

“I thank God for my handicaps, for through them,  
I have found myself, my work, and my God”

~ Helen Keller

Chapter 1: 1<sup>st</sup> Barrier(s)  
Chapter 2: School Stress  
Chapter 3: Different Jobs  
Chapter 4: My Family & Friends  
Chapter 5: Guidance  
Chapter 6: One Voice  
Chapter 7: The Artist Within  
Chapter 8: Extending a Hand  
Chapter 9: What I've Learned

## Chapter 1

### 1<sup>st</sup> Barrier(s)

No one expects to have a child with a disability or for one to develop a disability, but sadly, it happens. However, in no way should this be received as a life long tragedy. In my opinion having a disability only means that there is a barrier or barriers, a wall so to speak that is needed to be broken through or accommodated to in order to get around, to find something special. Whether it is an offering of a new and unique viewpoint, a thirst or passion to move forward through life with a smile, or a desire to work hard, it is there.

Having a disability, whether physical or mental, is nothing to be ashamed of. Unfortunately, saying that is much harder than actually living and doing it.

My life, along with family and friends, had come to a halt when I was at the young age of six. I include family and friends when I say this because even though their lives were not technically put on hold the way mine was, to say they were not affected would be silly and a bit selfish.

I had acquired a brain injury through a disease called Encephalitis, a very rare disease that affects a very small percentage of the population, 0.5 per 1000 individuals; an acute viral infection of the brain. This illness affects cognitive and motor skills and can become either focal (directed) or diffuse, (spreading) I had the later. It put me in a coma for two months and destroyed all memory and all skills and knowledge I had learned in my first six years.

The great doctors and nurses of Saint Michael's hospital in Toronto, and later North York General, did a tremendous job at getting me and my family through this. Many exercises and lessons facilitated by therapists were undertaken at the hospital and then later at home. Family and friends helped as well as much as they could, but as good intended as they were in their endeavors, in the end, it was still all up to me.

My biggest barrier was the fact that what I had to deal with was, and is, what is called a non-visible disability. I wasn't in a wheelchair or using a walker, I didn't have a speech impediment; these problems I had were all in my head. As time went by people would forget just how sick I had been and that I continued to struggle with various things. I felt alone quite often. I was confused about things almost

always. I had no idea, or little of it, as to where my place in the world was. In some respects, years later, I still don't.

Out of all of the things I've learned, I hold two lessons very dear and try to always reflect upon them. The first is "Patience" and comes in two parts, to not only be patient with others, but with myself. Number two is that I am not and never will be, the only person to feel lost and overcome with a disability; whether physical or mental. I truly believe any person with a barrier or barriers in life that come to terms with these rules and try to live by them deserve the utmost respect; especially in a world that does not have much time for leniency. For those of us who have come to appreciate a cautious approach to life offer a unique ability for the serene.

Everyone, whether in a wheelchair, being blind, living with depression, or just sitting behind a desk has their abilities and disabilities to offer this world, we just need to be patient enough to understand and see it.

## Chapter 2 School Stress

The ordeal I had gone through had kept me out of school for an entire year. I had been in the hospital for four months and then I remained at home and attending various therapy sessions for the next six. Summer followed and come fall I was ready to go back to school, or so I and my parents thought.

My mom had to fight with teachers, the principal and the board of education to get me enrolled, or re-enrolled. They said “He can’t be in a ‘normal’ class situation and thought I needed to be referred to a special school. I’ll admit that I liked the idea of being part of a special school, but I do not think my idea and their idea of “special” was the same. An agreement was come to that I would be allowed to continue my education in the public school as long as I went into a special education class and dropped back a year. Dropping back a year did make some sense, after all, I missed an entire grade.

Special Ed also worked well for me as I did have trouble keeping up pace and my learning skills were on a different level. There weren’t as many kids in the class either so it not only helped me relax a little, as concentrating in large group settings was difficult for me, but it also allowed the teacher to pay me more undivided attention. The class was fun too as we took extra field trips, took part in a story circle everyday where we listened to the teacher read, and got more gym time. Those years in public school attending that class taught me quite a bit and were sorely missed when I graduated to junior and then senior high school.

My graduation was not only from public school but from the special education classes I had attended. And now, I wanted a fresh start, to follow my education and see if I could do it without a rope, so to speak. I knew that I could, and I did manage on my own; I did not need to live by the stigma of a disability. Yes, things were awkward for me, I felt a little like an outcast and I’m pretty sure some people looked at me as being a bit ‘weird’ because I was slower at quite a few things. My challenges were not necessarily the work I had to bare but the attitudes of my surrounding peers.

Something I’ll never forget was writing an auto biography for one of my classes and mentioning the illness that I dealt with. I suddenly ended up with classmates befriending me that never even spoke to me before. Was this something I wanted? I quickly realized that this

befriending was actually pitying. I not only began to resent the project that I did but my disability all together. School after that became tough, I now really did feel different from others.

When my sister joined me in high school and began hanging out with me and including me and making sure things, socially, stayed at a healthy pace for me, I felt more room to breath. I felt as though I was now being accepted. As much as I sometimes feel my barriers are forgotten I know that they remain in the back of my sister's head. She helps me from having to struggle with things, but also guides me and encourages me to do it my own. It is that combination that helps me the most.

Unfortunately my sister did not follow my education pathway entirely (she was a couple of years behind me as well) so I was out there fending for myself quite often. In my college years, and even in my high school and public school years, I remained more or less a loner. I was shy, but I was also unsure. I didn't know how to talk to people or keep up with them. While the other guys were forming "cool" groups of friends, or "cliques", and getting girls, I was there standing alone, feeling awkward and not knowing what to do. I did have some friends but I still felt as though something was missing. I felt like a loser many times; though I never let it get me down too much. I remember one time the only guy in college that hung out with me once telling me that some of the others (his friends when I wasn't around) thought I was a bit of a "weirdo"; I didn't talk all that much, I didn't excel in many of the classes because I couldn't understand a lot of the stuff, and I was a bit slow in the thinking process.

I really tried not to let these things bother me, especially when I had a few good friends and people like my sister and mom pulling for me, but it proved to be hard. I now look back and think I really did learn some great, albeit hard, lessons in school.

## Chapter 3 Different Jobs

It can be difficult when you have a disability and wish to enter into the workforce. It can cause someone a lot of stress. There are so many things to consider. First, a person must decide whether or not he or she is actually capable of work, and then they need to figure out what the best fit is for them. Some disabilities you can see, like someone in a wheelchair or walking with a cane; others you can't necessarily see, such as a learning disability.

The scariest part though is probably going into work and dealing with this disability when it comes to management, supervisors, and/or co-workers. In most cases, a person with a disability already knows their limits. They have a strong work ethic and they know that (given certain accommodations) they can get the job done.

It'll probably surprise you to know that people with a disability will most likely have a better attitude and willingness toward the job than some others.

**Studies show that 90% of employees with disabilities rated average or better on job performance than their coworkers.**

People with disabilities tend to work harder and listen better; I'm speaking first hand here. I've disclosed after some time on a job to a manager who thought I was making excuses for myself and did not lift one finger to follow through on any of my simple requested accommodations. It was too bad that his attitude was so poor, because I would have gone that extra mile to make things work.

**Most often only 15% of employees with disabilities need accommodations that incur a cost. Of that, over half cost \$500 or less.**

Attitudes in the work place from others can be very hard to overcome. Some people can be mean, some can be ignorant. Usually this comes from one not understanding a certain disability or just disabilities altogether.

*People have ended being acquaintances, having working relationships or even friendships (even friends of friends) simply because one can't handle the idea of dealing with someone else's disability*

But an even worse problem is when a person with a disability finally works up the courage to disclose and the manager, supervisor, or co-worker, become over understanding and sympathetic. That guy or girl who just revealed something that was very difficult for them to overcome has most likely been dealing with their disability for quite some time, they know what it is and they know how to deal with it. He or she, or me, understand who we are.

So don't baby us, don't start treating us as fragile beings, and don't tell us you know what it is like by comparing our disability to something else. Every disability is different in the way that it affects a person. Every person's ability to deal and adapt is different.

Adaptation to a disability can sometimes only go so far, but most will find an edge and overcome certain obstacles. Whether physical or mental, a disability does not mean an inability to work, and to work well.

The ADA (Americans with Disabilities Act) came into play in 1990; the Human Rights Act was established in 1989 and amended in 1991 & 2007; The ODA (Ontario Disabilities Act) was put forth in 2001; the AODA (Accessibility for Ontarians with Disabilities Act) started in 2005.

Despite these increased laws that address employment discrimination and the practice of providing accommodations for qualified workers with disabilities, the employment rate for persons with disabilities has increased very little. The unemployment rate for persons with disabilities is a whopping 47%, (More than 1.5 million Ontarians, 13% of the population, live with a disability) and only 25% of that number represents people looking for work. **(The rate of people with disabilities is on par with the growth of China)**

This is not because people with disabilities cannot work or don't want to work, it is because most eventually give up. They become tired of the uphill climb, the myths and misconceptions. Employers have unfounded concerns about productivity, absenteeism, turnover and interpersonal situations; increased insurance, safety risks, accommodation costs. The reality is that most of these employers have made these assumptions without even having any experience, in any form, working with persons with disabilities.

Insurance rates are based on workplace hazards and safety, not employees; remember what I said earlier about employees with disabilities rating average or better on job performance. People with disabilities also rated 86% or better when it came to punctuality and reliability; the turnover rate is lowered because a person with a disability is more likely to stick with a job longer; accommodations, if really needed at all, come at a low-no cost ratio. An employer that does not hire someone because of their disability, proclaiming “undue hardship” in relation to any accommodation that would be needed, has to prove that. The onus is on them to show that it is too costly, a health related risk or a safety issue. Anything else is attitudinal and is discrimination. Of disability related complaints each year approximately 75% are directed at employers.

For a long time I did not want to ‘disclose’ my disability, not only when it came to work but in my personal life as well. I did not want to be treated differently than others. But as time went on and I graduated from school and became more focused on the workplace I realized the first step I needed to accomplish was coming to terms with myself, my barriers and how I saw them and then accept that I was REALLY no different than anyone else. My barriers may have set me aside from others, I may have needed and still need certain accommodations, but I could and can work just as well and be just as successful.

After quite a few years of being in the workplace with a few different jobs under my belt I’ve really only disclosed a few times; reactions always different and sometimes discouraging. (I already mentioned one of these times briefly)

As I worked for many years in theatre production, jumping from small stage to small stage I had taken on many part time jobs to fill in the gaps between theatre work. One of those jobs was working in a fast food restaurant and it was too quick paced for me so I eventually felt compelled to say something; I didn’t want to be seen as a slacker. When I disclosed a bit about my limitations I was looked at with surprise and not a lot of understanding. I’ll give them credit for trying

to give me a lower end position that was a bit easier, but the job itself did not really cut it for me and I left after a month.

My second time around came not during the interview but during the training session. I was working the front desk of a busy Toronto hotel and when I stepped up to say that I simply needed some time and accommodations to make certain information more accessible I was told matter-of-factly that it wasn't their problem. I was only asking for a little assistance in some areas, not that I couldn't do certain parts of the job. I left because of that bad attitude, the very attitude I think that keeps a lot of people with disabilities from putting forth the effort to gain employment.

The third time I disclosed was to an employer I had felt comfortable with and I was convinced that this person would understand. I was working at a "softer" hotel, more relaxed with customers. I was in a position where I could pace myself and make or get the assistance I needed to help. The owners were also very laid back and open to suggestions I had made about the working environment there. It wasn't that the reaction I got was a negative one or that there was no understanding, (although in retrospect I suppose there wasn't) it is that the response was to compare and empathize; telling me a similar story and saying, "**I know my friend, I know.**" Now even though this may have seemed harmless, it really wasn't; because over empathizing with something can quickly turn into belittlement. If there is one thing I have learned about mine or anyone else's disability is that no two are alike. Just because one person deals with and is affected by a stroke in a certain way does not mean everyone who has had or will have a stroke is going through the same thing. As much as I don't want to be treated differently because of my disability, to a degree I not only want the acknowledgement of it (if I disclose) but I want to work together to find the accommodation I need to work around any barriers. Making out that what I live with and have just disclosed is simply COMMON does not encourage.

People with disabilities do not need to be "fixed" or "cured"! Not from an employer anyway. When dealing with people who have a disability why is it that some employers tend to think they are psychologists or doctors? Then there is the complete opposite, employers who still ask the question "how can "those people" do this job"? Currently I work at a job, which I will detail later, where I see that those poor "They" and "Them" attitudes still exist.

I also must point out and recommend volunteering. Volunteerism not only looks good on ones resume and gives a person of good feeling about helping, but it can lead to opportunities. Employers love to see that hands, 'real life', on-the job training and hear of actual experiences. It can also be great for persons with disabilities to showcase their skills and overshadow any stereotyping or misconception.

*According to the **Equal Employment Opportunity Commission (EEOC)** an employer cannot discriminate or fire because of a disability but they do have the right to do so if they have been lied to; or in a round about way told a job could be done properly when it couldn't. Once a disclosure is made (acknowledging a disability but not going into detail) and any barriers discussed, accommodations can be made.*

***Accommodations** are defined as: any special arrangement that a person with a disability needs to allow them to do essential duties on the job.*

When I graduated from College in a Graphic Design field I could not successfully land a job, no matter how hard or often I tried, because I just could not keep up at all with the fast pace of the business. I volunteered at a nearby theatre to where I lived, working backstage and helping out with sets; I was still getting to be creative with my work. The employers there took quick notice of my talents and hired me very soon thereafter. I was there for eight successful years and moved up to Assistant Production Manager; duties included lighting, set design, set decoration, prop work and more. And through recommendations I landed gigs at other theatres where I did similar duties and more, such as Stage Managing.

I do often wonder though about "disclosure" and how things would have worked out if I had mentioned my having a disability and the barriers I faced. As I stated, I did a variety of jobs while there. Lighting included climbing up a tall ladder dragging up a heavy lamp to hook up onto a lighting pole and then focus precisely to a certain location; movement of this light and other things needed to be done on cue, sometimes at a moments notice. I ran the board a few times during shows and had to quickly push buttons to shine a light here or there. I even ran a spotlight once and had to steadily follow dancers

on stage and then stop at the drop of dime. All of these things and more I managed to do well and I achieved praise in what I did. It was because I worked hard and paid careful attention to details. I made some small mistakes but because I was patient and always willing to give one hundred and ten percent, my other co-workers and my boss excepted any mishaps. But balance and speed and accuracy are not amongst my list of strong skills, and even though I believe my employer to have been wonderful and accepting and would be all about equal opportunity, I still question sometimes if I would have been given the chance to do everything I did if I had started out by disclosing my barriers.

I have disclosed in the past, and even though I have never actually been fired, from my examples you can see that the outcomes have never really been positive ones. My current job as I write this, with One Voice Network, has kind of been the exception. And I thank them for that because it has made me stronger, as has every job. When I move on from here (it is a contract position) will I disclose? I can't say for sure. But what I can say for sure is that I have got to be confident in the abilities that I do have and know that I can do the job and work hard at it. That is why I succeeded in the theatre and it is why I will continue to succeed. Actions do in fact speak louder and better (sometimes) than words. The people at the theatre saw what I could do and therefore had faith in me to do what needed to be done.

Volunteering worked out extremely well for me and I recommend it to anyone, you never know where it will lead. (Refer to Chapter 7)

There is also a lot of assistance you can get through various outreach programs out there. Employment Specialists and Job Developers are there to help you find work, and it is beneficial to have someone working with you while finding employment. Doing it alone can be very difficult and add to the stress some may feel about his or her disability; thinking that perhaps no one will want to hire them. Discrimination is unfortunately still alive and equal opportunity isn't always that easy to find. But many of these providers that I refer to are fighting the battle to help change that. ODSP, (Ontario Disability Support Program) Seneca Employment, York Works, and Ability Services are just a few of the available services.

But no matter how good an Employment Service Provider is, they can not land you a job and keep it for you if you are not honest about the abilities that you have, the barriers you face, and the accommodations you need. (It is ILLEGAL for an employer to ask if you have a disability and you are under no obligation to disclose. – However, and regardless of what I’ve said about some of my past experiences, if your disability is going to affect your job I recommend disclosure...to a degree. You are doing yourself more harm than good by keeping quiet.) You are not doing yourself any favours by not being open and honest when it comes to getting a job; or anywhere in life for that matter.

Employers, even if willing to accept any barriers an employee may be facing, are sometimes afraid of doing or saying something offensive or wrong. They can’t read someone’s mind about what they may need. I was unemployed and I found myself a great Service Provider. She worked with me, offered some great advice, and even found me a couple of good job leads. One of those leads worked out for me; but I got the job because I was open and honest about my abilities. I needed my honesty and confidence to be at the forefront; but I needed a system, a network behind me that I could rely on for help. I get the feeling some people like to do it all on their own, (I did and still do to a degree) but everyone needs a little help and guidance once and a while.

The AODA, (Accessibility for Ontarians with Disabilities Act) which I briefly mentioned at the beginning of this chapter, is an act with a lot of prudent and useful information. Mandates that must be put into place at certain times. Things that are meant to help with equality. I see Accessibility Committees popping up all over; and that combined with what Service Providers can offer and the program that I work with now, One Voice Network, improvements to equal rights directed at people with disabilities are on the move. Every person should be on a level playing field, and it is their individual actions that should dictate where they go from there. Unfortunately when people are still saying things like, “those people can’t do the job”, you know that equality is not quite there..... yet

(Statistical informational resourced through **Business Takes Action** and **One Voice Network- The Untapped Labour Pool, A guide for Employers**)

## Chapter 4 Family and Friends

We all need a good support system in our lives in any situation encountered. Doing it all on your own can not only be incredibly difficult, it is just silly! Notice I said “difficult” as opposed to “impossible”? It’s just why someone would want to go choose the path of doing it all alone is hard to understand.

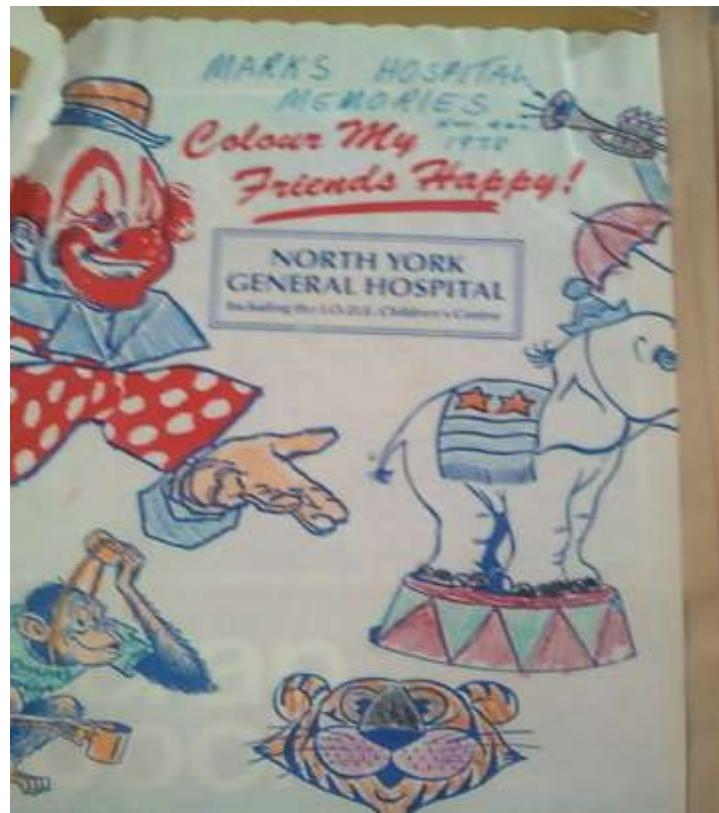
I get pride, and I understand the sense of accomplishment one can get when succeeding in getting something done. I’ve always thought of doing things on my own for a variety of reasons. I didn’t much like asking for help and to a certain degree I still don’t. I’m also a bit shy when it comes to asking for a hand. But really, it was mostly my disability. I wanted to prove I could do it all by myself, no help needed, the “I can do anything you can do” attitude.

For the most part I think we all need to do some stuff on our own, it’s the way we learn. But not wanting or asking for support, ever, is just not realistic. To a certain degree I would even go as far as saying that some of us need some sort of support.

I would not have gotten through my times in the hospital when I was sick if it were not for visits from my family and friends from the neighborhood where I grew up. I don’t even want to think about where I would have ended up within the educational system if it were not for my mom lobbying to have me put into regular public schooling. Even to this day my sister, Amy, assists me with my employment. I couldn’t do it all on my own, I wouldn’t want to. I know what it is like to feel lost and I readily admit that there are still plenty of times I feel just that. But I know that I have a back-up system to help me out, or at least bring me back from that place I’ve felt myself in more than once, spiraling out of control.

When I was in the hospital, North York General, recovering from my two-month long coma and trying to cope with my disability, it was my friends and family who helped keep my spirits up. Many ‘get well’ cards came to me from those back home as well and school chums. I recall one memory with great fondness and it brings a smile to my face every time, as it did then. Two of the neighborhood kids came with their parents to visit me and brought me a ‘Batman’ toy squirt gun. It looked really cool and resembled the batmobile; only in the

shape of a gun. These two girls helped drive me around the hallways in my wheelchair where I played mischief maker and shot water onto all of the nurses. To this day I can't remember if any of them got mad. I also recall and still have the scrapbook of short stories and drawings one of my best friends made me, along with a journal of my time away. These memories, along with the many visits from my sister, are what got me through and what still helps me with day to day life. Knowing people were and are there by my side, encourage me.



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In my early twenties I lived for a few years with my Aunt. She was without husband at the time and suffered from Dementia. She could not live alone. She was the sweetest and funniest lady. Her mood shifted a lot as the illness would dictate, but at times her attitude proved very inspirational. I can remember one day when I was at the house doing our laundry, which happened to be located in the bathroom, and my Aunt walked by in the hallway. She came under the impression that I was using the toilet and had left the door open. She looked straight ahead, raised her cane in the air and shook it and said "Oh Mark; I don't look, I don't look."

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A few years back, my mom fell and hit her head and the result was a blood clot and brain surgery. She now lives with a bit of a physical disability as well as some memory loss, confusion, dizziness and Aphasia; a speech disorder. My mom has come a long way and the starting point, if I'm remembering correctly, was one of the first days before my mom's therapy was supposed to officially start. My sister and I were being shown around the physical, cognitive and speech therapy area; my mom was with us as we pushed her along in the wheel chair. At one point we came to a rest where a group of people were at work in an exercise session, and without any probing on anyone's part, my mom raised her arms as much as she could and started exercising along, slowly, with the rest. To see this woman who could not speak at the time and offered minimal facial expression, start doing this, helping herself all on her own, brought tears of joy to quite a few eyes that day.

Since my mom got released from the hospital she has gotten herself on a great road to recovery. The CCAC provided in-home therapy for physical, cognitive and speech for the first eight months. Through them my mom was referred to the York-Durham Aphasia Centre and the Ontario March of Dimes; both offering great programs. These things came at little to no cost and it is nice to know that services are out there to help with disabilities.

At present time, my mom has slowed as to how much she can improve, but things have been pretty miraculous all together! I now truly believe in the "silver lining" thing, and like Shane Koyczan once said, "***Everything that is beautiful in the world is right now.***"

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I have lost friends in the past. People have just picked up and walked out of my life for no apparent reason; well at least not to me. I've never had much luck keeping chums from school or jobs. With the exception of a few, most of my friends in my life are my sister's. I've always been considered a "loner" or weird. When my mom had her accident she lost some friends too, and then I started to think, *can people not handle the disability? Is anything considered "not normal" or different or unknown too scary?*

*It can't be that; at least I hope not. I'm being too negative.*

I laughed to myself one day when I was typing out a word document on the computer and out of the corner of my eye, down on the desktop bar, some automatic 'save' thing was going on and it said, "saving to 'normal.'" So what is normal? Is a person with a disability and barriers not normal? Is losing the odd friend here and there considered abnormal? That is when my confidence, about everything, myself, my friends, my skills, rose. To me there is no normal; there just is, accept it or not.

Life is difficult, disability or not. We all face our challenges; some have more barriers to get around than others. School is tough; unemployment is tough, being employed is tough; running a house or dealing with an apartment can be hard; paying bills; dealing with negativity, driving in traffic. It is all up there and can make life problematic. Add having a disability on top of that and you could literally drive yourself into an isolated depression. I don't have a huge family or many friends, but what I do have I cherish. I have an awesome family and some great friends!

## Chapter 5 Guidance

I will never forget my special education Teacher. He was a great guy, took his time teaching and showed quite a bit of patience. But regardless, I don't think I was ever properly assessed when I was in school. When I graduated from public to high school my disability was never really part of any discussion, and I did not feel it was something I needed to bring up. I don't know what information about me was ever, if anything at all, written in notes or transcripts and passed on from elementary to high school but no guidance counsellor ever talked to me about the barriers I faced and struggled with. (I admit, part of the problem may have been that I never said anything to them either) I moved on from high school to college with little worries, I was considered an average to below average student just squeaking by. I graduated from a Graphic Design program but found it difficult to get any employment in that field. The time was smack dab at the forefront of the dawn of the computer, something which we really did not focus on in school, and I already spoke of the difficulties I faced with that. I began my theatre journey and because this was a summer employment gig (May – Sept) I spent much of my time bouncing from small job to job. Working in video stores or anything I found to be at a pace I could easily learn at and keep up with. Some things worked out, some did not. I began to realize that the assessment on myself I had always unknowingly needed, regarding my barriers and limitations and what I was good at and had real difficulty with, was finally being conducted, by me, going through life. Then something happened that I did not foresee or expect; though who really could. My mom, my main care provider, had an accident which caused a brain disability that she now lives and which will affect her for the remainder of her life; just like I will continue dealing with certain barriers in my life. With my family being small and my father already having passed away when I was thirteen, home life was left to me and my sister. I was now facing even bigger challenges than just employment and I found new abilities I had to offer and new difficulties my brain could not comprehend. Life itself was becoming my biggest and best (and worst) guidance counsellor.

Technology, something I feared was too quick for me and had set me back after college, provided a very useful tool in steps to understanding what I really had suffered in my childhood. I researched my symptoms from before my sickness as well as the challenges I had faced since. Asking questions to those who were around (then and now) also helped paint a picture. I'm not sure if this makes sense, but knowing the exact illness I suffered from helped settle my mind in many ways.

Then through the help of my sister I took another giant step in this awareness process and found an employment counsellor, who, after listening to me, referred me to a Psychometrist. A Psychometrist is a professional who administers and scores psychological and neuropsychological tests under the supervision of a licensed psychologist or neuropsychologist. The testing I underwent was hard, a lot of it made me feel stupid at times, though I know this was not the intention. The assessment took two grueling days but I was determined to get through it all. My hope was to come to a further understanding of where I was at, why some things were easy to get through and others really difficult. I needed further guidance and the results I got were exactly what I wanted. This was not a test for pass or fail but understanding. Some things were confirmed and new challenges were faced. Because of that test I learned how to deal with and sometimes even get around the barriers I face. I realize that there are still things I can simply not do, and I have come to a place where I am ok with that.

One of the more recent steps I've taken in the helping and self awareness campaign has been to enlist the assistance of an employment service provider. I was introduced to a program/workshop that I participated in for a week, called 'Career Paths'. This excellent program helped me come to even more conclusions about myself and my abilities, the different ways to further educate one self, and the possibilities of employment goals. Times change and things improve but I feel that your greatest guidance counsellor is sometimes yourself. You know you best. I found that as long as I am open with others and myself and willing to learn and willing to, every so often, tap on that support system, even if it's only one or two people, that that "lost" feeling is a little more bearable and success can be easier to achieve.

## Chapter 6 One Voice

For quite some time I felt that I was alone in certain aspects of life, buried with the depression a disability, whether physical or mental, can bring. I guess you could say that in a way we are all alone when you break it down to all individuals being different, all disabilities being different. But that is as far as it goes. There is always someone out there willing to listen, and there are a lot of services that include people with open ears. No one has to be alone. It took me quite a while to figure that out and I still need to be reminded of it from time to time. For some reason people seem to be looking for some kind of comfort that doesn't really exist as opposed to what is actually there..... and the depression a disability can bring down on someone definitely does not help.

*"Mark, what is it that you are looking for?"* (As in assistance) The question actually stumped me.

It wasn't until my mid twenty's that I really came to understand myself and feel comfortable in my own skin. It took even longer for me to come to terms with talking to others and listening and accepting that my difficulties, my barriers, don't have to be my own. I also found a very good outlet in writing; keeping a journal or jotting down notes and thoughts. (I've included a couple of examples of this "Spirit-lifting Writing" at the end of this chapter.) Speaking and letting it out and sharing, it is very therapeutic; and it can also help others, and yourself, learn things.

I acquired a job that deals specifically with persons with disabilities, services that are available to people with barriers, disclosure and equal opportunities. As much as people can be harsh and rude and not having the time of day, there are a surprising amount of people willing to listen and services that are offered to help with future endeavors. I obtained this job through one of those services, by willing myself to talk and open up a little.

Today's world is a tough one; it seems to be on constant fast forward. People seem to be in such a hurry. It is all about money and numbers. It can be very confusing. I find myself confused quite often, and overwhelmed in the fact that I think I need to keep up with a speeding train and I cannot. I don't get this whole technology thing, well, at least not as fast as it comes and goes and changes. But I can

stop and take a breath, because I've found that there a lot more people than I realized that are fine with that. Some of them even feel the exact same way as I do.

Finding ones way through, finding a job, socializing, making any sort of life in this world, can be tough. Having a disability can definitely be a hindrance in any one of those things. But it can be done. For me, realizing that my one voice is not unheard or alone made all of the difference in the world. Even though I still have my troubles, things are much easier knowing that I'm not alone. With Family and some good friends, I know that to a certain degree I would never "REALLY" be alone, but hearing from people who have not known me my entire life and accept me opened up avenues, ways of thinking that I never knew existed.

As much as I have difficulties with technology I think it is so helpful in so many more ways than most acknowledge. For me, a guy who has trouble talking on the spot and saying things to others that aren't people who have known me my entire life and truly understand, I find things like email and Facebook and Twitter avenues that allow me time to say what I want to new friends and associates. I can go over my words and feel a little more confident that I'm understood. I've found associations and groups too that have made me realize I can do so much more than I used to give myself credit for.

<http://www.kickstart-arts.ca/about.html> found on Facebook

I mentioned this job I have, One Voice Network, it helps to break down the obstacles and challenges people with disabilities face when trying to achieve employment. The organization is provincially funded and the position I hold is contract; but whether it lasts or not my eyes have been opened to things I kind of knew were there but not fully. There are quite a few individuals and services that I've referenced to out there in the world working with, listening to, and supporting people with barriers in life.

The best thing I've found about One Voice Network is that it not only helps to bring employers and their vacant jobs to people with disabilities, it helps open up that communication barrier. You know, the one where a person with a disability feels uncomfortable disclosing. By just applying to a position posted by an employer through One Voice, and because the employer is already

acknowledging that applicants with disabilities are welcome and will be provided certain accommodations, the so-called “elephant-in-the-room” about disclosing is already done.

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Samples of Mark’s “Spirit-lifting” writing:

## **A Little Something About Me**

**By Mark Koning**

At age 6 I was hospitalized with a viral brain infection. I was inches from losing my life. I had lost those 6 years and had to re-start everything. EVERYTHING!!

At age 13 I lost my dad. I miss his guidance.

Because of these two events I went through my teenage years confused and feeling awkward.

I lost both my grandparents, my Oma to Emphysema and my Opa to Cancer.

When I was 29 my mom fell and hit her head, resulting in a brain injury that will most likely plague her for the rest of her life.

In between I’ve dealt with other family health issues, alcoholics, my aunt having Dementia, inconsideration, lawyers, doctors, lawsuits, deceit, financial woos and uphill battles.

I’ve had problems with distant relatives.

I’ve had friends turn their backs and walk away.

I’ve experienced sorrow, tears, and loneliness.

I’ve been sick and to the doctors for many things.

Because of the brain infection that once was, I easily get confused. I have trouble keeping up.

I get tired, I get headaches.

I’ve been lied to.

I’ve been made fun of.

I sometimes feel inferior.

Relationships have not worked out for me.

I may lose more than I will ever win.

I sometimes hurt and I sometimes cry.

I know what it feels like to have your heart broken.

But.....

There is a lighter side; a side which I try to focus on.

Sometimes I may hate my life. Sometimes I may love my life. I usually try to find somewhere in between to rest, it’s what gives me the most satisfaction, the most

happiness.

As much as I may have been wronged by others, I do not hate anyone.

I always see the good, or at least I try to.

I have a lot of love to give.

I accept that I will never find true perfection, only what I accept to be perfect.

I understand that there is no 'meant to be'.

I've learned to be good and true with my word.

I try not to assume.

I realize people will come and go.

I have some of the best people in my life with awesome qualities that I don't think they even realize.

I am proud of my sister and of my mom and of all that they accomplish.

I am proud of where I live, my community, my country.

I'm not rich, but I'm not poor.....in so many ways more than financial.

I do have certain expectations.....but far less than most.

I know that change is inevitable and as much as it can sometimes hurt I've learned to roll with it.

The sun will always come up and there will always be a new day.

Regardless of all the crap I've been through in my life's journey .....

I still smile.

When I take my dog for a walk I plug in my MP3 and sing to the music.

I still laugh.

When I make dinner I can be caught doing a little dance in the kitchen.

I treasure other people's happiness more than my own.

A lot of the time I am alone but not necessarily lonely.

I am independent.

I am creative.

I am sensible.

I am a laid back individual.

I understand compromise.

I have good character.

I am patient.

I am strong.

I am a dreamer.

I am so much more than this.

I am..... Me.

# **Taking The Time: When life creates a detour you must not rush through!** • by **Mark Koning**

Published March 31st, 2009

In the year 1978 I was seven, and it was by far the worst one of my life! I was missing a lot of school due to asthma and a fever. Mom and dad heeded every word my Doctor said, but still, I wasn't getting any better. Then on a cold November afternoon, things got worse and a sudden seizure episode struck!

My parents wasted no time in bundling me up and heading for North York General from our Scarborough townhouse while my younger sister went to stay with neighbors.

Dad literally screeched into the Emergency parking lot! With my mom screaming for help, Doctors came scrambling and immediately lent aid. The results of my condition took forever. Mom prayed while dad paced. The Doctors were stumped. What the hell was going on with this sickly kid? They worked effortlessly for answers, but things came up short. I fell into a coma soon after I was brought into the hospital.

My parent's hearts crumbled. The Doctors were at a loss for words. I was transferred to the intensive care unit where I remained in this comatose state for eight weeks. I even had to miss my sister's birthday.

The day I finally opened my eyes my mom's face lit up along with the awaiting Doctors who were fast to take action, determined to this time get answers. As soon as possible, I was taken to Sick Children's. I was given an MRI and poked and prodded and then finally diagnosed.

I was being haunted by a very rare condition called "Encephalitis". Only a tiny fraction of the population suffers from this, approximately 0.5 per 1000 individuals, making it poorly understood. Encephalitis is an acute viral infection and inflammation of the inner brain.

Once discovered, I was treated with anti-convulsions and steroids for the seizures, and plenty of ventilation to bring down the swelling. It was now all too clear that the seizures, respiratory problems, altered consciousness, and vomiting were all symptoms of the illness. The ghost of this disease laid to rest and spread and was inoperable.

The infection I endured varies from being focal, hitting one part of the brain, to diffuse, hitting basically everything. That last one is what I got. A combination of cognitive, motor, and sensory skills were wiped clean out.

“Squeeze my hand.” A few of the first words I learned. Almost everyday someone would come into my room, read my charts, and get me to squeeze their hand. I had no strength. It was a long while before I could resemble anything close to it. But I tried hard; at everything.

The Doctors had me on a daily routine of medication for the seizures and exercises. The Nurses would push on my arms and legs, .....*con't*

Read the conclusion of this short story and others by visiting my website at:  
<http://www.markkoning.com>

## Chapter 7 The Artist Within

I think I was always an artsy type individual, but I cannot say for certain because I do not know if I had any inclinations toward creativity before my illness. But regardless, what I do remember is that I always liked to draw and create, to come up with stories and play out fantasies.

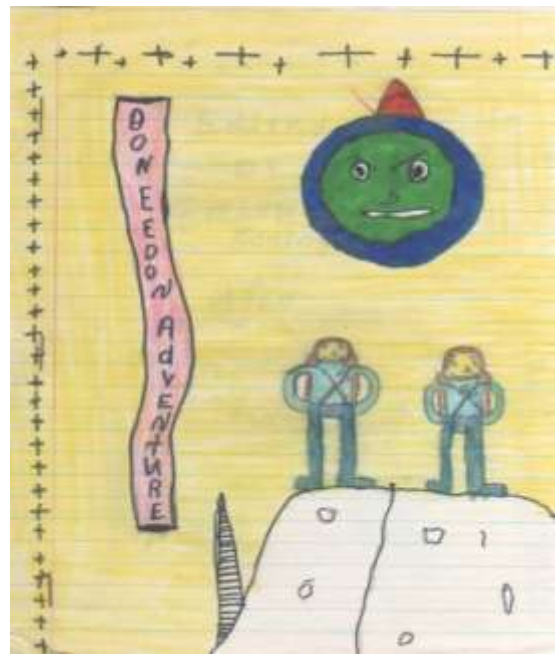
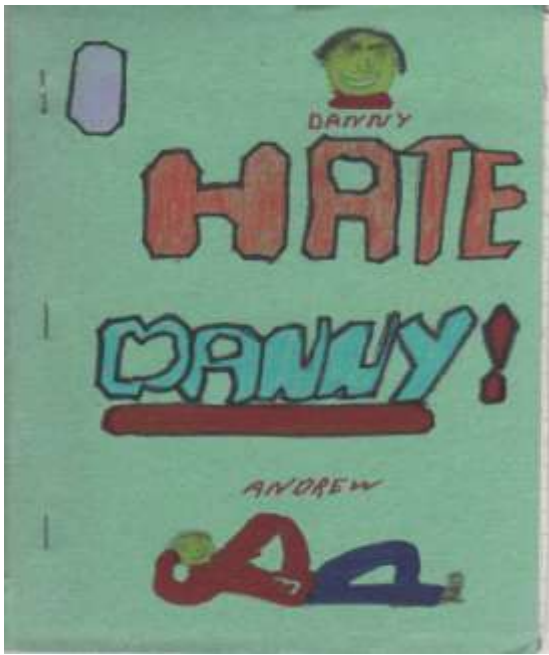
Our Timberbank townhouse basement became a stage for me and some of my friends that were willing to indulge my creative side. Musical acts were put on as well as neighborhood plays scripted and acted out..... well, scripted might be a loose term. We had quite a few records, yes records, of children stories incorporated with music. One of these records was of a toy story and my sister, myself and about five or six of our neighborhood friends acted it out. It was our Toy Story without Woody or Pixar or any of that. This production was put on for parents as well as one of our public school teachers who liked it so much that we were asked to perform it to her class.

Art classes in school were always my favorite, along with English Media. I could draw and critique and add my own flavor; or simply make one up. I could express myself and be heard and all at my own pace; dealing with my own thoughts.

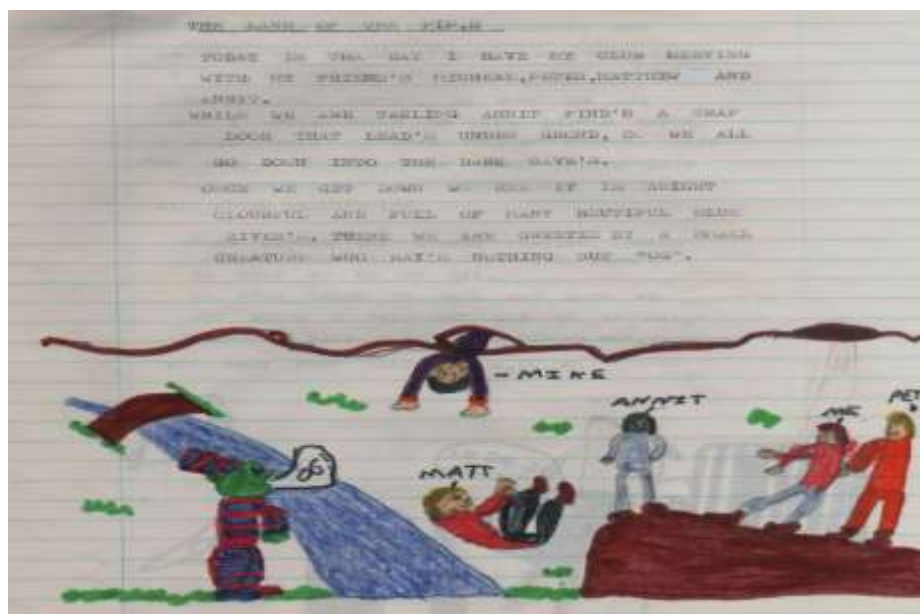
My hardship with the speedy technology world that I faced upon graduation of my college Graphic Design program lead me to another creative outlet, theatre production. I was still within the arts community and able to do the things I enjoyed the most.

I often say that my interest in writing came from my years in the theatre, sitting backstage reading through scripts and thinking, *I can do this*. Since my career in theatre production I have taken a correspondence 2 year program in Creative Writing. I graduated with honors and have already written and published quite a few articles and one novel. Writing, to me anyway, and I would guess for others, is very therapeutic. It can help people deal with any barriers or problems they may face. It can resolve issues and bring about self-understanding. Refer to my story and poem at the end of the previous chapter.

But it is not entirely true that writing came to me in my later years; I have always been making up stories and I have put pen to paper more than once. (I wasn't using keyboards in my younger years)



The “Doneedon Adventure” inspired by the TVOntario 80’s educational program, “**Read All About It.**” <http://www.imdb.com/title/tt0212687/>



“Land of the Pips”

An adventure of me and my friends to a world underground.

**Below are just a few links to show how writing and other creative works can be therapeutic.**

- [\*\*An article on the act of \*writing as a therapy\*\*\*](#)

*Writing Therapy* The Act of *Writing* is on trial, we are here to prove that it is a healing art. The trial is to take place in the Inner recesses of the ...  
[www.lifepositive.com/mind/personal...therapy/write.asp](http://www.lifepositive.com/mind/personal...therapy/write.asp)

- [\*\*Writing Therapy\*\*](#)

*Writing Therapy* is a new way of healing, having been researched since 1970. It is currently the hottest form of healing on the market because it is so new ...  
[www.healingwithsoul.com/Writing\\_Therapy/writing\\_therapy.html](http://www.healingwithsoul.com/Writing_Therapy/writing_therapy.html)

- [\*\*Counselling and Art Therapy - About Art Therapy\*\*](#)

*Art therapy* is for everyone. Everyone has been creative at some point, as a child. Then often around age 10, many people stop *being creative* either because ...  
[www.counsellingarttherapybc.com/arttherapy.htm](http://www.counsellingarttherapybc.com/arttherapy.htm)

- [\*\*Dance Therapy\*\*](#)

*Dance as therapy* came into existence in the 1940s, especially through the pioneering efforts of Marian Chace. Psychiatrists in Washington, D.C., ...  
[www.nccata.org/dance\\_therapy.htm](http://www.nccata.org/dance_therapy.htm)

- [\*\*Creative Therapy Sessions\*\*](#)

Melissa Solorzano is a registered, board certified and licensed creative arts therapist. *Creative Therapy Sessions* explores the different types of creative ...  
[www.creativetherapysessions.com/](http://www.creativetherapysessions.com/)

## Chapter 8 Extending a Hand

Sometimes I think I'd like to win the Lotto Max simply so I could retire from my working job and become a philanthropist. I like volunteering and helping others out and doing 'charitable' work. That's not to say that I don't do things that are only for me. And it is not to say that anyone else not volunteering or giving back is not ok. I use the term 'giving back' there loosely. I believe that as long as we are dealing with things, barriers, life, people, and doing a good job, being nice, respectful, cheerful, and helping to crack a smile, that we are giving back. Maybe to a lesser degree than others, (like my dedication to philanthropy) but we are still giving; we are living.

Volunteerism can be beneficial in so many ways. It helps you at the same time that it helps others. It shows heart, it shows character, and it also can open up real opportunities. Without having to worry about fitting into certain qualifications outlined in an application, you get to showcase your abilities, show-off your skills. As mentioned earlier, this is how I got my job in the theatre; and that turned into an eight year long (good) career.

When applying for a new job or getting some sort of position in life I feel can be of benefit I mix things up a bit and often use my volunteer coordinators over former (or current) employers as references.

Volunteering can also help build a social life, and that is something I can always use. I get to do something I like and create friendships that you can't always find in a "paying" job or anywhere else. I think we all need to build ourselves a community (size is irrelevant) where we all feel accepted.

## Chapter 9 What I've Learned

We all learn something every single day of lives, whether it be at home, in school or outside playing on a winters day in the snow and sliding down an icy hill with your jaw line bandaged and stitched up from a previous fall. People are more book smart than others, some are more street savvy than others; but as long as we are all trying to take the time to really look around, appreciate and understand, we are all learning the best we can.

Learning has been hard for me; the thought process behind understanding certain things can be difficult. But I give it my all and if it doesn't work, hey, it doesn't work. If people, after getting to know me a little are not willing to be patient enough with me to wait or help explain further or just not bother me with it at all and say "it's fine", than it is their lose; not mine. It has taken me thirty plus years to learn this, but it makes things so much easier for me.

Don't misunderstand, every thing and situation is different, but more or less I now believe one hundred and ten million percent that I posses a lot of great qualities and ABILITIES that far overshadow any of the barriers I've talked about. I need to remind myself of this every so often because I forget and can often bring myself down. I need to remain positive, focused and centered.

People who know me, even those that I consider closest, I think tend to forget the things I have to deal with. But that's ok, because everyone has their own things and everyone is busy; and I'm not prepared to play "cry me a river" and bring things up all of the time. I don't need anyone feeling sorry for me, but at the same time I do need to know and remember to tell them when I'm overwhelmed with something. Then, like I said before, they either accept this or not. I used to think that people would come to the conclusion, possibly, that I was making either my entire disability story up or that I was overstating certain things as an excuse. That's just not so anymore. I'm being honest with them, just as I'm being honest with myself.

Honesty is a big thing I've learned. For a long, long time after I was hospitalized I was so confused about things and I didn't know how to act. That was the problem; I did not need to act in any way other than being myself. Though I suppose you could say that if you wanted to get really philosophical about things, that I didn't really know how to

be myself. It was a big circle; a merry-go-round. I was afraid of getting off, afraid of making mistakes and falling down. But I learned a while ago the truth that always was, disability or not, we all make mistakes and fall down; it is what life is all about. Some of us make bigger mistakes and fall down harder but I think sometimes it is us, ourselves, that don't allow ourselves to get back up.

I had this tragic thing happen to me and I have to live with certain barriers in my life, probably for the rest of my life. Outsiders, and that's anyone to my own self, aren't always going to be able to fully appreciate some of the difficulties I have to struggle through. But, in many situations, and there are quite a few of them I think, my main problem is me. I lack a certain confidence about being able to accomplish certain things; but hey, at least I'm able to be honest about it.

I spoke about mistakes, they are a natural part of life, and even though it is hard, I have learned not to shy away from them. Not to say I'm proud of any the mistakes I've made; but I am proud that I have learned from them.

When I was in my mid to late teens I made a whopper of mistake; well to me it was a big one because it was one of those emotional, people related mistakes that mean the most to me. Anyway, I said some really strange, not rude, but strange, and certainly not called for, things to a person in my life. After I made this mistake I had no idea how to deal with it. In fact, I don't even know why I said these things. I know the reason the words were said; but I think because I was confused and scared and lost, (in a manner of speaking) the words were mixed up and didn't come out entirely right. I probably should not have said them at all. Or maybe I should have waited until I understood the words I was saying and myself better.

Regardless, it was done. For years it was like a dark cloud hanging over me every time this person was around, (this person remained in my life regardless of my major faux pas) it was very awkward. But I think it was a combination of this person not completely abandoning me, for whatever reasons, and me realizing that it was ok to be confused and scared, and that allowed me to come to where I am now. I had to be honest; I had to live up to my mistake; I had to not be afraid. I lived through that mistake. My friend and I have talked it out. I was honest and open, not only with my friend, but with myself. And ultimately, I think we both felt better for it. I did.

I try to approach everything in a similar fashion, with honesty and openness. My disability, any barriers I face, and any jobs I may obtain. It's all very difficult, but I know that I cannot be afraid.

I've learned that people need things to hang on to in order to get through all times, not just difficult ones; whether it is a person, an object, or a song. And I think that it is ok to have more than one thing to guide you through.

I had the sesame street character Grover, (I still have him) he was a stuffed toy buddy I kept in my room. He was good for cuddling, throwing around and even talking to. He was a replacement for an early childhood stuffed animal I clung to, Snoopy. Poor Snoopy got himself dirty one day and we tried to wash him in the washing machine, but..... I'm sure that you can see where this is going. But I learned to love my Grover just as much.

Something that I cherished while I was in the hospital was an orange racing car. It is gone from my life now and I can't remember what exact type of racing car it was, but I know it was orange, and it made me smile every time I saw it. By sheer coincidence my hospital room roommate happened to be a kid named 'Mark' who happened to have the same orange racing car. We solved any issue of confusion (between the cars) by putting a bandage on the bottom of my racer.

I've had and still have a tonne of things in my life that mean something to me and help me get through, as I'm sure we all do, but those two stick out as far as my illness went. The car was with me in the hospital and Grover was there to sit with through my first night back at home.

Something that I discovered quite a few years ago that helps empower me, to get me through and deal with, various stressful situations is a song called "Take Me Away" by Avril Lavigne. I'm sure it was not written about a person with a disability who deals with barriers and other frustrations, but never-the-less, it helps me. Those lyrics "**I can't handle this confusion, I'm unable, come and take me away.**" I get pumped up, I sing it aloud in my car and I know that I can handle it, because like I said before, I'm not afraid.

Having a disability and having to face barriers is not the same as dealing with the boggy man; or maybe it is. Regardless, it can be dealt with. I learned after years of confusion that really and truly, the one and only person who can ever tell me that I can't do something and be one hundred percent correct about it, is me.

Sometimes you win, but you never lose; you only move on and learn. It is a tough world, a fast paced world. (I sometimes feel like the slow Elmer Fudd watching the Tasmanian Devil spinning circles of blurring dust around.) I never knew that being part of the human race actually meant that we were in a race. And because of this race I don't think blame can really be placed on anyone's shoulders.....; actually scratch that, sometimes it can be.

Whether it is about accepting my disability, or anyone's, personally or professionally, things have to slow down. Maybe not completely, but just enough to allow me to get on board and stay there. Some people can be completely ignorant and unwilling to learn, but there are also others that are more easy going. They do slow down. They do take the time. Unfortunately, once I get settled and things seem to reach a comfort level, those same people who slowed down forget and are back on the fast train. That is not their fault; like I said, it's a fast paced world.

It is now my job to show my abilities, to be patient, to not be afraid or embarrassed to remind them that I am one step below, on the slower moving mall escalator.

Patience is a virtue; and for me it is also a necessity.

All I want to do is see others be happy and to reach their maximum potential. I do not think that having a disability or facing barriers should hinder this from happening. Accommodations will be needed for certain goals to be achieved, but I think sometimes the only real disability that one should worry about the most is ignorance. Maybe a little self-fear too.

Seek out and allow those stories of inspiration into your life. This is something I have learned and could have easily placed in Chapter 5 because it is also a form of guidance. These things not only can help us get through but motivate our accomplishments.

I get inspired by quite a few things. With all of the craziness this world can bring you got to really open your eyes sometimes; but inspiration is really all around us all the time.

I get inspired by the thoughtful and powerful words expressed to me by the minister at my church. I already mentioned to you my song by Avril. There are friends of mine that have published their own books or created their own music..... the list is rather long. My mom whom I have mentioned lives with Aphasia and an ABI (acquired brain injury) and does amazing stuff every day; right in my own home. Check out these sites and read some truly great things:

**Jessica Cox**, pilot, karate graduate, motivational speaker- born with no arms

<http://rightfooted.com/>

**Claire Theriot Mestepy**, published writer, television producer- lives with Cerebral Palsy

<http://clairetheriotmestepey.com/>

**Harvey Alter**, motivational speaker- lives with Aphasia

<http://www.nytimes.com/2008/04/22/health/22stro.html>

The **Honourable David C. Onley** has championed disability issues on many fronts and for many years. Having lived with polio and post-polio syndrome since the age of three, he has broken through social barriers and become a role model.

[http://www.lt.gov.on.ca/en/Their\\_Honours/HisHonour.asp?nav=1&sub=1](http://www.lt.gov.on.ca/en/Their_Honours/HisHonour.asp?nav=1&sub=1)

**Mark Koning**, famous creative writer with a learning disability

<http://www.markkoning.com>

Remember that last one.

And then of course there are the ones we all know very well:

Terry Fox

Rick Henson

Helen Kellar

This could go on and on.....

And don't forget you. We are all inspiration in the works. Be proud and stand tall and don't let anyone tell you, "that can't be done because....."

Acceptance.

I have a disability; a disability that I have accepted and learned from. My disability has freed me and brought honesty to my life.

I am not afraid of my disability. It has allowed me to appreciate others and the world around.

My disability has given to me opportunities and abilities that I am proud of. With provided accommodation and the acceptance of others I can show those abilities and skills that I have learned.

But as much as I will stand up and state matter-of-factly that I have a disability, and be proud of it, I know that I am not defined by it.

The world is about difference, we ALL need to accept that and move forward together. You got to have faith, YOU have to be your biggest champion, because you know your abilities best. Once you do that and let them and yourself shine, other things will fall into place.