

# The International Journal for Direct Support Professionals

## Voices from a Silent Journey

By: Melodie Cook

**Benjamin Disraeli says “*There is no education like adversity.*” I have come to appreciate this, although I find the tuition to be rather high.**

In September of 2014, I began to experience right sided pain in my mouth and throat. The pain eventually migrated to both sides of my mouth. It is a constant severe burning sensation which is made worse when I speak and when I chew roughly textured food. After two years of appointments with specialists, I was given the diagnosis of “Burning Mouth Syndrome.” For those who have never heard of this, it is a central nervous system disorder. In some cases it is mild, causing numbness or burning in the lips, palate, tongue or gums. In my case, it causes severe burning of my entire mouth with the worst pain at the back of my tongue and in my throat. The result has been that, over the last two years, I have been on a journey of mind-numbing medication to take the edge from the worst of the pain and have been quite disabled in terms of speaking. Each day I work with an undeterminable limit of words, from none to no more than a few sentences. I cannot project my voice, even across a large table. The repercussions of saying just a few too many words are that the pain worsens until I am pacing or constantly tapping my foot in an effort to trick my mind from feeling the worst of it.

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I am the kind of person who loves to interact verbally with people, loves to laugh, loves to joke and, most of all, loves to tell stories. It has taken me some time to realize that this is my new reality. It has also taken me some time to realize that I have learned many lessons regarding what it is like to live with a disability, to be non-verbal or verbally limited, the problems this creates and others reactions to it. So, with my limited verbal skills, I have resorted to writing. Following are some of my personal reflections on lessons learned about myself, about our world and about the things we do to the people we support who may struggle to be understood.

### Common Sense and Context

One of my first experiences was trying to communicate my difficulty communicating. It would go something like this: An acquaintance or sometimes agency employees would start a conversation. I would motion towards my throat and mouth, “I can’t talk.”



I would then be asked why. This occurred so many times I lost track. But I can tell you that, if you can't talk, offering up a verbal explanation as to why is not an option. It surprised me sometimes who would step up and help, and who would not. Oftentimes co-workers would say nothing, fearing that to say something was divulging personal information. Contrary to this, I felt it was just being helpful. There are ways to be helpful to people you support without giving their entire medical history. The result for me was increasing isolation from employees and co-workers as I would literally avoid situations where I might have to socialize or explain my situation. I stopped eating in the lunchroom, I avoided "brainstorming" with people who reported to me, and I increasingly felt as though I wasn't making the contributions I could.

***Lesson #1: People with intellectual disabilities are often socially withdrawn whether they communicate verbally or not. This has nothing to do with their ability to contribute but has lots to do with our social world which tends to value verbal communication which is fast paced. As supporters, we need to be mindful of the pressure this creates for people with disabilities and work to lesson this. Good communication often comes from taking time to put your thoughts together and express them. It takes time, space and mindfulness to ensure that people with disabilities are truly included in conversation, both in terms of understanding and responding. Take the time to do this, and you will not only lesson the frustration for people, you will also reap a richer conversation.***

Eventually a somewhat helpful speech therapist recommended a "Boogie Board" which is like a Magic Erase Board brought into the 21<sup>st</sup> century. You write a note. Once it has been read by the other person, you press a button and it erases. While this helped, there were a couple of problems. Firstly the pace of conversation always outpaced my ability to respond in writing. I would often find that, by the time I had written a thought down, the conversation had moved on, and I would end up erasing my thoughts, feeling they were no longer relevant. The same problem occurred with the text-to-voice options I found. In fact they took even longer. I wonder how often we outpace the people we support, and don't allow time and opportunity for reciprocal communication. I wonder how many times it makes them want to give up trying altogether, as it is just too exhausting to keep up.

***Lesson #2: People who struggle to make themselves understood need support to find assistive devices to help them communicate. Help the person get a referral to a Speech and Language Pathologist to find the best system for them, access potential funding for it and, most importantly, train the person and their supporters on how to use it. Then make this a priority. Having communication technology that supporters don't use and respect essentially silences the person's voice all over again.***

My other issue was that I have very poor handwriting, particularly when I am trying to write fast. This left my co-workers guessing what I had written. But the guesses were out of this world. "Good, we'll do it" became "God will do it." Conversations about finances turned into comments about zoo animals. I found myself repeatedly writing "CONTEXT." I wonder how often, when we are attempting to guess what people are trying to tell us, we really think about CONTEXT.

***Lesson #3: Working with people who we struggle to understand takes skill in recognizing context. What is going on? What has happened or is about to happen? What subject have we been talking about? What other things is the person communicating with their gestures and body language? Believe me I understand why people we support want to hit us sometimes. CONTEXT.***

## Watching Others Communicate

This disability has given me the opportunity to watch how people communicate. Do you know that often the loudest voice gets heard first? The loudest voice often drowns out the voices of others. The most dominant people often interrupt. I am not suggesting for a minute that I do not have these faults, but I certainly see and hear them more clearly now. These are poor social skills that we are role modelling to the people we support. I have noticed many times when people we support will either speak louder than is socially necessary, or will interrupt. I don't wonder why any more.

***Lesson #4: Remember that people you support are paying attention to what you say, and how you say it. Supporters need to remember to model communication etiquette that includes people and teaches reciprocal communication (taking turns), and respect for differing points of view.***

## Surprises and Assumptions

I discovered pretty quickly who my allies were, and I also discovered they were often outside of our field. People in stores would do their utmost to assist me and attempt to understand what I needed. Did you know that, at every Tim Hortons drive-through, there is a sign on the intercom which says, "Those experiencing speech problems please drive up to the window?" I never noticed this sign until I went through a drive-through after this voice issue started. Interestingly, people outside our field also never asked what was wrong. For the most part, once they realized my problem speaking, they went out of their way to determine a different means to communicate reciprocally. I did encounter one difficulty. On occasion when I would mouth, "I can't talk" or scribble it on my Boogie Board, the person would start writing back on my board, or on a piece of paper. Many times it was assumed that if I couldn't talk, I also couldn't hear. You could see the light bulbs go off when I would write back "I can hear just fine."

***Lesson #6: I think we often categorize the abilities of people we support. It may not be as blatant, but I do think many times we assume certain abilities aren't there just because of one characteristic. People need the opportunity to show us their stuff. When we make assumptions, we deprive people of doing and learning to do.***

I also found allies in my co-workers. When I was eventually able to talk a bit, a portable microphone was purchased so I could be heard in larger meetings. I take this thing everywhere. I also noticed that the person sitting next to me would notice the minute I turned it on and would alert others that I had something I wanted to say. Eventually the whole group started watching for when I would turn it on and the discussion would halt so I could contribute.

***Lesson #7: Again, I wonder how many times we miss using technology to enhance people's opportunities for communication. Communication gives opportunity for choice, contribution and control. Communication technology has come a long way. The more people use it, the more it will develop. Be creative and do some research to find something that helps someone you support increase their ability to be understood. Locate a Speech and Language Pathologist for help getting the right system.***

## Picking My Battles

I have learned during this journey that medications can rob you of your personality. It has only been in the last few months, after getting a correct diagnosis, that I was switched to a medication that does not make me so drowsy. I have had numerous people say, "You're back" when I was never aware I was gone. I have found myself picking many battles. There is the battle between pain reduction and personality reduction. There is the battle between prevention of depression and maintenance of focus. I wonder how hard this is for people we support. I was fortunate to have family looking out for me. What about people we support who rely strictly on direct support professionals who rotate through shifts and jobs? This speaks so much to the importance of helping people maintain and develop relationships with family and friends. I have learned first-hand that Tegretol, a common drug in our sector, is not a pleasant drug to be on. Unlike other medications, Tegretol provided me no consistent therapeutic effect. I would experience varied states of drowsiness, dizziness and double vision that occurred randomly rather than on a continuum, like most other medications. I felt that I literally couldn't count on me. Switching medications provided another form of agony. Despite weaning off of a medication slowly, there were nasty side effects. Some side effects could be eliminated by the temporary use of another medication. Some medications created incredible thirst. These were issues I was able to maneuver by always carrying water, and keeping a mouth-moisturizing spray and chewing gum on hand.

***Lesson #7: I suspect many people we support experience medication side effects similarly, but we may struggle to recognize it. How do they let us know they are experiencing these things, and how do we help them maneuver? It is so important for supporters to know the reactions and side effects of the medications people are taking to be on the alert and sensitive. If I had relied on someone else to understand my thirst, I am sure I would have suffered far more. There is also a delicate balance between symptom relief and personality theft. Be vigilant in helping the person to find this balance.***

Getting a diagnosis was a battle. Once I realized things were serious, I started to keep a journal of symptoms which I would summarize to present to specialists because I couldn't communicate much verbally. Once, after waiting for months to see a neurologist, I was asked to explain my symptoms. I provided her a five page summary which would have taken five minutes to read. She put the papers aside and said, "You're going to have to tell me. I don't have time to read all of this." I let her know, with a very soft voice, that it was painful for me to speak. She said she understood, but she didn't have time. She proceeded to grill me with questions in no particular order which took 10 minutes and all of my vocal stamina to answer. I left in incredible pain with the diagnosis that it was not a brain tumour but some "atypical neuralgia." **(Note to those of you who have heard a diagnosis involving the word "atypical," it really means the doctor doesn't know).** Afterwards I realized that I had missed communicating some of my symptoms. This likely affected her rather vague diagnosis.

***Lesson #8: While most doctors were great, much like my bad experience, we often have to help people we support battle the medical system to be heard. Despite the lack of respect for my symptom journal with one doctor, this was an invaluable tool for most of the doctors I saw, and something we must make sure we help the people we support with.***

My other constant battle has been the need to choose when and how much I speak. I know when I am done I will suffer the consequences, often for hours, so I have had to save my words for what I really feel is important. Two years ago, my husband and I bought a small modular home in a 55 plus gated community in Florida. The following April, I went down by myself for two weeks to paint the house and also to have some time alone where my voice wasn't required. After a day of painting, I would reward myself with a couple of hours at the pool. We bought this home not just for the community amenities but also for the community itself. Never have I met so many thoughtful, caring and cheerful neighbours. My husband says the cheerfulness is due to the fact that they are all retired.

During one of my afternoons at the pool, I saw a man who I had never met before, as he made his rounds talking to everyone. This man had a booming voice and I could hear him quite well across the pool as he spoke to a woman he had just met. At some point, I started to listen because his voice was so loud I could not block it out. I listened as he said that his brother had Down syndrome and then I heard him say the R-word. He said that often, when he was teasing his brother he would call him the R-word as a joke. He said it was a "brother thing" and said his brother would often laugh. He talked about going to a restaurant and when the waitress would ask, "How many people?" he would say, "Four adults and one...R-word." I was horrified but unable to speak. I ended up leaving the pool and feeling horrible that, because there were no dissenters, this man's permission to be cruel had been perpetuated.

The following November, my husband and I were in Florida and met a couple who were close to our age. We decided to meet for drinks. By this time, I had some limited use of my voice. During conversation, they discovered that we were going to be there for the U.S. Thanksgiving and kindly invited us to join their family for the meal. Later the wife left to go to the bathroom and my husband went to the bar to get us drinks. The husband began to tell me that he was flying to another state the following day to bring his brother back for Thanksgiving. He said his brother had Down syndrome and he was concerned about him flying alone. He had decided to fly down and then back with him. I commented on what a nice brother he was and went on to tell him the story about the man in the pool a few months before. After listening to the story he replied, "Oh, yes, that's my brother." He then began to defend his brother and said, "You don't know what it is like to have a family member who has a disability." He then said his brother laughed when they called him the R-word. I noted that this did not make it right, and his brother was likely laughing out of embarrassment or perhaps because he did not realize that he didn't need to accept this. I went on to explain that I worked for over 500 people who had a similar disability, and they found the word hurtful and wanted it stopped. There was no changing his mind. At that point, his wife and then my husband returned. Neither of them knew what had occurred but felt the tension. After we left, I told my husband what had happened and that there was no way we could accept their invitation because, if we did, and I heard the R-word, something would happen, and it wouldn't be "Thanksgiving." A few days later, the wife approached me. She had heard about my disagreement with her husband, and said the brothers had been doing this for years and she didn't agree either. I replied, "Then say something." Days later, I ran into the woman again. She commented that, when we had turned down the invitation for dinner her mother-in-law had wondered why, so she told her. Her mother-in-law had no idea this had been going on and "gave it to the boys" (all in their 50's). I did have the opportunity to meet their brother, a very sweet man who I instantly liked. This battle was well worth the pain.

**Lesson #9: *It is never okay to let cruelty of any kind go unchallenged.***

Although my chronic pain and voice problems continue to be a bit trying at times, this experience has also offered me the opportunity for reflection. There are so many “life” lessons I have learned, but the best one is that I can still communicate and contribute, and have influence, and participate, and enjoy life. Just my voice has changed... and perhaps... my perspective.

**In memory of my grandson, Kai**

**About the author:**

Melodie Cook is currently the Operations Director for Community Living Windsor. She has held a variety of positions during her 33 years in the sector.

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