

## Living with Brain Injury: Five Survivors Speak

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Acquired brain injury. It has been called "The Invisible Disability." Some brain injury survivors, of course, are left with obvious, severe impairments, but for many of us the effects are much more subtle. Physical disabilities, vision or hearing problems, speech and language difficulties, cognitive and memory problems, personality changes, headaches, seizures and fatigue -all can result from ABI.

Because the impairments resulting from brain injury are not necessarily observable, people often forget or misunderstand the difficulties survivors experience. They may expect us to function 'normally' and become impatient or irritated when we can not. On the other hand, they may assume we are intellectually disabled or mentally ill. They may feel uncomfortable around us or scared of us. And their expectations may be unrealistic; either unreasonably high, or unreasonably low.

Some brain injury survivors say that other people's attitudes and reactions disable them more than their actual impairments do. Others talk about the risks of being open about their disability and the need to balance these risks with their need for understanding or support. One brain injury survivor said, "The advantage of having a hidden disability is that you can hide it; the disadvantage is that it's hidden." It is a sentiment that resonates with many of us.

The writers of this article are five people with acquired brain injury. Our experiences have, in many ways, been quite different. We acquired our injuries in different ways and at different ages. Our resulting impairments, too, are different. And so is the context of our lives. All of us, though, live with hidden disabilities. And all of us cope with them, in our own ways.

*Ria*

Half a lifetime of abuse and two brain injuries have left me with multiple impairments, some obvious, others hidden.

People see my dragging foot and curled hand, or hear my slow speech, and make assumptions. Assumptions about who I am, and what I can - and can't - do. Usually, their expectations are low, and their assumptions quite wrong.

My physical limitations are a nuisance, yes, but I'm used to them and there's really very little they prevent me from doing. I may be slower than most people, and more awkward, but things get done. I walk better with a stick than without one, I've realised, so I use a stick and decorate it creatively. I groan inwardly when I see a flight of stairs, but I can struggle up them if I really have to. I can't ride a bicycle, but my turquoise three-wheeler has become a familiar sight around town. And when my friends and I go swimming, it's me who plows up and down the lap lane; they splash in the shallows.

It's my hidden impairments, much more than my obvious ones, that frustrate me.

It wasn't always like that. Ever since my first brain injury, at age 3, "autistic tendencies" and seizures have been part of my life. For a long time, I tried to pretend they didn't matter. They were a nuisance, yes, like my physical impairments, but they were something I could cope with.

Despite my learning differences - and years of severe abuse and homelessness - I made it to university, studying teaching, psychology and music. Then the unthinkable happened. I had a second brain injury. It left me with further cognitive and memory problems and left the life I'd built for myself in tatters.

I tried to continue my course, but found myself in a day program, drinking endless cups of bad coffee and wheezing on others' cigarette smoke. I had no idea what I could do with my new life. Indeed, I wasn't sure could do anything.

Then, serendipitously, a friend asked me to help out at a disability advocacy organisation. The rest, as the saying goes, is history. In the last few years, I've become a respected disability activist, consumer consultant and community development worker. I'm a published author and a regular radio presenter. With the Brunswick Women's Choir, I've also recorded a CD. I've even gone back to study.

I've learned to compensate for my memory problems, mostly. My diary has become a prosthetic brain for me and I write everything down. Still though, I struggle. Everything takes longer than it used to, and requires more effort. I live with fatigue, overload, and far more confusion than others realise.

It's hard for me to know where my limits are. I'm a workaholic at heart, so I often push myself until I just can't function any more or until I wake up in hospital, sore and exhausted after yet another seizure.

Then there are my depressions. Again and again, they've robbed me of energy, robbed me of hope and of joy. For weeks at a time, they've taken my very will to live. Somehow, though, I've survived. And I've kept going.

I'm nothing, if not a survivor. I've faced so many challenges in my life, but I've endured despite them all. I've built my life and rebuilt it, and I've achieved more than I would have dreamed possible.

I still  
sometimes miss her,  
the woman I once was -  
but I'm proud of the woman I  
become.

*Janet*

There was nothing hidden about my brain injury. My skull was smashed open in the violence of a motor vehicle accident. The brain was so obviously damaged no one expected me to live that night: "I think this is the most extensive bony fracture upon which I have ever operated. The whole frontal part of the bony skull is loose, and I really have no way from this operation today of determining the limits of these fractures... there is no way at this early stage of putting this all together." (Neurosurgeon's operative report)

I was released from the hospital with a crippling headache and cortical blindness. Showing little sign of other physical disability, I soon felt pretty hopeless with the continuous pain. If you don't think hopelessness is a disability, you try living with the doctors insisting "you'll never get any better," "your vision will never get any better," and "you'll have that headache for the rest of your life." For life? Never seeking treatment or amelioration of the pain just because some neurosurgeon said I "should just feel lucky to be alive?" As if being alive is enough for any human being, let alone a highly intelligent, self motivated, A-type, veterinary surgeon.

The ophthalmologist said I had enough visual acuity in one eye to read. In fact, I could see the print; I could not read. It was over two years before I was told my brain had gone blind. If you can see well enough to "get around," see books, and appear to watch television, no one allows you to claim to be blind. Most of the time you can't even tell yourself that you are not seeing things straight, or understanding or remembering what you can see. I struggled with this diminished vision for years, unable to read books, unable to get around safely, and unable to drive.

Years later, after completing my first quarter in graduate school, I discovered my

visual problems caused a learning disability. Finally I was referred to a behavioural optometrist. Dr. Fuerst's initial exam revealed I was reading at the 2nd grade level. He determined I was totally blind in one eye because the sensory input from it was being suppressed by my brain. I was not seeing double, but going to school had suddenly become too hard.

Vision therapy started in 1986. After doing my eye exercises every single day for 10 years my vision improved to 20/20 bilaterally. My depth perception was restored as soon as I could see with both eyes. I can now navigate doorways without mishap and was able to complete my master's degree. My brain and body have learned to accommodate for the permanent loss of my lower visual fields. I still have trouble recognising faces and with visual memory. But for all that, I am getting around remarkably well, even driving again. I still have a learning disability, but my magnificent brain has developed many strategies for remembering, understanding, and learning.

### *Geoff*

My brain injury came about in a car smash in 1956. It took me some months to get over the physical effects of the accident and even when I did, I still had ongoing problems. These included lapses of short-term memory, the inability to concentrate well at school, and the onset of grand mal epileptic seizures, bouts of depression and serious headaches.

I missed out on a huge lot of education. At the time of my accident, I was near the end of primary school. Soon after I headed into technical school where I had to learn many new subjects, trade skills, mathematics, science and graphic arts. There was great pressure on me here. It was very hard to retain all these new skills when bouts of epilepsy would arise. This not only upset me, but placed a barrier of doubt in my friends' minds: they didn't know whether I could be trusted to stay conscious (a great worry for my trade teachers also!).

After leaving school at an early age, I decided to try my hand at working, mainly in low-skill or laboring jobs.

By the early 70s, I had stopped having epileptic seizures, though I was still taking medication for this disorder. I decided to seek employment in another state thinking that distance, new faces and an employer who did not know my history would help me put my past behind me. I applied for a job on a mine site at Dampier. The job interview and skills review went smoothly and I told the necessary white lies at my health check-up. The company took me on and I worked there for almost four years. It was the best job I ever had. I had some problems, though: taking medication and trying to hide this from others, and a distinct realization that I was not, and would never be, totally like my peers. The ongoing drama caught up with me in the end when I went to the local chemist to restock my medication. The on-site chemist balked at the need for a company person to be taking potent anti-convulsants, and almost immediately contacted the personnel department. Very soon, I was not an employee of the company any more. Even someone with a hidden disability, it seems, cannot hide it indefinitely.

I tried many other jobs always trying to pass for normal. Each time, though, I ended up feeling stressed and unskilled. I was never quite able to cope. Eventually, I realized I just couldn't rely on myself and I applied for an Invalid Pension.

When I was assessed for the pension, the Commonwealth Medical Officer gave me a thorough physical checkup. After that, he said, "I cannot pass you for such a benefit. You look fine. You're 100% fit." I then told him about the car smash, and the following disorders: my epilepsy, my headaches and my bad memory. I told him I'd repeatedly tried to work. And that I'd never really been able to cope. It was found that I had "some form of hidden psychological disorder" and my application for the pension was passed.

That was in the early 80s. Since then, I've lived on the street and spent years in boarding houses and group homes. I approached disability services several times, but they didn't deliver what they promised. Eventually, I joined Bear in Mind - a self-advocacy group

for people with ABI - and my life changed. Through Bear in Mind, I found support and regained my self-esteem. I now work to help others.

*Neil*

Living with a hidden disability can be one of the most frustrating experiences known. On the one hand there is the need to function in a world that does not accept any gross deviation from what is considered 'normal'; on the other hand is the need for recognition. People who are blind or who use a wheelchair are easily recognised. Offering a seat to someone who is pregnant or elderly is considered polite. How often do you see someone offer a seat to a person with bilateral clonus in their lower legs? You can't see the problem but the person with the condition can feel the cramps and often needs to sit down before they literally fall down.

Am I truly a person with a disability? I have a learning disability and an acquired brain injury. Yet I can still write and work and reason and think. For all intents and purposes I go about everyday life without showing any outward sign of my disability. The symptoms don't appear on the surface, they're hidden just below my public persona. Every now and then they get an airing. They manifest themselves in ways that are not easily recognised as the signs of a disability. Take my forgetfulness.

Short-term memory loss and lack of immediate recall are easily hidden. All I have to do is write down what I have to remember and then remember to read it. Everyone forgets, it's part of the human condition. How often have you forgotten birthdays, anniversaries, appointments or the location of something. How often have you gone to the fridge and asked yourself 'why am I here?' It happens to me every moment of my waking life. But we all forget, don't we?

I once received an award for creative spelling. Dyslexia is such a wonderful experience. What other disorder gives the person with it permission to spell incorrectly or write using bad grammar? What other disorder is so misunderstood that the people who have it are labelled lazy, uncoordinated or, in some severe cases, intellectually challenged?

People with dyslexia are able to hide their disability and most do. Why? Is it the shame of not being able to function as well as colleagues at school or in the workplace? Or is it the fear of being labelled illiterate in a world that deals with information in a textual format? Or is it because explaining the difference between dyslexia and illiteracy takes up too much time and energy? Being labelled dyslexic has cost me more than one job over the past decade or so.

Being aware of a hidden disability can also cause problems. How do you judge the extent of the disability? If someone says to you, 'I have an acquired brain injury,' yet they look 'normal,' how do you deal with it? Do you assume that they need support? Do you wait to be asked? What if they are too shy to ask?

When someone is labelled with a hidden disability, they have been given two disabilities. The actual disability and the fact it is hidden. Why not just label them people and work around the facts of their humanity? We all forget, we all make spelling errors and we all make mistakes. Some of us more often than others. But then if you can see the cause, there is a ready made excuse. Isn't there?

*John*

My accident occurred later in life. This gives me a number of assets that are not available to the majority of people with ABI. I am in a long standing, loving relationship. At the time of my accident I was at the peak of a fifteen year career as a lecturer in nursing. Now retired, I am active in a number of community groups.

My accident left me with a raft of sensory, cognitive and physical impairments,

most of which I can manage. My hidden disabilities are not primarily the result of my ABI. Rather, they are secondary consequences of being labelled ABI.

In particular, I am required to accept the professional definition of my 'problem'. I find that I am treated differently because I am perceived as needy or as a problem. As a client, I need to understand the disabling nature of professionalised definitions of need and remedy.

I won a prestigious award for painting. The judge was a respected painter whose work I admire. He commented on my choice of subject, my composition and my rendering of textures. He said that it was simply the best painting in the show. There was no mention of my ABI and because all the works had the signatures masked off for the judging, I knew my disability couldn't have influenced the judge's decision. I had won against a large field of established artists and I had won on my merits.

The trouble came when I went to make my acceptance speech; I burst into tears and could not continue. This could have been seen as a classic case of ABI problems, but it wasn't. Instead, the President of the Art Society came to me and said, "Don't worry John, we all get emotional about our work." Later, the local paper wrote it up under the heading **ARTIST IN TEARS OVER WINNING PRIZE.**

This story says a lot about assumptions and perceptions. Just as my disability can be made visible it can be made invisible if we change the mindset of others.

After my accident I had the opportunity to submit to a government inquiry into head injury. As a Nurse Educator, I raised the issues of professional training in ABI. I also talked about the information that my family had received about head injury. This led to a consultation and then to a training video.

When the video was done, a project worker was engaged to follow up the issues raised by the participants. Eventually, we developed a sophisticated community education kit designed to put people with ABI at their best advantage.

The kit has attracted interest from Texas, Ireland and New Zealand and, like the painting, it stands up well against the competition. Nobody considers that its authors are disabled.

## **Conclusion**

Collectively, our experiences as survivors of brain injury reveal a great deal. In our stories, we talk about being labelled and challenge conceptions of 'normality.' We discuss issues of disclosure and face professionals who assume the invisible does not exist. These difficulties are common amongst people with ABI and shared by many others with hidden disabilities.

As our stories show, people with brain injury share much with other disabled people; not only in terms of coping with physical, cognitive or emotional challenges, but in dealing with the social effects of being devalued and marginalised. Like so many with disabilities, we face issues such as poverty, being excluded from the workforce, meaningless day programs, homelessness or inappropriate housing, inappropriate or non-existent supports, a fragmented and often uncaring service system, prejudice, discrimination and abuse.

Many brain injury survivors talk about the need to raise community awareness. If the social consequences of brain injury are to be minimised, understanding and acceptance are crucial. Professionals must be educated and community attitudes changed.

One brain injury survivor said, "It is time that we took up the belief that there is no such thing as a disability, only an unmet need." In a world of unmet needs, we dream of a future where those of us with ABI - indeed, all of us with disabilities - can have our needs met.