restore the person to a sense of "normalcy."

### Social model

In contrast to the medical model, the social model of disability recognizes biology as only one variant that plays a role in the construction of disability. Instead, disability is shaped by the mutual influence of physiological and social, political, historical, and geographical elements. Disability emerges from historically and socially informed attitudes, perceptions, and representations of how individuals view, understand, and respond to physical difference. For example, Americans viewed the figure of the disabled war veteran in different terms in 1945 than in 1978 than in 2010. The nature of the disability (i.e. amputees, blindness, mental/emotional disorders) is only one component of how people perceive the disabled veteran. Other elements that impact this understanding are political leanings, popular film and television representations, social stigma, etc. The social model places disability on a spectrum of diversity similar to race, religion, gender, and sexuality. As a result, the individual becomes an active participant in creating their social and personal identity. The social model also allows for a greater degree of intervention and activism to promote education,

awareness, and dialogue around disability as a construct that can be socially and politically altered.

### Inside my mind: (A scary place!)

I grew up in a pretty simplistic middle-class family with my mom as an unpaid, stay-at-home mom and my dad working a typical 9–5 corporate job. I did not have access to a lot of resources, technology, or even information. I was diagnosed in 1985 with Becker MD; I could not have trolled the internet even if I wanted to. In retrospect, I think that mom and dad were at an advantage in their limited access to information. Today a doctor might say "Well, we think it's Lupus," and before the rest of the words can even leave the Doc's mouth, mom and dad have their iPhones at the ready, Googling Web MD to read through a bunch of apocalyptic sounding phrases like "Could cause permanent..." and "If left untreated..." In the instant of diagnosis in the digital age, *reality constricts if you allow it to*. Visions of baseball games, gymnastic meets, and family vacations to the beach become crowded out by leaden thoughts of hospital rooms, lab tests, and specialists. Fortunately for my parents, sister, and ultimately me, the moment of diagnosis and realization became less about "How do we stop this from happening?" to "How do we factor this development into the mix of baseball games, gymnastic recitals, and family vacations to the beach?" My parents focused on integrating my condition into the rhythms of life, not isolating it to arrest my social and personal development. This meant rejecting the attitude of defeat and alienation and nurturing behaviors and activities that kept my childhood on track like any other kid my age growing up. It meant that if I wanted to play baseball, I played baseball. If I wanted to go to the amusement park with my friends, I did so with friends I could count on and who would give me the extra time I needed without making a big deal about it. It also meant attending to all the normal things that parents must in order to raise adjusted human beings: when my sister or I got out of line we were punished; we learned responsibility through chores and obligations; we were fed a strong work ethic and good values; we learned the meaning of respect for our elders; we screwed up; we fought; we did the kinds of things that become embarrassing family anecdotes like any other kids; and we got threatened more times than I can remember with being sold to the first batch of gypsies to knock on our door.

My parents parented the best way they knew how, and in the process they were able to recognize that it was critical to separate their own confusion and anxiety from how they perceived of my

E-mail address: [pmoes@comcast.net](mailto:pmoes@comcast.net)0960-8966/\$ - see front matter © 2010 Elsevier B.V. All rights reserved.  
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disability in order to do what every parent strives to do: put the well-being and happiness of their children *first*.

Although it would be nice (obviously?!), I am not waiting for a cure; I'm not putting myself in the hands of other people who have control over my life. I am moving forward, living forward, every day regardless of what science might someday offer. A cure can heal the muscle, but it cannot feed the soul, it cannot tend to the heart, and it cannot nourish the spirit. A cure can repair the body, but it cannot make the self whole.

**Patrick Moeschen** teaches middle school music and band full-time, and is an active drummer. In addition to his teaching duties, Patrick travels as an advocate for people with muscular dystrophy and has presented at conferences around the world. Currently, Patrick is working on a book about the role a disabled teacher plays in the classroom of America's children. He lives in Salem, New Hampshire, and can be contacted at [pmoes@comcast.net](mailto:pmoes@comcast.net).