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Abstract

Helen Cox wrote this short paper explaining her disability which is acquired brain damage (ABD). She discusses her rehabilitation and how, in hindsight, she feels individuals should be instructed as though they will regain all their former abilities, but she also questions whether or not saving a life at any cost should continue. Another issue to consider is that of access - current access modifications are usually for people in wheelchairs, a different category to the 'walking disabled'. And finally, Cox discusses people's attitudes to her disability where she is usually seen as disabled first and a person second. **Keyword: Attitudes**

TREAT ME AS I AM

by Helen Cox

No-one can label themselves as immune from acquired brain damage (ABD) - within a split second they can become a victim.

I am physically disabled from a horse-riding accident just over nine years ago which left me with ABD and this caused severe disabilities. I wasn't expected to live, was on life support, in a coma for five and a half months, couldn't walk, talk, eat. In fact all I could do after I came out of Intensive Care was breathe.

One of the consequences of ABD which I have is "increased tone". Everyone has tone; physically it tells the muscles when to work and when to relax. The injured brain is unable to differentiate between the two. Initially both my arms had an increase of tone which caused them to work constantly and this meant they were continually clenched up tight touching my chin. Both legs were constantly relaxed and this meant they were extended out straight but rigid and I was unable to move. The injury caused increased tone with my emotions as well. All my feelings became extreme, for example increased love or hate, and they were similar to those of a child rather than a 21-year-old woman.

Since the accident I have been rehabilitating and am now a hemiplegic which means one side is affected, in my case the left. I can walk short distances and have some use of my arm. I have matured emotionally although if I have too much emotional activity, for example a lot of pleasure, hurt, or anger, the tone which causes stress and immaturity becomes very increased. Therefore to act maturely I need to avoid stress by trying to keep myself on an even keel emotionally, which is easier said than done.

My major problem is that I am unable to walk freely. I have to first act out in my mind how to place both my feet for every step I take, then force them physically. My increased tone has often caused me to fall by suddenly working uncontrollably. This is called "spasming". Therefore, because the injured brain is unable to tell the body how to relax naturally I need to compensate by consciously, actively relaxing, both physically and emotionally.

Walking has always exhausted me and this could be partly due to the fact that I step incorrectly on my left foot. It was assumed that I would never get to where I am now so there was no point in putting me through more hardship by telling me how to do something which was impossible at that stage. I can partly understand why because at present the exasperation of knowing how I should walk but being unable to put it into practice leads me at times to the point of wanting to commit suicide. Yet despite these feelings I think it's better if every individual is at least instructed as though they will regain their former abilities. Being unable to walk with safety and freedom causes me extreme exasperation. I feel as if I'm in no man's land. I can't fully relate to people in wheelchairs because I no longer use one, yet neither can I fully relate to or keep pace with able-bodied people.

Having increased emotional tone is almost as frustrating as being unable to walk freely - except that I can actively, physically work towards improvement with walking, whereas with my emotional injury the healing comes mainly from my mind which is harder to tolerate. Even so, if I could walk with more freedom I'd be more active so my mind wouldn't work overtime. In my case physical and emotional increased tone go hand in hand. The more active I've become the less thinking time I've had so I'm of the opinion that this has helped the degree of healing to my emotions, as have time, common sense and maturity.

However, if someone shows real empathy to me, even now, it sometimes results in a feeling of extreme affection for them. It seems that every vibe in my body feels only a one-tracked emotion. Every waking minute I'm subconsciously or more openly aware of the person I have increased feelings for. When the awareness is open I have a constant craving desire to be in their company and nothing or no-one can completely eliminate the absolute longing I have. It's an unnatural state in the sense that emotions work overtime with concentrated extremity on one feeling only; in the same way increased tone keeps my left arm constantly working.

Although living with the aftermath of ABD is traumatic I am a Christian and through my faith I am given strength to cope with the consequences and frustrations. The only possible way I can keep from becoming a total prisoner to my emotional feelings and thoughts, and physical disability, is by accepting the help God gives and keeping Him in the forefront of my mind so that He takes pre-eminence instead of a person. I have to live with ABD 24 hours a day, 365 days a year and I cope with it by knowing that there is Someone readily available who is willing to listen, to comfort, to be my Confidante, who doesn't get bored with or sick of my limited physical ability.

Another major problem for me caused by ABD is pre-menstrual tension, from which I suffer a great deal. Previously I had absolutely no trouble but now most months I'm fortunate if I get a week of continually feeling alright. It's thought my pituitary gland is injured and it sends the wrong signals to hormones. The consequence is that I continually get extreme emotional symptoms. Therefore life is generally very stressful because most days I face some degree of emotional or physical pain. This is very tiring, therefore brain draining.

Brain tiredness has to be experienced first hand to understand that it isn't like normal, natural tiredness. The same way that a car runs out of petrol and simply won't go, I run out of brain power and simply can't go. Every single thing I do causes stress through brain tiredness. Whether I have an enjoyable or difficult time, the fact that there's not one action or movement that comes naturally or automatically, plus emotionally I need a tremendous amount of self discipline for my feelings to resemble anything near normal, means that just existing is an exhausting experience.

As a severely brain-injured person I strongly believe that serious consideration needs to be given to deciding whether or not saving life at any cost should continue. As I've already outlined we ABD people are often left with horrific

physical and/or emotional disabilities and there's no guarantee, despite all the therapy we might do, that we will recover. People frequently look at me and see me only as I am now. The comment is often made, "Look how far you've come" - and I have - however, recognising that fact does not alter my inability to walk freely or have ease with any of the things I can now do. I have spent nearly nine years in the prime of my life rehabilitating and I don't know how much longer it will take. I know some people would argue that no-one can, or wants to play God by turning off life support. My argument is that it's no less trying to play God by keeping life support turned on and thus, by artificial means, maintaining life. As a victim I hold this view because I know that a brain-injured life is so unnaturally hard.

Medicine has advanced to the extent that it can now save lives which previously would have been impossible to save. With those lives comes a need of extra compassion and care. Yet I get the idea that disabled people are expected to be better than the anticipated "norm". All humans need to feel wanted and loved and that fact doesn't alter because of ABD.

There is also a need for more facilities for people with disabilities so that we can take for granted public conveniences as able-bodied people can and not feel that we should excuse ourselves for living.

If I need to use a public toilet those provided for people with disabilities are unsuitable. They are really only geared for wheelchair users - a different category to walking disabled. I cope better in an ordinary size toilet with a bar installed which enables me to balance, because the open space of a toilet for disabled is too nerve wracking for a walking hemiplegic. In view of the fact that not everyone has use of the same side, it would be relatively easy to install a bar each side in one toilet in every block of public toilets as well as having what is now termed a toilet for disabled. This would mean a greater number of people were catered for relatively cheaply. As it is at present I need someone to help me balance in public toilets.

Ramps are fine for wheelchair-users but for walking disabled people they are very unsuitable. Steps with a hand-rail are easier to cope with.

It would be helpful if every shop had at least two chairs available to sit and rest: one for the disabled person and one for their helper. Able-bodied people don't have to ask to sit down; the only reason people with disabilities do is because we are usually too tired to walk to where we know there is seating.

Able-bodied people also don't have to give a thought about suitable eating utensils when eating out but unless I take my own I have to ask to have my food cut up and have difficulty keeping it on my plate. For a relatively small financial outlay all eating places could have one or two rocker knives and plate guards which are essential for people with only one good arm to retain independence when eating.

It's obvious then that ABD is dramatically life changing in the sense of physical or emotional disabilities, or both. Apart from the problems I have directly associated with ABD there's a social stigma combined with being physically disabled. It's life shattering to suddenly discover limbs that are

either partly or totally disabled, plus, for me, the consequences of having injured emotions. However it's almost as life shattering and unreal when I'm frequently not regarded as an equal simply because of lacking physical ability. Being unable to walk freely doesn't automatically remove one's intellect, yet I often feel that people see me first as disabled and then treat me differently because of it. Nor does being disabled mean that my emotions are inactive. I still feel hurt, left out and frequently annoyed by being stared at. It's time that the primitive analysis of assuming that when someone is physically disabled it means they are lacking in intellect was totally obliterated. There's real people trapped inside unresponsive bodies and injured emotions. After continually being judged on limited physical ability, then treated as inferior, it's hard not to act in like manner.

Many people wonder how to treat people like me. I would like to be treated as a person who has a broken arm or leg, obviously not fully physically able and therefore needing a bit more consideration but not needing to be cushioned against every negative experience as though I'm a child because in the end this hurts more. All I ask is to be treated as I am - physically disabled and therefore needing the common courtesy given to an equal in distress.

HELEN COX is the author of *To Helen With Love*, a book which documents her rehabilitation and the issues which particularly affected her.

BOOK REVIEW

Cox H.A. (1988) *To Helen With Love*.

To Helen With Love is a personal account of the author's life after she sustained acquired brain damage. It documents her rehabilitation and the issues which particularly affected her. This book, through the author's description, develops an awareness of the needs and behavioural responses of a person with ABD and the demands that are imposed on their carers and family members. *To Helen with Love*, in the second edition, which includes a revised appendix, is a book which portrays the progress and improvement that Helen Cox makes.

The strengths of this book lie in Helen's ability to report the experiences and associated moods which have ensued from her head injury, and to follow these up with strategies which she developed to justify and manage them. Helen provides many thoughtful, honest and personal anecdotes which describe her life after the injury. The substance and manner of writing provides the reader with a knowledge of the common sequelae of ABD. It is with this first hand knowledge that the reader can be reassured when confronted with troublesome problems. Helen Cox illustrates many adaptations and practical family solutions to problems. An important quality of her book is that it sets a model to which other people with ABD can set their goals.

To Helen With Love is a book which displays the ability of a person to reshape a damaged life by employing motivation and energy. It describes invention which springs from the necessity to modify activities in order to maintain a

quality of life. This book should appeal to a wide range of readers, however there are some factors that may limit this. The author has tended to devote much of her book to religion and biblical texts to explain and justify the injury and events resulting from it. This may be abstract and not important to many people who are young, active males, who make up the majority of people with ABD.

Also, the author has made little reference to the effects of her injury on the members of her family and friends.

I congratulate Helen Cox for writing this book and recommend it to those interested and involved with acquired brain damage.

James Forbes