

*Room for a view***Optimism born out of circumstance**

Health professionals are often assumed to not have disabilities of their own. This became very obvious to me as a medical student during the SARS crisis in Ontario. Because precautions were in place, everyone had to be screened prior to entering hospitals. I approached the accessible, main entrance of my own hospital and showed my staff identification. The guard told me that, as staff, I could no longer use that door and would have to go around the block to the staff entrance. I pointed out that my very visible physi-

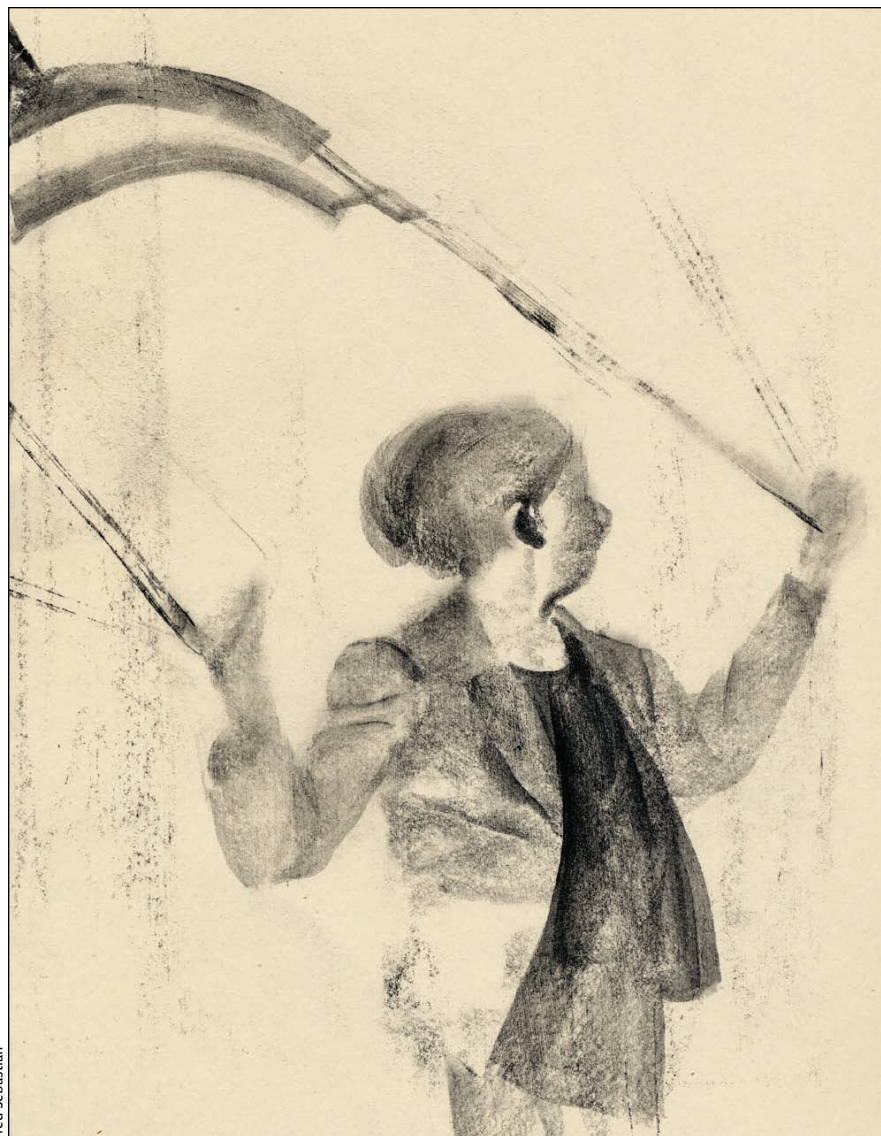
cal disability makes it difficult to walk even short distances. Despite this, I was not allowed in. I eventually did go around the block, only to be faced with a flight of stairs going up to the staff entrance door.

I was diagnosed with Facioscapulo-humeral Muscular Dystrophy when I was twelve. During my childhood, I had a large number of diagnostic tests, as well as surgeries. There was never a doubt in my mind that I would enter into medicine, the profession that had for so long taken care of me. My disability was a non-issue to my young, optimistic mind.

I made the assumption prior to medical school that if any group would understand my situation, physicians would be it. The supervisors who at first took me on had experience working with people with disabilities and were quite accepting of me. Time and time again since then I have been reminded that this is not always the case. Physicians traditionally have been seen as the epitome of health. They can treat the ill but when one of their own is sick, they are often at a loss. As such, some individuals find it very difficult to overcome the first impressions of my physical condition.

At the start of my clerkship, a well-meaning attending suggested that I compose a letter for my prospective patients explaining that I am a medical student with a disability. This letter would be given to them as they waited to see me in the clinic. My attending believed that without an explanation, lay people would make an assumption regarding my mental ability because I had an obvious physical disability. I was taken aback at first by this suggestion because I have never had an experience like the one proposed in a clinical setting. I put myself in the position of my patient receiving a letter like this and thought it would set up a very awkward situation in which both parties would be forced to focus on the doctor's issue rather than the patient's reason for appointment. I politely declined the suggestion.

How do I approach my disability with my patients? It depends on the situation, but I am forward and honest whenever someone asks about my condition. I gauge if a patient appears uncomfortable when I introduce myself or appears as if he or she would like to ask questions. I have found most adults feel different degrees of unease when they ask questions so I approach it casually but professionally. I tell them I have muscular dystrophy and then explain that I was born with it and it is slowly progressive. My scooter has become a topic of conversation as an ice-



Fred Sebastian

breaker. Kids love it, they think it is “cool” and the elderly have called it “quite a Cadillac!” The most common response to seeing me is one of praise for what I am doing. Another common comment, especially from the older population is, “I have nothing to complain about when I see what you are doing under your circumstances.” I am humbled by their words of praise and encouragement. It also reminds me that I play an important role in the education of others, including my teachers, peers and patients.

My experience with children often contrasts sharply with my experience with adults. What I love about children is that they are brutally honest and then they move on. Of any patient group, they are the ones who ask “What’s wrong with you?” or “Why do you walk funny?” For most ages, I developed a simple explanation that works well. I tell them that some of my muscles are not very strong. I then get them to show me how strong their muscles are by flexing their bicep. This gets them involved and usually includes a giggle or two. I make a big deal about how strong they are and then explain that because my muscles are not strong, it makes me walk differently than others. I try to use the moment as an opportunity to explain that we are all different and unique. Children are very accepting after their curiosity has been satisfied.

Working with children who have their own physical disability is especially rewarding. While working in developmental pediatrics, I had the opportunity to meet a boy with Duchenne muscular dystrophy. In the often uncomfortable environment of a neuromuscular clinic, where a patient is shuffled from one doctor to another, only other patients can truly understand the stress this causes. He was able to relax in my presence, as I told him about my own experiences.

The hardest challenge through medical school was the emotional impact that accrued with time. I can honestly say that I was not prepared on entering medical school to be considered “different.” All medical students are put

under a tremendous amount of stress to learn large amounts of material, to perform, and to be drilled by residents and attendings. This was magnified in my case. In the context of wanting to help and prepare me for the future, clinicians often put the emphasis on my disability and where my disability caused difficulties. The person behind the disability was forgotten. Yet diffi-

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culties should be balanced with strengths, as these are equally important. And strengths do not always have to come from academics, a connection often made but one I find puzzling. A comment by one of my attendings reflects this. “You must be very strong academically to have made it this far, considering your disability.” How are these two connected? Everyone accepted into medicine has strength in academics but this has not taken me any further than my colleagues. I need to prove myself clinically just as others do.

At the other end of the spectrum of people focussing on my difficulties, there are those who do not want to give me any negative feedback. For example, they make their own assumptions about what I can do, and then don’t give me challenges or criticisms that they would give to an able-bodied student. I learned at the beginning of rotations to talk openly with my supervisors and asked them to be honest and point out concerns. This meant a dialogue was started and weaknesses were noted early, when there was time to make adjustments. They had a chance to criticize and I had a chance to show my best.

Today, my disease affects both my upper and lower proximal muscles.

As the name suggests, my facial muscles are also affected. My speech has adjusted to its environment and although my lips do not move very much, I am able to enunciate well. I make up for the lack of overt facial expressions with my eyes and tone in my voice. The involvement of my hip girdle and progressing lordosis in recent years is making it more and more

difficult to ambulate. I may have quite a waddle, but I am still walking. I use a power scooter in the hospital to commute quickly from place to place. There will always be missed conversations with colleagues in the stairwells of hospitals. Can I deal with this? Yes, definitely. I will never know what runs through their heads as I meet up with them on my scooter but more often than not, I do not think it is negative. There will always be sceptics, but I rarely worry about that. My classmates were with me for four years. To them, I was just another person contributing to the class and they were always more than willing to help. When they interact with disabled colleagues in the future, or they themselves become disabled, it will not be a new situation. It is my hope that because of my presence in their class, and now my presence in a residency training program, people will be more likely to advocate for those with differences in the future.

I realize that an optimism born out of circumstance in childhood has taken me on quite a journey!

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