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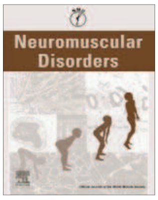

Patient's forum

Living with muscular dystrophy: Personal reflections

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A day, week, month, and years in the battle with dystrophy

With the growing interest in day-to-day measures of value to patients, it may be of help to understand what goes through the minds of those who live with dystrophy every day. We don't think about 6MWT or the density on an MRI. It is much more practical than that. It is falling, broken bones, struggling to breathe, watching one ability after another vanish. As a scientist, I think in equations, models, variables, and predictability. I want to, and can, describe dystrophy in this sort of sterile way. I do think about dystrophy that way. But, I feel it very differently as I watch one muscle after the other decay and vanish.

I have one of the "slow" ones—LGMD. I have lived with it for more than 45 years and watched as one ability after another vanished into the past. My knees are blackened with the remains of embedded coal cinders from a fall while trying to run around a track in the 9th grade. It seems as only yesterday that I slipped and fell in a snow bank, in darkness, hoping that someone would come along who could get me back on my feet. I could still get up from the ground—but not where it was slippery. In the distance lay the lights and warmth of the college cafeteria I'd just left—and where I looked with hope that someone would come my way. Finally, they did and a friendly hand helped me up. A slip, even a tiny push, meant falling. The hundreds of falls are a swirl of memories—broken bones, concussions, blood seen through a haze, ambulances, and surgeries. In my early twenties, I saw the ability to step up curbs vanish in the short space of a week. For a long time after that, if I came to a curb, I had to find a car I could lean on to leverage myself from the street up to the curb.

Others abilities took longer. A year ago, I could pick up my phone. Today, it is a struggle to even move my arm 12" to the right, much less pick up the phone. Throughout the night, every night, machines whir away to keep me breathing. At my computer, I begin to feel very sleepy—look at my oximeter—see I'm down to 80% O2 sats—and reach for my vent's mouthpiece. In a few minutes the head clears as I move to 98%. But, I wonder what happens the day it doesn't go up. I know if I can't get above 93% that I call 911—emergency.

Dystrophy is relentless. It never rests—never lets up. Sometimes fast and sometimes slow, but the muscles only go one direction. One of the best things I ever learned when I was still young, and had enough muscle to do it, was to do a somersault. This is basically just a tuck and roll. Throughout my entire life the ability to do this saved me in many, many situations where I fell. If I had a little bit of forward motion I was able to go into a tuck and roll and avoid any serious damage. But this wasn't always true. Life was filled with slips, kids' toys on the floor, struggling to keep weight down—but the falls kept coming. I doubt I have even one of my kid's whom I didn't fall on at one time or another. I am 6 feet tall but for my entire adult life I kept my weight at 135 lb. I discovered if I went even a few pounds over this that I would fall almost every day. So I deliberately kept myself thin. My friends wondered why I ate so little. There was a reason that few of them knew.

Once I was trying to exercise-running in place (such as my "running" was)—and I just lost it. I fell straight down and when you do that something has to give. It was my tibia snapped in two. I still have a steel plate in my leg to keep that memory fresh. I fell at work more times than I like to think of. Once there was a little bit of water on the floor and I slipped in it. I remember my boss looking down at me through my hazy blood filled eyes. I had a serious concussion and was bleeding all over the place. At least I got a nice ambulance ride out of it and my boss finally realized that I really couldn't travel all over the country at the drop of a hat. The falls never stopped. I could always count on one or two a month. It was a fall in the shower that finally convinced me my days of walking were over.

I was able to stand up from a chair almost till the very time I stopped walking. It was pretty complicated and dangerous. Whenever I went to a dystrophy clinic the docs wanted everyone to see how I did it. They couldn't believe it was possible. I would place my left hand on the front of the seat between my legs. Then I would place the left elbow on my breast bone. Using that as a lever I could lean forward and bring my legs straight. But this was only half the job. I had to have a table or surface of some kind right beside me. So once I got my legs straight I had to quickly move my right arm to the tabletop. If I didn't fall in the process, at that point I could use both hands and slowly work my way into a fully standing position. I always wondered when the breast bone was going to break—but fortunately it never did.

There are questions that still haunt every waking moment:

- Am I tiring so fast during the day that I'll collapse into a near coma? I have done this and scared myself and my caregivers to death.
- Is that absolutely mandatory hour or so of rest time after lunch getting longer and longer—and when will it be all day?
- Can I still pick up that cup of coffee? If I do pick it up, does my muscle fatigue so fast that I drop the cup before I get it to my mouth?

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- That pressure sore on my butt hurts, how can I shift weight to get off of it?
- I can't reach the switch on my computer monitor. How can I turn it on and off?
- Earlier on It was wondering when the next fall will come—how bad will it be?

These are practical, rubber meets the road, kind of issues—and hard for researchers to model. What does 6MWT really have to do with any of this?

Yes, this is all terribly stressing to patients and families. What they (and I) need is hope that this whole horrible thing can be reversed. I'd like to see a change such that my shoulder muscle comes back. Then, I could reach the 12 inches to my right and actually pick up my phone handset. I'd like to get off the *#@*! ventilator I'm tied to day and night. If I fall forward in my wheelchair, I'd like to be able to get back up without calling my wife to come and lift me back up. I'd like to actually bathe myself—get into the shower or tub. Ooh, how good it would be to feel running water over my body—what a blessing that is. I'd like for my wife to be wife and not caregiver. I would like the un-ending pain from decaying muscle fibers to just end. I'd like to stop taking my pain meds. From the patient's point-of-view—from mine, improvement is measured by regaining lost abilities-by being able to do something—anything—today I couldn't do yesterday.

If you understand this you understand the day to day life of a dystrophy patient.

In some contrast to the preceding short commentary, I actually am quite at peace with my condition and my life. Of course, I would love to be well and to be able to function like anyone else. But, there have also been so many good things that have come because of my condition that I would not give those up for anything. Life is what we make of it no matter what our condition and I've had the opportunity to do work that I love, meet and work with people whom I admire and love, and most of all to learn true empathy toward the issues that all of us deal with in our lives.

Dr. Munn graduated with a Doctorate in Physics (General Relativity Theory), has served as a Chief Scientist and Director of Research at Lockheed Martin Corporation, and has taught as an Adjunct Professor in the School of Business at San Jose State University in California. He has written books and scientific articles and developed workshops on creativity.