

Empowering Family Members when there is a mild TBI a personal perspective

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Outline

- Who am I
- Definitions
- My story
- Issues surrounding mild brain injury
- Caregiver questions and concerns
- 14 years later / Resources
- Closing thoughts



Definition of CARE

Care as a noun: A burdensome sense of responsibility; a cause for feeling concern, attentiveness, consideration, kindness,

Care as a verb has connotations to provide, to hand over, to dedicate, to do



CARE

Quotes

Love begins by taking care of the closest ones - the ones at home.

Mother Teresa

If you find it in your heart to care for somebody else, you will have succeeded.

Maya Angelou <http://www.brainyquote.com/words>



Definition of GIVING

Giving is an act of being charitable, philanthropic, benevolent, bountiful



GIVING

Quote

When I chased after money, I never had enough. When I got my life on purpose and focused on giving of myself and everything that arrived into my life, then I was prosperous.

[Wayne Dyer](#)

- <http://www.brainyquote.com/words/gi/giving169168.html>



Caregivers

Caregivers are backstage working to help the star performers – the people who have sustained a traumatic brain injury – shine.



This latter caregiver role isn't usually one expects or trains for....

.....but rather a role that one unwittingly steps into right after an accident happens....

often on a journey to where or for how long?





Once Upon a Time

And the story continues....



The Next Day.....



Family Member With A Brain Injury

Pre Injury

- Love of life - Willing to try new things
- Major provider and breadwinner
- A huge appetite
- High energy individual - Very fitness oriented
- Looking forward to starting a family
- Detail oriented – trained as an engineer



Post Injury – Physical Issues

- Fatigue and Pain
- Altered sleeping patterns:
- Poor coordination, clumsiness
- Headaches, dizziness, nausea
- Light sensitivity
- Soft tissue injury and aggravation
- Loss of appetite



Mental Issues

- Mental fatigue - **HUGE**
- One research study concludes 1/3 of a large sample of MTBI patients experiences severe fatigue 6 months after injury, (Stulemeijer M, et al, 2006)
- Memory Loss
- Lack of concentration and focus



Emotional Issues

- Irritable
- Traumatized by the accident
- Nightmares



Communication Issues

- Takes everything I say very literally
- Huge pauses in conversation
- What he is saying and his body language do not agree
- Unaware of his tone of voice
- Gets lost in conversation
- Perseveration (tendency to continue or repeat)



Legal Issues

If your client, spouse, or child has acquired a brain injury from an accident where insurance is concerned, litigation will most likely be a part of the recovery process and it is something that often the whole family gets brought into whether or not they were in the accident.



Our Court Case

A 5 week court case presided over by judge and jury

Jury found in favor of the insurance company.....We lost

To appeal or not? Final answer no.....



Bankruptcy

Filed separate bankruptcies

Another new role....

A new learning curve....




Lessons learned in Bankruptcy

- To truly appreciate the little things in life
- To be comfortable with my self I don't need to be busy all the time
- Realized that people stopped doing things with you when you did not have a car
- Noticed there were those that did help out



Family Member Without the Brain Injury

- Each person's story is different.
- We have experienced some similar and uniquely different things as we deal with the family member who has a brain injury
- Each person's story will depend on which family member has sustained a brain injury and from that point on the other family member(s) jockey  for new positions or new roles in the family.

Family member's thoughts and concerns

- Striving to stay positive and being proactive throughout this experience
- Sense of isolation
- Walking on eggshells
- Wanting to grieve
- Feeling like I am flying by the seat of my pants



- Watching my husband struggle on a daily basis with what used to be very simple tasks
- Scared
- **Close relatives of people with TBI, experience great uncertainty for a long time** (Bond, Draeger, Mandleco & Donnelly, 2003; Crisholm & Bruce, 2001; Duff, 2002).



Family members' thought provoking ?????

- Will we be able to have children?
- Will I always have to be the major provider?
If so, how will I balance all my other responsibilities and duties?
- Will my husband be able to advance in his career after having had this accident?



- Will we ever be able to share in-depth conversations again without very frequent and long pauses?
- Will be able to look back on this time in our lives and say we made it and we beat the odds?



Family Members' new roles

- Struggling with all these new roles
- Financier, taxi driver, walking & talking daily planner, case manager, public relations person, provider, role model, garbage man, chef,
- Snow White living with the 7 dwarfs



- In the literature **Family caregivers must help TBI victims confront the barriers in their path and *It validates the importance of having clients and family caregivers describe their reality*** ([Jumisko E](#), [Lexell J](#), [Söderberg S](#) 2007)



A Brain Injury is a Brain Injury

The Mild Traumatic Brain Injury Case is not an open and shut book. There are many factors that need to be considered. It is not a black and white issue but rather very gray in colour.

The level of stress experienced by the family members of patients who have TBI is such that



professional intervention is appropriate, even after 10-15 years. Not the severity of the injury ***but the nature of the injuries determines the level of stress.*** ([Verhaeghe S](#) 2005)

Highs and lows of lingering symptoms will come to our attention one day but not the next



The reality of dealing with an individual who has a brain injury and who you love unconditionally is a constant and continual struggle in more than one way every day. It can be stressful, tiring and a very anxious time in people's lives.



14 years later where are we?

- Working full time +
- Referred to a sleep clinic
- Referred to sports medicine doctor and physiatrist for prolon treatment for hip
- Visits to two different chiropractors and a physiotherapist now on a need to have basis



14 years later....

- Assessed by an audiologist– diagnosed with Central Auditory Processing Disorder
- In home audio training (about 1 hour each day) under the direction of the audiologist



14 years later

- Optometrist diagnosed visual processing difficulties - Post Traumatic Vision Syndrome
- Completed 20 1 hour weekly one on one vision therapy sessions
- Had ½ hr daily home vision therapy exercises



14 years later

- Swim Director for a local Triathlon Club
- Competed in the 2010 & 2011 Western Subaru Triathlon Series



14 years later

- Returning to workforce following my ambitions to help those less fortunate than me
- Looking to create new friendships
- Dealing with my own NST and working hard to rid myself of that



In his new found element...



What would we do differently

Funny you should ask that, we had that opportunity about two years ago.....

- **Be Proactive** from the start
- Seek out those who have the needed expertise, and a listening and caring attitude
- Keep a positive attitude and ask questions



Resource Toolbox

- <http://www.barralinstitute.com/>
- <http://www.neurolinkglobal.com/>
- <http://www.soundidears.com/>
- http://www.lynnvalleyoptometry.com/vision_links.html
- <http://www.swingleandassociates.com/>
- www.positscience.com
- <http://www.asha.org/>
- <http://tbilaw.com/>
- <http://www.wellspouse.org/>
- <http://www.rosalynncarter.org/>



Other resources

- <http://www.biawa.org/>
- <http://www.nucca.org/>
- http://www.soundidears.com/aud_process.html
- <http://www.bcftbi.org/resources.html>

Coping with Mild Traumatic Brain Injury – by Dr. Diana Roberts Stoler

Chronic disease self management courses -

<http://patienteducation.stanford.edu/>

Save your Brain – by Dr. Colgan

(www.colganinstitute.com) check all products – books by Dr Colgan



How did I make it through?

- My Faith played a huge part
- Sourcing out ways to help Donald and find professionals that would listen to ME
- Finding someone to talk to who was not going to pass judgment



Coping continued

- I spent a lot of time second guessing me, who I am what I stand for, what I believe in, who are my friends..
- Taking time for myself and looking after myself
- Had a mindset - We are getting through



A poem to leave you with

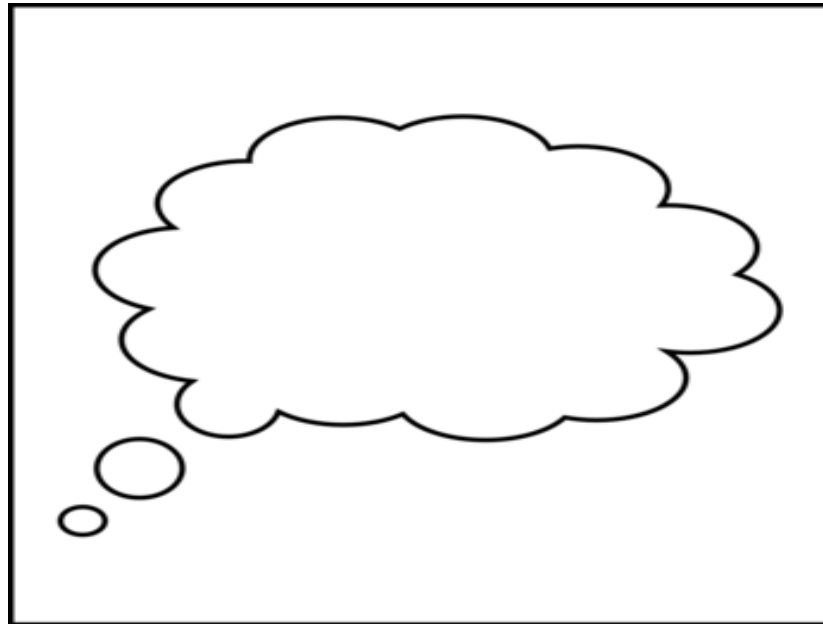
There is no thrill in easy sailing
When the skies are clear and blue
There is no thrill in merely doing things
That anyone can do

But there is some satisfaction
Which is mighty sweet to take
When you reach a destination

That you thought you couldn't make. author unknown



Some closing thoughts



Any comments, questions or
thoughts?

