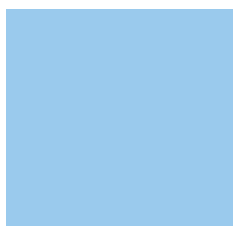
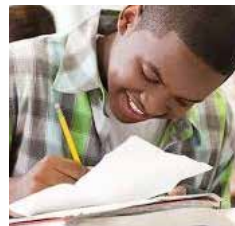


# Brain Injury Association Of London And Region



## Resource Guide for Parents: Children with Acquired Brain Injury

Second Edition





# **Resource Guide for Parents:**

## **Children with Acquired Brain Injury**

### Second Edition

Published by the Brain Injury Association of London & Region

June 2015

The Brain Injury Association of London & Region recognizes the generous sponsorship of Lerner LLP in the production of this publication

Designed by Stephanie McGill

Printed by M&T Print

***This publication is dedicated to the many children and their families  
living with the impact of a brain injury.***

## Legal Information

No part of this publication can be reported for a commercial purpose without the prior permission of the Brain Injury Association of London and Region (the Association). We hope that the health care professional as well as survivors and their families find this text useful and, if so, they have the Association's permission to use and copy any part of this text in any way they find helpful.

This Association is not engaged in rendering medical, legal or other professional advice. Neither the Association nor the Community Awareness Committee endorses any organization, professional, therapy or advice given in this resource guide. While we have made efforts to provide information that could potentially be helpful to clients and their families, neither the Association nor the committee can take responsibility for any advice or actions taken by any organization, professional or individual as the result of any of the materials listed in this resource guide.

The Community Awareness Committee has worked hard to ensure that the information provided in this text is comprehensive. Any errors, either of omission or accuracy, ought to be reported to the Association. We do expect funding will allow further editions where such errors can be corrected.

## A Word From the Executive Director

Brain Injury is often described as the 'silent disability'. Unless your life has been personally affected by brain injury, or else you work in the field, very few people know about this hidden affliction that affects approximately half a million Ontarians. Brain injury is one of, if not THE most mislabelled, mis-diagnosed, and misunderstood disability.

If your child has sustained a brain injury, you will meet many experienced and knowledgeable professionals who will become your child's treatment team. You may experience many different emotions along the way, from shock and anger to guilt and loneliness, and not know where to turn. Rest assured that you are not alone.

The Brain Injury Association of London & Region is here to help you and provide you with support services to assist you on your journey. We offer support groups where you can be among your peers to learn and talk about particular issues you may be having. Our Peer Mentor Program is a provincial wide program that matches you with someone who has had a similar experience. They are there for you to talk to and get support from. Even if you just need a place to ask questions, we are here for you.

We found our quarterly newsletter, *The Monarch* is an excellent source of brain injury articles but does not always address child and parent specific topics. In response to this growing need for information, we are pleased to offer our second publication of the *Monarch Junior*. We are hopeful that this compilation of articles will give you and your family information that will help you along the journey you are now on.

Donna Thomson,  
Executive Director

### Brain Injury Association of London & Region

560 Wellington Street, Lower Level  
London, ON N6A 3R4  
Phone: 519-642-4539  
Toll Free: 1-888-642-4539  
Fax: 519-642-4124  
Email: [info@braininjurylondon.on.ca](mailto:info@braininjurylondon.on.ca)  
Website: [www.braininjurylondon.on.ca](http://www.braininjurylondon.on.ca)



## Acknowledgements

This Publication is a result of many months of planning by volunteers who serve on our Community Awareness Committee. The Brain Injury Association of London & Region wishes to thank all the contributors and volunteers for making this publication possible.

### Committee Members

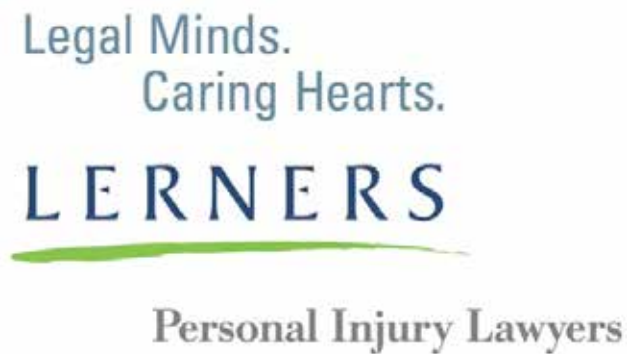
Cheryl Bunzenmeyer-Remple, MSW, Survivor  
Stephanie Hutton, Survivor  
Nancy Attrill, Parent  
Matthew Dale, Lawyer, Leners  
Henna Butt, UWO Student  
Stephanie McGill, Communications Coordinator  
Jessie Dougall, Services Coordinator  
Donna Thomson, Executive Director

### Authors

Paediatric Acquired Brain Injury Community Outreach Program (PABICOP)  
Dr. Lisa Fisher, Fowler Kennedy Clinic  
Dave Ferguson, BEYONDtheCheers  
Jean-Marie Fiala, MRI Appointments  
Edmonton Epilepsy Association  
Dr. Cheryl Letherin  
Cailee Farough, Registered Dietician  
Stephanie Hutton  
Frank Nitra B.A. (Psych), Board Certified Assistant Behaviour Analyst  
Stephanie Ellis, Speech-Language Pathologist  
Dennis Radman, Rehabilitation Therapist  
Katie Muirhead, Ontario Brain Injury Association  
Synapse.org.au  
Henna Butt  
Ontario Brain Injury Association  
Nancy Attrill  
Jill Bowen  
Marty Rempel  
Cheryl Bunzenmeyer - Remple, MSW  
Angie Blazkowski, Occupational Therapist



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## About Us

The Brain Injury Association of London & Region began in 1982 in response to the lack of awareness and services available to those who were affected by acquired brain injury. At that time, patients were being sent home from hospital with very little to no after-care support, and family members were left to cope on their own.

Although acquired brain injury remains one of the most mislabeled, misdiagnosed, and misunderstood disabilities. The Association has taken the initiative to change this by living up to the mission statement it adopted in 1995: "We are committed to maximizing the quality of life of individuals living with the effects of acquired brain injury through support, education, advocacy and public awareness." The Association strives to achieve the goals of the mission statement through the provision of the following services:

### Support

- Monthly Support Groups in Elgin, Oxford, Perth, Huron, London/Middlesex Counties
- Peer Support Mentoring Program
- All Ages Social Group in London
- Social/Leisure Group in Perth and Elgin
- Respite Care Program

### Education

- Annual Brain Injury Conference Workshops
- Brain Basics Course
- The Monarch Quarterly Newsletter
- The Monarch Junior Quarterly Newsletter
- Resource Materials

### Advocacy

- Assist Survivors, Family & Caregivers with complex issues (locating appropriate services, housing, funding, school, etc.)
- Brain Injury Services Directory
- Camp Dawn Partnership
- Disseminate relevant information
- Encourage local, provincial and federal policy changes

### Public Awareness

- Public Awareness Presentations
- Helmet Fitting Training
- Helmet Fitting Clinics
- Helmets on Kids Partnership

The Association was incorporated in 1986 and registered as a charity in 1993 and is governed by a board of twelve directors.

With only 3 paid staff members, the Association relies heavily on the over 80 volunteers who play a significant role in the provision of the programs and services offered. They are board and committee members, office help, support group leaders, fundraisers, or presenters at public events.

The Association does not receive any public funding and derives its primary income from grants, fundraising events, conferences, workshops, donations, sponsorships, golf tournament, advertising and membership fees. As well, some supporters choose to donate their marketable securities in exchange for a charitable tax receipt or bequeath a legacy in their will. The Association constantly seeks financial support to continue offering such invaluable services and resources.





## Where to Find More Information

The Brain Injury Association of London & Region services the Counties of Middlesex (including the City of London), Elgin, Oxford, Huron, and Perth. One of its purposes is to provide information on community services in this catchment area to anyone who requests it. The directory provides basic contact information for a variety of organizations, government departments, and professionals in the five counties. The Association will help people seeking information by phone, e-mail, regular mail or office visit.

Other helpful sources of information include government listings (check your telephone book), websites such as [www.thehealthline.ca](http://www.thehealthline.ca), public libraries, health units and Community Care Access Centers. The Brain Injury Association of London & Region will help users of its directory locate existing services they seek. Through the network of Brain Injury Associations across Canada, the London Association will help in finding information from other areas.

### **Local: Brain Injury Association of London & Region**

Email: [info@braininjurylondon.on.ca](mailto:info@braininjurylondon.on.ca)

Web: [www.braininjurylondon.on.ca](http://www.braininjurylondon.on.ca)

### **Provincial: Ontario Brain Injury Association**

Email: [obia@obia.on.ca](mailto:obia@obia.on.ca)

Web: [www.obia.on.ca](http://www.obia.on.ca)

### **National: Brain Injury Association of Canada**

Email: [executive.director@biac-aclc.ca](mailto:executive.director@biac-aclc.ca)

Web: [www.biac-aclc.ca](http://www.biac-aclc.ca)

## Introduction

Your child has just been given the diagnosis of a brain injury. The doctor's words have been flashing through your mind. How can this be? What will we do now? How will we cope? Many questions will arise after this diagnosis.

This has been written especially for you and is directed towards parents, family members and caregivers of children who have been affected by a brain injury. On the following pages, you will find a wealth of information that we hope will help you through this difficult time. It has been designed to help you learn more about this diagnosis, the possible treatments, and many of the services available to your child and your family.

In the days, weeks, and month ahead, you will meet many professionals that will be involved in your child's care. It is important that you are an active member in your child's health care team. This team may be made of pediatric neurosurgeons, psychiatrists, neurologists, nurses, social workers, pharmacists, dieticians, and neuropsychologists, to name a few. You will be meeting health care professionals in various fields that will be new to you.

There are many ways that you can be active in your child's care. Keeping the lines of communication open with your child's health care team is essential. Do not be afraid to ask questions and write down the answers. It is often easy to forget specific instructions when trying to understand everything that is happening. Having these answers and instructions written down will often help.

Keep a journal on your child's day to day care. In diary form, you may want to track your child's progress and write down concerns. This will help be a valuable tool to report any important information back to your child's health care team, such as symptoms, and any side effects from treatments or medications. Keeping a journal is an effective way to keep track of appointments, medications and dosages, phone numbers and emergency contacts, as well as any questions as they arise. It is important to remember that you must be an advocate for your child.

Trust is the most important link between you and your child. Always tell your child the truth and answer his/her questions honestly so that they can understand. This trust will give strength for both of you as you deal with the challenges ahead of you.

This has been prepared to assist you in the weeks, months, and years ahead as you live with your child's brain injury diagnosis. It does not provide all the answers. Our hope is that with this resource as a guide, you will be able to learn more about your child's diagnosis, and know where and how to ask for help.

# Raising a Child with a Brain Injury: Patrick's TBI Path To Recovery

**Submitted by: Angel Ajabi, Parent**

The cold harsh winter is behind us now. I know this because as I sit on my front porch with only a light jacket to protect me from the teasing warm winds. The snow has been melting leaving only a damp musty smell, but my favourite part is the sound of the birds rejoicing as my 24 year old son Patrick pulls into the driveway, and I smile. He exits the car with a heavy foot, his blue factory uniform shows remnants of a rough day and his hair sports signs of a long overdue haircut. "Hi Mom" he says as his long strides walk past me" I am glad to be home."

Mother's Day is fast approaching and with it the reminder of Patrick's near death experience. We often celebrate the day with a "survival cake" happy that Patrick is still alive and the best Mother's day present I could have, my son. He was only 10 when his TBI happened, and we spent Mother's Day in the hospital. A hard object had cracked his skull causing internal bleeding and putting pressure on his brain. We are forever grateful to London's Children Hospital and their team of experts who worked quickly to operate and provide us with a follow up recovery team, PABICOP. They helped to educate us in what to expect and accept that Patrick's life was now headed in a different direction.

Their school liaison was my long term partner in advocating for Patrick's rights and capabilities for educational expectations. I had found that with each school year we had to revisit the situation and give Patrick's new teacher a review of the invisible injury and why he was performing at lower levels. It was incredibly frustrating to have a teacher insist that Patrick underline in RED ink, and make that an issue, clearly not understanding how everyone's injury and recovery is unique.



With that being said let me be clear. Your child will never be the same again. This is not to say that the brain will not find new ways to route itself and they could have an amazingly successful recovery, but as a parent you need to accept this complex fact, the better you understand and accept this the healthier their holistic recovery will be. The first four months post TBI, I made Patrick wear a bicycle helmet every time we left our house.. I knew his head could not handle another blow and to me the bicycle was life. Today looking back, I am aware of how extreme that was but at the time when your family has experienced a trauma like this your mama bear instincts kick in. Patrick remembers the pain of other children teasing him, calling him helmet head and more. Not only was he no longer feeling like himself , fatigued, confused, memory loss, changes food preferences, and migraines to name a few, but socially he felt

less confident, his self-esteem damaged. He was aware of how people stared at his 5 inch scar, his hair never growing back over it, and tired of curious people asking what happened. Even well-meaning people, looked at Patrick with sadness and pity, this ingrained a message to Patrick that he cannot erase. He was now different than everyone else and the stigma of a brain injury he carried on his shoulders. Growing up is difficult time for children, adding this extra complication is a challenge.

High school was a better time for him with the school having computer programs such as drag-on, and a defined selected education level. He was a fantastic well behaved teenager, sadly probably due in part to his lack of energy and social skills. He avoided all activities and was very much a house hermit. He abstained from alcohol and drug use but did sport various hair colours and radical hair styles that would otherwise be stereotyped with defiant behaviour. Patrick's reasoning for going against the norm, was that it made people have to look at his insides to know him instead of

focusing and judging his outer appearance. After high school he attempted college. He chose not to be identified and did not ask for any resource help. Patrick was not coping well and withdrew within the first semester.

As a young adult Patrick maintained a few retail jobs and is currently at a local factory full time. Residue remains from the TBI, such as migraines which he does periodically miss time from work due to them. Also his fine motor skills are still weak, frozen in time, but he is an avid reader of novels. Patrick thrives on routine, is easily stressed, often moody, and socially awkward and still fights fatigue. He is a devoted son, an amazing brother, and a loyal friend. Patrick was forced to learn the secret of life at a young age; the glass is half full... with the lemonade he made. As for myself, I have decided I like lemonade.

# She was Catastrophic!

Submitted by: Jennifer Wannamaker

**She was catastrophic! When you have never heard that word before and medical staff tries to explain what that is with all the chaos going on, you cannot comprehend what that even means. My name is Jennifer and my daughter, Alyssa, was deemed catastrophic when she sustained serious head injuries on June 20<sup>th</sup>, 2005. She was only eight years old.**

Alyssa had the proper safety helmet, but on this day, she chose to ride her bike outside without wearing a helmet, and a truck hit her. She was on our street and, to the best of my knowledge, just playing with friends as she had done on so many previous occasions. Little did I know that my worst nightmare would come true when there was a knock on my door. All I remember from that day was a neighbour saying to me that my daughter had been hit. I didn't even know what that meant. I rushed outside, and that's when I saw her. She was laying on the ground, her bike was mangled and the front end of a truck was damaged from the impact of hitting her. It happened just steps away from my front door. A doctor that happened to be riding his bike and saw everything was now trying to stabilize my daughter as ambulances and police cars arrived. How could this have happened? I was only steps away and I had just spent the day on a school field trip with her at Storybook Gardens. I yelled at my other daughter to go back into the house to try and shelter her from the scene of seeing her sister. Within minutes we were off to the hospital to deal with the unknown. It seemed as if I was waiting for hours before doctors would talk to me about the injuries my daughter sustained and to be honest, that was just the beginning of a long journey that has forever changed our family. Walking into the room where Alyssa laid, I was advised that she was in a coma and I will never forget the doctors telling me



would make it. Alyssa had to undergo a craniotomy to try to reduce the swelling of the brain. While she managed to pull through and awoke from her coma eight days later, nothing prepares you when it comes to dealing with a child who has sustained a brain injury. When she woke up, Alyssa was not the child I knew anymore. While I knew that was my daughter, she forgot all her basic skills such as how to talk, walk, eat, read, write and all that had to be retaught. While coming to terms with what it meant to have a child with a brain injury, no one can tell you what the outcome will be, because every case is different.

In addition to trying to put the best plan in place for my daughter's recovery, I couldn't forget that I had another daughter at home who needed me too. As my youngest daughter was passed around from family members and friends, I couldn't have imagined the impact that would have long-term on her sense of security. My other daughter experienced years of insecurity and attachment issues as I was gone for a month and she was being passed around. She feared so much that she slept with

me every night for years or at the foot of my door as she was afraid that I wouldn't be there for her, just like I wasn't while I tended to Alyssa in the hospital. So much focus was spotlighted on dealing with the brain injury that I couldn't even see the detrimental effect this had on my other child. Years of therapy we would soon find out were not just for Alyssa but our family as a whole.

At her stay at the LHSC, in those 31 days, Alyssa had a team of medical staff that specialized in areas such as a case manager, speech, physiotherapy, dietician, occupational therapy and so many more. When Alyssa was finally discharged, I knew we would continue to have appointments on her road to recovery and I even remember a medical staff telling me to be prepared to have your privacy end because the appointments were just beginning. Several arrangements had to be made before Alyssa could be discharged such as a medical team in place and some minor renovations into the home to help with her balance issues. Finally she was released from the hospital as we did multiple therapies a day, Alyssa napped in between because one of the biggest side effects of a brain injury is fatigue. As she learned to do all the things she once did prior to the MVA, it was with the help of several agencies in the London area. The brain is a funny thing, because when one has a brain injury, there are not always visible scars. Alyssa's hair grew back and physically she looked great and therefore, people thought she was fine. A brain injury can effect one cognitively and intellectually, and this was the case for us. Impulsive was the word I heard most often as she made decisions before thinking them through. Little things such as crossing the street she could no longer do alone as she didn't always know the consequences of looking both ways.

While I could go on forever about all the neurophysiologists, assessments, appointments and how our lives revolved around them, I also know that Alyssa wouldn't be the person she is today if it weren't for all those agencies out there that had a huge part in helping her back to the road of recovery. Deal-

ing with someone close that has a brain injury can be extremely overwhelming and lonely at times. Like a lot of illness, family and friends are there in the beginning but as time goes on, everyone goes back to their own lives, and you feel like the only people who understand the complexity and severity of the injury are the therapists and so they become your friends. One of the most challenging part as parent was when I didn't agree with some of the suggestions that therapists made. I had my daughter in a French first language school prior to her accident and when we decided to re-integrate her back it was highly suggested that I put her in an English only school. I knew my child and I knew what kind of future I wanted her to have and decided to leave her in the French school system. We would find a way to make it work through hard work and extra tutoring. Making some of these decisions is difficult because part of you loses hope at times that the future you once envisioned for the child is even possible.

It takes a lot of people assisting in one person's recovery when it comes to a brain injury and I couldn't have had a better team in place. The Brain Injury Association helped us along the way and now almost ten years since her accident, I am happy to say that Alyssa is a thriving 18 year old. She has survived a lawsuit that stretched nine years, she graduated high school six months early, completed her first year of college at College Boreal and is already working in the French school system. While fatigue continues to be an issue and she may not always make the right choice due to impulsivity, she has overcome more than anyone I know.

Living with a brain injury is possible. I truly believe that you just need to know where to go to get the right supports put in place. While not everybody was as lucky as we were, my greatest advice to parents is prevention. As the summer months approach, lock up the bikes even when it's in your backyard, and do not allow your child to ride without a helmet. The consequences can be devastating.

# THE EARLY DAYS - FACT SHEET

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**Child rearing brings challenges to all parents, and for parents of a child with an acquired brain injury (ABI), the challenges can be magnified, such as striking a balance between protecting your child from harm, while encouraging self-reliance and independence.**

## **Challenges Faced by Parents**

It may not be clear, in the early stages, what problems the Acquired Brain Injury has caused, and it can be difficult to predict how much a child will recover, and how fast. It is easy to focus on the differences - to feel that the young people with Acquired Brain Injury, and the family, are different from other young people and families. But in general, most parents face a very similar range of challenges. Aim to focus on these similarities and claim your place, and your child's place, as part of your local community.

At times the emotional challenges can seem overwhelming. Grief, in some shape or form, may always be there. Parents can feel they've lost their privacy and sense of control - everyone else has 'good advice' and knows best. You may feel isolated and 'different' from other families, or that there is no one there to help.

But many parents also say that this life-changing event has also helped them realize what's really important and value what they do have. Many families also discover they're not alone-many find that linking up with others in a similar situation provides great support.

Alongside the difficulties, lots of good things happen, and families need to recognise and celebrate these. By and large, families with a child with Acquired Brain Injury get on with life very competently.



## Will My Child be Okay?

This is the most important question for parents in the early days after an Acquired Brain Injury-be it either accident or serious illness. You probably won't take in much of the information you are told at this stage so get people to write things down for you.

Your child may be in a coma-not opening his/her eyes or responding in any way. Coma may last for minutes, hours, days or longer. As your child comes out of coma, he/she will move into a 'twilight' zone-awake but confused, disoriented, maybe agitated, and not making sense. This is known as post-traumatic amnesia, or PTA.

In PTA, your child may remember things from the past, but won't remember things happening now, from minute to minute. Ordinary things may look strange or different, or your child may imagine things that are not there-an experience that can be frightening or confusing. Later on, your child will remember little or nothing of this time, or may have a sense of it as no more than a blurred dream.

PTA may last for minutes, days, weeks or months. The length of time in PTA provides a reasonable basis for predicting how well your child will recover. The depth of coma and how long it lasts provide another indicator.

Talk to the staff on the ward-doctors, nurses, therapy staff, and be ready for answers to change and become clearer over time.

## Things You Can Do

The most important thing for your child is feeling held, loved and supported by family and friends-even while in a coma. Always talk and behave as if your child is conscious- we simply do not know whether people at this stage can hear or understand anything of what is going on.

During PTA your child will be less able to deal with the amount of noise and activity around, and might easily become more agitated or restless. Try to pace interactions and inputs, so things happen at a quiet pace and only one thing at a time.

Bring in photos, and favourite things to create a familiar environment. Help the staff to get to know your child-his/her interests, personality, habits, quirks and talents. You may be able to do some of the day-to-day routine care for your child, if you wish to. Talk to the nursing staff about this.

As the days go past, keep a book to record what's happening. A book of this nature can be reassuring to a young person who realises, some time later, that they have 'lost' and forgotten some days or weeks of their life.



## Look After You

You will need all your strength to get through this difficult period. Make sure you look after yourself while your child is in hospital (and afterwards). Make chairs into a bed to get some sleep and keep your energy up with meals at the cafeteria. If you want some quiet time, go to the hospital chapel. Accept offers of help from relatives and friends, so you can spend more time with your child and your family.

Pacing yourself is still important when your child comes home from hospital. This can be a time of major readjustment for parents. Quite apart from the physical demands of caring, changes to your child from the Acquired Brain Injury may suddenly become distressingly clear. Being prepared for this can help you to cope with it and continue the process of readjustment.

## Should My Child Be Assessed?

If you are concerned about difficulties your child is having with, for example, learning, memory, speaking, balance, vision, or handwriting, such problems should always be thoroughly assessed-whether or not your child is known to have an Acquired Brain Injury. Careful and thorough assessment is vital to find the best way to help your child - whatever the cause or the diagnosis.



## **In the Months Ahead**

The long-term effects of a brain injury may not be evident for some time. Some may show up only years down the track, when the child is challenged to learn increasingly complex skills and deal with more complex situations. Any of the following changes suggest the need for a thorough assessment to determine how best to help the young person:

- Difficulty with new school work or activities
- Problems in concentrating and remembering instructions
- Slowness in thinking about new things
- Less ability to join in familiar games and activities
- Difficulties understanding what's said or following a conversation
- Decreased ability to re-tell the day's events or find the right word
- Inappropriate sexual discussions or activities

## **Talking to Doctors & Other Professionals**

If you are concerned about any of these symptoms in your child, or if there is any question of a possible brain injury, tell your doctor of your concerns. The doctor will normally examine your child and may make a referral to a specialist doctor such as a neurologist, rehabilitation specialist or paediatrician. Other specialists who may be involved in assessment include a neuropsychologist, speech pathologist, physiotherapist and/or occupational therapist.

### **If possible, provide the doctor or specialist with the following information:**

- When your child was hurt, injured or ill, and what happened
- What was done in the Emergency Department
- The name of any doctor who treated your child
- The changes you've seen in the child
- Problems your child is having in school, with friends or at home-you may need to contact teachers and get feedback from friends
- Examples of how your child seems different now
- What you do to help your child

## Frequently Asked Questions by Parents

**Submitted by: Paediatric Acquired Brain Injury Community Outreach Program (PABICOP)**



### **When Will My Child be Back to Their Pre-Injury Self?**

Recovery from an acquired brain injury varies dramatically, depending on the severity and mechanisms of the injury, and the child's pre-injury functioning. We know that children who had pre-injury developmental delays often have a greater challenge post injury. Some children recover fairly quickly, while others have ongoing problems for some time. Some children continue to have ongoing challenges throughout their childhood and adolescence that will require intervention and support, especially in school and social situations.

That being said, we never know what a child's potential for recovery is, and encouraging a child to reach their potential is an integral part of brain injury rehabilitation. Children who are injured in infancy and early childhood often have more challenges due to the brain's immaturity in the early years. Sometimes the injury effects are not seen until the child grows older and greater challenges are placed on them. Often, recovery is most marked in the first year, however, children continue to recover (even very small gains) on an ongoing basis as they grow.

The bottom line is that we simply don't know when or whether a child will return to their pre-injury self. Children are a work in progress and although a brain injury may change the trajectory they are on, with ongoing support and encouragement they will continue to develop and progress. Appreciation of this fact is why PABICOP is available to provide support and service to children with acquired brain injuries along the continuum of their development, from infancy through adolescence.

## **Why Doesn't My Child Seem to be Able to Maintain Friendships Anymore?**

There are a number of reasons why children with acquired brain injury often have difficulty in social situations. First and foremost, children who have been injured are often 'out of the social loop' for a chunk of time due to hospitalization, home based rehabilitation and progressive return to school. Children who return to school after an injury may be 'different' to how they were pre-injury. This may be difficult for their pre-injury friends to understand. They may have difficulty reading social cues, non-verbal language and may get over stimulated in group situations. This can lead to either withdrawal from social situations or inappropriate reactions such as outbursts and aggression.

There are a number of strategies that may help. Holding a 'Circle of Friends' with the child's social group may help them to understand the impact the injury and why it is difficult for the child to manage in certain situations. It is also a great way for groups of friends to support the injured child and help them feel part of a group again. Encouraging a child to maintain one or two friendships, rather than a 'crowd' is often more successful in the beginning. Fatigue often prevents children from socializing as much as they did pre-injury. Sports restrictions can also make socialization a challenge post-injury. Being aware that it is important for the child to have opportunities for social interaction can prevent children from becoming withdrawn and depressed. This may involve creative solutions, such as bowling instead of hockey or being team scorekeeper for a season.

## **What is the Risk of Re-injury if My Child Returns to Sports or Active Play?**

There is well-documented evidence to support two important facts with regard to re-injury. First, children who have sustained an acquired brain injury are at a high risk for sustaining a second injury due to the ongoing sequelae of the first injury (inattention, impulsivity, balance). Second, sustaining another injury during recovery from the first injury places a child at a high risk for more severe and potentially permanent brain damage.

There are concerns that cannot be stressed enough. PABICOP has a list of post injury sport restrictions that may be helpful to parents, teachers, and coaches. We are also available to discuss any questions with regard to return to activity at any time. If a child continues to be symptomatic (headaches, fatigue, memory, etc.) we strongly advise that a child does not participate in any contact or high-risk sports activities at all. Once the child is no longer symptomatic, a gradual return to activity is advised, in accordance with the Parachute Canada Guidelines, which are available on their website and endorsed by the Canadian Paediatric Society. It is important to remember that a concussion is a brain injury and repeated concussions can result in serious and long term damage, especially if they occur within a short time frame.

## **Where Can I Get Support for My Child and/or My Family as a Result of the Injury?**

There are many sources of support for both you and your child and your family that specialize in issues related to an acquired brain injury. Some are fee for service (private providers), and others do not charge any fee (publically funded, such as PABICOP). Contacting the Brain Injury Association can help you link with either private or publically funded services in your community. They are also a great source of information and resources to help support your child and family. The main point is to ensure that your child and family receive the help and support that is needed during a difficult and often frightening time.

Often just having someone to answer questions or process thoughts, fears and feelings with is a great source of reassurance. Having good and accurate written information to refer to is also an important source of support. It is sometimes helpful to link with another family who has had a similar experience, and these contacts can be made through the Brain Injury Association or PABICOP.

## **Should I Consult with a Lawyer?**

Seeking and retaining legal counsel is advised in many acquired brain injury cases. The reason for that is that children who sustain brain injuries may require funds to support their rehabilitation that exceeds public or insurance amounts. Also, children and families may require financial supports that are specific to paediatric brain injury issues with regards to future care and support costs that are not immediately evident.

When children sustain an acquired brain injury, they still have their whole life ahead of them, and there may be many 'unknowns' with regards to recovery. It is hard to think ahead to the future to what supports (if any) your child might need many years down the road, but a personal injury lawyer will be aware of what these issues might be for you.

They will also be aware of special testing for assessments that may help in making that determination. Make sure that the lawyer you choose has experience with paediatric brain injury and that you are comfortable with having them represent you. Most personal injury lawyers will offer a free one hour consult session to help you decide whether or not you have a case and what some of the issues might be. The Brain Injury Services Directory has an excellent selection of lawyers and their contact information listed in the Legal Services Section.

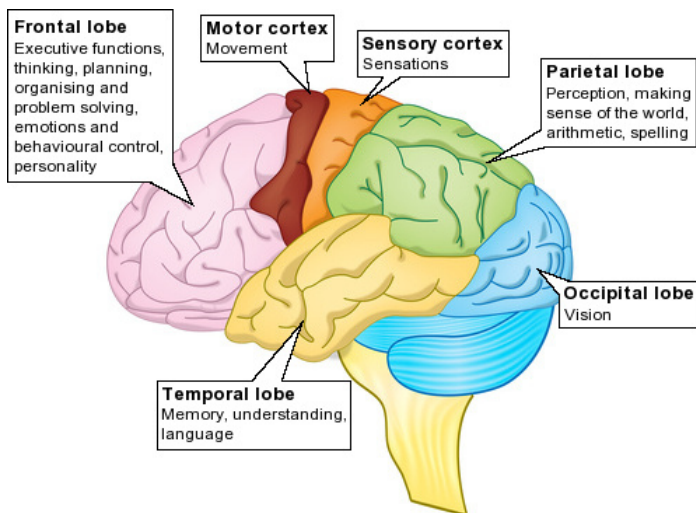








## Areas of the Brain



### Frontal Lobes

The frontal lobes of the brain are very vulnerable to injury. After frontal lobe damage children may not be able to appreciate the extent of their own deficits. They may also have difficulty appreciating how their behaviour impacts on others. Disinhibition may be a concern; the child may be unable to refrain from engaging in behaviours. Children with ABI sometimes have a great difficulty stopping behaviours on their own once they have initiated it, as they may not recognize the inappropriateness of the behaviour.

Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"> <li>Primarily responsible for putting things in order and sorting things out.</li> <li>The “executive functions” of the brain are controlled by the frontal lobes.</li> <li>Initiation (starting a task)</li> <li>Problem Solving</li> <li>Judgement</li> <li>Inhibition of behaviour planning</li> <li>Emotional responses</li> <li>Awareness of abilities/limitations</li> <li>Concentration and attention</li> <li>Abstract thinking</li> <li>Foresight</li> <li>Speech</li> <li>Gross and fine motor planning</li> <li>Knowing what we are doing within our environment</li> <li>Responding to our environment</li> <li>Remembering how to do things</li> </ul>	<ul style="list-style-type: none"> <li>Loss of simple movement of various body parts</li> <li>Inability to plan a sequence of multi stepped tasks</li> </ul>

## Parietal Lobes

Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"> <li>Primarily responsible for the sense of touch and the ability to have a sense of body position.</li> <li>Sense of hot/cold</li> <li>Sense of hard/soft</li> <li>Self-perception</li> <li>Visual attention</li> <li>Manipulation of objects</li> <li>Constructional ability</li> <li>Words and thought formation (left parietal lobe)</li> <li>Understanding of the spatial nature of the world such as recognizing faces and shapes and knowing directions (right parietal lobe)</li> <li>Paying attention to what we are doing</li> <li>Controlling movements</li> <li>Using different senses together</li> </ul>	<ul style="list-style-type: none"> <li>Inability to attend to more than one things at a time</li> <li>Inability to name an object</li> <li>Inability to locate words for writing</li> <li>Problems with reading</li> <li>Difficulty distinguishing left from right</li> <li>Difficulty doing mathematics</li> <li>Lack of awareness of certain body parts or surrounding space</li> <li>Inability to focus visual attention</li> <li>Difficulty with eye and hand coordination</li> </ul>

## Temporal Lobes

Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"> <li>Primarily responsible for auditory reception (hearing) and some processing of visual information.</li> <li>Sound recognition</li> <li>Sound discrimination</li> <li>Sound comprehension</li> <li>Voice recognition</li> <li>Auditory and visual memory storage</li> <li>Emotional control</li> <li>Interpreting what we see</li> <li>Talking</li> </ul>	<ul style="list-style-type: none"> <li>Difficulty recognizing faces</li> <li>Difficulty understanding spoken words</li> <li>Disturbances with selective attention to what we see and hear</li> <li>Difficulty identifying and naming/describing objects</li> <li>Short term memory loss</li> <li>Interferences with long term memory</li> <li>Increased or decreased interest in sexual behaviour</li> <li>Inability to categorize objects</li> <li>Increased aggressive behaviour</li> <li>Language and hearing</li> <li>Speaking and communicating</li> <li>Right lobe damage can cause persistent talking</li> <li>Expression of intense emotions (e.g. intense anger at the slightest provocation)</li> </ul>

## Occipital Lobe

Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"><li>• Responsible for visual reception.</li><li>• Recognition of objects</li><li>• Visual scanning</li><li>• Effectively integrate symbols</li><li>• Recall of visual images</li></ul>	<ul style="list-style-type: none"><li>• Visual field impairments</li><li>• Difficulty with locating objects in the environment</li><li>• Difficulty with identifying colours</li><li>• Production of visual hallucinations</li><li>• Word blindness – inability to recognize words</li><li>• Difficulty in recognizing drawn objects</li><li>• Understanding what is seen</li><li>• Seeing objects or people clearly</li><li>• Recognizing movements of an object</li><li>• Some aspects of reading and writing</li></ul>

## Cerebellum

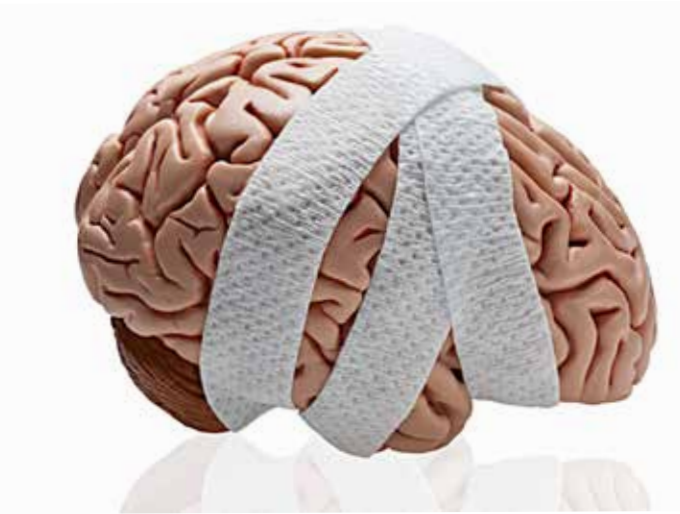
Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"><li>• Primarily responsible for regulation of balance, breathing and posture.</li><li>• Coordination of voluntary movement</li><li>• Balance and equilibrium</li><li>• Some memory for reflex motor actions</li></ul>	<ul style="list-style-type: none"><li>• Loss of ability to coordinate fine movements</li><li>• Loss of ability to walk</li><li>• Inability to reach out and grab objects</li><li>• Tremors</li><li>• Dizziness</li><li>• Slurred speech</li><li>• Inability to make rapid movements</li></ul>

## The Brain Stem

Function	Observed Problems When Injury Occurs in this Region
<ul style="list-style-type: none"><li>• Responsible for:</li><li>• Maintaining breathing</li><li>• Maintaining heartbeat</li><li>• Swallowing</li><li>• Reacting to sudden noises and sights</li><li>• Controlling, sweat, blood pressure, digestion, temperature and level of alertness</li><li>• Sleeping</li></ul>	<ul style="list-style-type: none"><li>• Dizziness and Nausea</li><li>• Difficulty with</li><li>• Breathing</li><li>• Swallowing food or fluids</li><li>• Organizing or perceiving the environment</li><li>• Sleeping</li><li>• Relaying information between the brain and the rest of the body</li><li>• Eye movements</li></ul>

# Traumatic Brain Injury - Fact Sheet

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**Traumatic Brain injury is the most frequent cause of death and disability world wide. It can be the result of a motor vehicle accident, fall, assault or external blows to the head.**

## **What is Traumatic Brain Injury?**

A Traumatic Brain Injury or TBI is an injury to the brain caused by a blow to the head or other external force, which may cause rapid movement of the brain inside the skull. This may occur through an event such as a car accident, assault, fall or sporting accident. A traumatic brain injury can be described in different ways, depending on how the injury occurred. A traumatic brain injury can be described as being a closed or open brain injury:

### **A Closed Head Injury**

Closed injuries mean that injury to the brain has occurred without the skull being broken or penetrated and the brain has not been exposed. An example of a closed head injury is when the rapid movement of the head backward and forward (acceleration-deceleration movement) causes the brain to move inside the skull and slam against its hard inner bone.

## An Open Head Injury

A traumatic brain injury may also result from the head hitting an object or an object piercing the skull and brain tissue (open or penetrating head injury). A traumatic brain injury can be focal or diffuse, meaning damage may be isolated to one specific area of the brain in focal injuries or wide spread in the case of diffuse injuries.

## How is the Brain Damaged?

With a Traumatic Brain Injury the brain may be damaged as a result of a blow or rapid movement of the head back in cases of whiplash. As a result the brain may be torn, stretched, penetrated, bruised or become swollen. A traumatic brain injury can be diffuse or focal; however the two often occur together. Diffuse damage involves damage to axons, the brain's microscopic communication pathways, which extend from brain cells. Damage occurs when the axons are stretched or severed.

Focal damage involves damage to specific areas of brain tissue. Types of focal injuries include contusions (bruised brain tissue), which often occurs under the sight of impact, lacerations (torn brain tissue), and or haematoma (a collection of blood inside or around the brain), which can be the result of haemorrhaging and can lead to increased pressure on the brain.

A traumatic brain injury often results in secondary injuries, which arise due to the brain's reaction to the first injury. These further injuries include brain swelling and haemorrhaging. Complications such as brain swelling, puts pressure on brain tissue, which can restrict oxygen supply to other parts of the brain leading to cell death. Often treatment of a traumatic brain injury is focused on controlling the secondary effects to prevent further damage.

## How do We Know How Severe the Injury is?

A traumatic brain injury can range from a mild brain injury, or sometimes thought of as concussion, to severe or profound brain damage. Two reliable indicators of severity of damage include how long the person is in coma and the length of time in post-traumatic amnesia. Another widely used indicator of severity is the Glasgow Coma Scale (GCS). This scale measures a person's level of consciousness on a scale of 3-15, with 3 being the lowest level of consciousness. Scoring is based on verbal, motor and eye-opening reactions to stimuli. Generally, a score of 13 or above on the GCS is considered a mild brain injury or concussion, 9-12 as moderate and 8 or below severe.

# Anoxic and Hypoxic Brain Injury - Fact Sheet

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**Although only two percent of our body weight, the brain consumes 20% of the body's oxygen supply. Brain injury can occur quickly once there is insufficient oxygen being supplied.**

Hypoxic brain injury is caused by a reduction in oxygen supply to the brain and Anoxic brain injury when there is a complete lack of oxygen to the brain. Both conditions can occur despite sufficient blood supply to the brain. Some causes include stroke, near drowning, heart attack, drug overdose, strangulation, accidents involving anaesthesia, carbon monoxide inhalation and poisoning. Hypoxia can also occur as a secondary injury following a traumatic brain injury, for example, when there is serious blood loss resulting in low blood pressure or as a result of brain swelling that restricts oxygen supply to areas of the brain [1].

Oxygen is crucial to the brain as it is used to metabolise glucose, which provides energy for all body cells. Most of the brain's glucose is used to send impulses and keep cells alive. Brain cells are sensitive to the effects of restricted oxygen supply and may begin to die within minutes of oxygen restriction [2]. The immediate outcome of severe oxygen restriction is often coma and in very severe cases brain death. Long term outcomes can be problems with cognition, emotions and movement.

## Types of Anoxic / Hypoxic Injury

- Anoxic Anoxia - inadequate oxygen to be breathed in and absorbed by the body, for example altitude sickness or suffocation in a non-ventilated space.
- Anaemic Anoxia - inadequate oxygen supply to the brain resulting from a decrease in total haemoglobin or change in the haemoglobin's ability to carry oxygen [3].
- Stagnant (ischaemic) Hypoxia (or hypoxic-ischaemic injury) - inadequate oxygen supply to the brain due to reduction of Cerebral blood flow or blood pressure. Injury can be localised or generalised, but typically causes general, diffuse damage to the Cerebral Cortex and Cerebellum. Causes of this type of brain injury include stroke, heart attack and brain haemorrhage. Pressure on the brain caused by hydrocephalus or brain haemorrhage can also be a cause of stagnant hypoxia [4].
- Toxic Anoxia - toxins or substances that interfere with oxygen utilisation [5]. Also known as histotoxic anoxia. Carbon Monoxide poisoning also falls into this category, but the classic example is cyanide poisoning. Toxic anoxia can also be caused by exposure to narcotics, alcohol, formaldehyde, acetone, toluene, and certain anaesthetic agents.

## How Long Before Injury Occurs?

Generally speaking, injury will set in after a lack of blood flow to the brain for around three to four minutes, with longer restriction of oxygen leading to more severe brain damage. This is why it is so important the emergency medical team quickly re-establish normal oxygen supply to the brain upon contact. Later a ventilator may be used to maintain breathing and oxygen in the intensive care unit [1].

## What are the Possible Effects of a Hypoxic Brain Injury?

The overall effects of a hypoxic/anoxic brain injury vary depending upon the the severity of damage. Areas of the brain particularly vulnerable to lack of oxygen include the Purkinje's fibres of the cerebellum and the parieto-occipital cortex, which play a large role in coordination and movement, and the hippocampus which is one of the major structures responsible for memory [5.] A significant hypoxic brain injury may result in coma and possibly post-coma unresponsiveness. Symptoms following return to consciousness may include cognitive deficits, specifically memory difficulties, abnormal movements, weakness in arms and legs, lack of coordination and visual problems [5]. Movement disorders are quite common, including lack of coordination, Spasticity (involuntary muscle tightness), tremors and impaired ability to adjust the body's position [5].

As with other types of brain injury, challenging behaviours may be presented. Individuals may also experience emotional problems including, depression, agitation and a reduced ability to tolerate stress and frustration.

## Outcomes and Recovery

Recovery is similar to that of other types of brain injury, however because a hypoxic injury usually results in diffuse damage to the brain, the outcome may not be as good. However, the level of recovery cannot always be predicted, as some patients make a better recovery than expected, despite serious injury.

A number of factors can provide an indication of the level of recovery to expect following a hypoxic injury. Such factors include how long oxygen supply to the brain was restricted, age of the person and the severity of the resulting brain damage [6]. If someone only experiences a brief duration of unconsciousness, generally a good outcome can be expected. Other strong indicators of severity of the injury and therefore outlook for the individual include duration of coma and post-traumatic amnesia following hypoxic brain injury. One study found length of coma and post-traumatic amnesia to predict daily life functioning and quality of life 2-7 years after hypoxic injury caused by cardiac arrest [7].

Length of time in rehabilitation will depend upon the issues that are identified. To maximise recovery it is important that the individual receives a holistic level of support, meaning that all areas of the person's functioning are being assisted in the recovery process. This means having help from a physiotherapist and occupational therapist for movement disorders, speech pathologist for communication difficulties, and a neuropsychologist to assess for cognitive deficits and how rehabilitation can be provided for these problem areas [5]. Support from a good team of specialists and family and friends will mean an optimal recovery.

# Shaken Baby Syndrome - Fact Sheet

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**Shaken Baby Syndrome is a form of Traumatic Brain Injury that occurs when a baby is violently shaken causing damage to the baby's fragile brain. It causes long-term and permanent damage to the baby's brain, which can result in learning difficulties and behavioural problems later in life.**

## Why do People Shake Babies?

### **Some reasons for why Shaken Baby Syndrome occurs include:**

- A person may lack experience with babies, be unprepared and have little knowledge about babies. As a result a person may become overwhelmed and frustrated at inconsolable crying and lose control.
- According to research by Becker (1998) [1] inconsolable crying is one of the most commonly cited reasons for aggression towards children.

The Shaken Baby Prevention Project (SBPP) developed a model to show some of the complex contributing factors leading to shaking. The Model shows the parental behaviours, environmental factors and child characteristics that may contribute to a shaking episode [1]. All these factors are coupled with no knowledge about the effects of shaking a baby may contribute:

### **Factors about the baby:**

Age, crying behaviour, high needs

### **Factors about the environment:**

Isolation, domestic violence, lack of resources

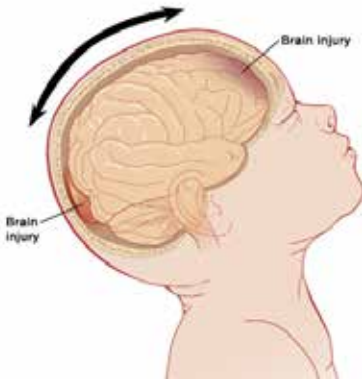
### **Factors about the carer:**

Isolated, depressed, frustrated

## How Common is it?

Shaken Baby Syndrome is a widely under-reported and misdiagnosed condition. Less severe forms of shaken baby syndrome can be misdiagnosed as a viral infection by GPs and emergency room doctors who are less familiar with the symptoms of shaken baby syndrome. Also, survivors are likely to suffer learning problems, epilepsy and behavioural problems, which may be diagnosed as other conditions. For this reason it is difficult to get accurate numbers for Shaken Baby Syndrome.





## What are the Signs of Shaken Baby Syndrome?

Shaken baby injuries usually occur in children younger than 2 years old, but may be seen in children up to the age of 5.

### Injuries related to Shaken Baby Syndrome:

- Brain hemorrhages
- Permanent Brain Damage
- Bleeding in the eyes
- Spinal cord damage
- Fracture of the ribs and bones

### Other Symptoms:

- Irritability
- Poor feeding
- Breathing problems
- Vomiting
- Pale or blue skin

## What Damage does it Cause to the Family and Individuals?

- Suffering an inflicted brain injury at an early age places children at risk of significant impairment in their development. Learning difficulties, behaviour problems, epilepsy.
- Mild to severe impairments can impact cognitive, social, physical, emotional and behavioural functioning. This can lead to problems with meeting milestones in life and adjustment difficulties
- There may be difficulties in the school system.
- Costs to family to provide additional support
- Any cognitive/behavioural difficulties may be mistaken as a personality flaw and so a person's relationships can be impacted.
- Problems due to brain damage may go undetected causing lifelong difficulties with employment and relationships

## Consequences of Mild Brain Injury



Minor brain injuries does not necessarily translate into minor disability. Somatic symptoms, cognitive deficits, and emotional symptoms often occur within 25 hours of the injury: these may resolve within a few months or linger for a year or more after trauma. Psychosocial dysfunction and secondary psychological symptoms can occur later in recovery, when the person attempts to resume the full load of pre-injury activities.

### **Somatic Symptom:**

- Headache
- Dizziness
- Nausea
- Vomiting
- Blurred vision
- Tinnitus/hear problems
- Drowsiness
- Seizures (rare; possible more common in children than in adults)

### **Cognitive Deficits:**

- Amnesia for event
- Short-term memory problems
- Disorientation
- Confusion
- Slow thinking/information processing
- Shortened attention span
- Distractibility
- Poor judgement
- Mental fatigue

### **Emotional Symptoms:**

- Agitation
- Irritability
- Apathy
- Depression
- Sleep disturbances (insomnia, nightmares)
- Labile emotions

### **Psychological Dysfunction:**

- Confrontational attitude
- Impatience
- Explosive temper
- Thoughtlessness
- Ill-naturedness
- Fearfulness

### **Secondary Psychological symptoms:**

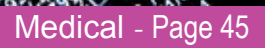
- Anxiety
- Frustration
- Anger
- Guilt/self-blame
- Fear of 'going crazy'
- Feeling of helplessness



## Possible Consequences of Traumatic Brain Injury

**Each brain injury is different. A survivor may experience any combination of symptoms or none at all. Severity of symptoms varies with each individual and may change over time.**

- Lack of stamina
- Fatigue
- Sleep dysfunction, i.e. insomnia, day and night confusion
- Problems planning, organizing, and initiating tasks
- Difficulties with multi-tasking and sequencing, i.e. keeping track of two things at once
- Need for structure and direction to accomplish tasks
- Poor concentration, attention and memory
- Problems retrieving information from memory
- Although intelligence remains intact, there is slowness in processing information, particularly new information, especially if fatigued or over stimulated
- Problems pacing activities
- Difficulty with judgement and decision making
- Perseveration, i.e. mind gets stuck on one issue
- Distractibility
- Impulsivity
- Difficulty dealing with change
- Socially inappropriate behaviour
- Isolating self as feeling different, and therefore treated differently
- Hard to “keep up” in social situations
- Poor coping strategies which impact on interpersonal and vocational efforts
- Vertigo (dizziness), light headed feeling
- Tinnitus (ringing in the ears)
- Light or sound sensitivity
- Smell and taste alterations
- Visual, speech and hearing disturbances
- Stress related disorders; depression; frustration
- Emotional lability. i.e. crying for no apparent reason
- Emotional/behavioural outbursts
- Compulsive talkativeness
- Balance and co-ordination problems (motor co-ordination)
- Personality change
- Chronic pain, including headaches
- Inability to return to work, or, if able, at reduced capacity with great effort
- Possible misdiagnosis as, for example, psychiatric illness or malingering







# Concussion and Return to Activity

Submitted by Dr. Lisa Fisher, Kennedy Fowler Clinic



## What is a “Concussion”?

A concussion is a brain injury that cannot be seen on X-Rays, CT Scans or MRIs. It affects the way a child may think and remember things and can cause a variety of symptoms.

## What are the Symptoms and Signs of Concussion?

It is important to know that your child does not need to be knocked out (lose consciousness) to have a concussion. A variety of problems may happen after a concussion including

Thinking Problems	Child’s Complaints	Other problems
<ul style="list-style-type: none"><li>• Disorientation - Does not know time, date, place, period of game, opposing team, score of the game</li><li>• General confusion</li><li>• Amnesia - Cannot remember things that hapwpened before and after the injury</li><li>• Trouble remembering or trouble concentrating</li><li>• Trouble paying attention and learning new things</li><li>• Has trouble following directions</li></ul>	<ul style="list-style-type: none"><li>• Headaches</li><li>• Dizziness</li><li>• Feels dazed</li><li>• Feels “dinged” or stunned; “having my bell rung”</li><li>• Sees stars ; flashing lights</li><li>• Ringing in the ears</li><li>• Sleepiness</li><li>• Seeing double or blurry vision</li><li>• Stomachaches / stomach pain /nausea</li><li>• Feeling like he/she might faint</li><li>• Gets tired easily</li></ul>	<ul style="list-style-type: none"><li>• Poor coordination or balance</li><li>• Blank stare / glassy eyed</li><li>• Vomiting</li><li>• Slurred speech</li><li>• Slow to answer question or follow directions</li><li>• Easily distracted</li><li>• Poor concentration</li><li>• Strange or inappropriate emotions(ie crying laughing getting mad easily_)</li><li>• Not playing as well</li><li>• Easily distracted</li><li>• Sleeping more</li><li>• Gets tired more often</li></ul>

## What Causes a Concussion?

Any blow to the head, face or neck, or a blow to the body which causes a sudden jarring of the head may cause a concussion (ie a ball to the head, being checked into the boards in hockey)

## What Should You do if Your Child Gets a Concussion?

Your child should stop playing his/her sport or activity right away and NOT return to play on the same day. He / She should not be left alone and should be seen by a Doctor as soon as possible. If your child is knocked out, call an ambulance to take him/her to a hospital immediately. Do not move your child or remove any equipment such as helmets until the paramedics arrive.

If your child exhibits any “red flags” he/she should be seen in the emergency dept immediately

**Red flags include:** dilated pupil, decreasing level of consciousness (drowsy and can't be woken up) , vomiting, worsening headache , severe neck pain, can't recognize people or places, behaves unusually, seems confused, has difficulty understanding speech or directions, is irritable, has any seizures (arms and / or legs jerk uncontrollably), has weakness/ numbness/ tingling (arms, legs or face), is unsteady walking or standing, has slurred speech.

## How Long will it Take for Your Child to Get Better?

The sign and symptoms of concussion (see above) often last 7 to 10 days in adults but may last much longer in children ( 3 to 5 weeks ) .

In some cases, symptoms may become more persistent, lasting weeks to months.

Having had previous concussions may increase the chance that a child may take longer to heal and increase the risk for recurrent injury.

## How is Concussion Treated?

**The most important treatment for concussion is rest.**

The child should not exercise, go to school or do any activity that may make him/her worse (like riding a bike , play wrestling with brothers, sisters, friends, video games, reading or working on the computer), at least until acute symptoms settle .

If your child goes back to activities before he/ she is completely better, he/she may feel worse, and have symptoms longer. Once symptoms have improved, your child should start a graduated return to learn



program, gradually introducing school work and time at school as long as symptoms do not get worse. Once your child is completely better at rest (all symptoms have resolved) and back to full school, he/she can start a step-wise increase in activities. (see When to return to Sport). It is important that your child is seen by a Doctor before he/she begins return to activity, to minimize risk and ensure safe return to sport.

**If possible, your child should be seen by a doctor with experience with concussions.**

## **When Can My Child Return to School?**

Sometimes children who have a concussion may find it hard to concentrate in school and may get a worse headache or feel sick to their stomach if they are in school. Children should stay home from school if their symptoms get worse while they are in class. Once they feel better, they can try doing some work at home, then progress to going to school part time to start (eg. For half days initially) and if they are okay with that then they can go back fulltime.

## **When Can My Child Return to Sport?**

**It is important that your child NOT go back to sport if they have any concussion symptoms or signs. Your child should also be back to full school activity prior to any return to sport.**

**Return to sport and activity must follow a step wise approach:**

1. No activity, complete rest. Once back to normal and cleared by a doctor, go to step 2.
2. Light exercise such as walking or stationary cycling, 10 to 15 minutes.
3. Sport specific activity (ie skating in hockey, running in soccer, for 20 to 30 minutes NO CONTACT .
4. "On field" practice such as ball drills, shooting drills and other activities with NO CONTACT (ie no checking, no heading the ball etc)

Medical clearance is required before the athlete progresses to any contact (step 5/6)

5. "On field " practice with body contact , once cleared by a doctor.
6. Game play.

**NOTE:** - Each step must be a minimum of one day - If your child has any symptoms of a concussion (eg headaches, feeling sick to his/her stomach) that come back either during or later that day, your child should stop the activity immediately and rest for a minimum of 24 hours, then progress if symptoms stay resolved.

## When Should I Take My Child to See the Doctor?

Every child who gets a head injury should be seen by a doctor as soon as possible. You should take him/her back to the doctor IMMEDIATELY if after being told your child has a concussion he/she has worsening of symptoms such as:

- Being more confused, difficulty following directions or speech
- Headache that is getting worse
- Vomiting
- Becoming drowsy or can't be woken up
- Trouble walking
- Seizure activity
- Strange behavior, increasing irritability
- Numbness, weakness in arms or legs or face
- Increasing neck pain
- Dilated pupil
- Slurred speech

Problems caused by a head injury can get worse later in the day or night. The child should not be left alone and should be checked for several hours after the initial injury to assess if they are getting worse. If he/she seems to be getting worse, you should go to the emergency room

**NO child should go back to sport until they have been cleared by a doctor.**



# Concussion Tips for Parents

**Submitted by Dave Ferguson of BEYONDtheCheers**

Each year school and sporting activities begin around the same time. As parents we tend to enter the fall season with much excitement anticipating our children's participation in sports.

However with increased media attention towards concussion in sports, some parents may be apprehensive when considering enrolment of their child in any sport where body contact exists.

The intent of concussion awareness and education is to better equip parents with knowledge about signs, symptoms and treatment--not to generate fear. Informed parents, coaches and officials who recognize the symptoms of concussion will be more likely to respond appropriately, if they suspect a child has been concussed.

Concussion is just one type of brain injury. There may not even be a bump, bruise or scratch visible. A concussion results from a sudden blow or jolt to the head or body which causes the brain to move around inside the skull. Your brain is like jello within your skull. When an impact takes place, the jello is swished around and bumps into the hard skull. This type of brain movement is what causes concussion symptoms.

Throughout life, most children bump or hit their heads more than once without any damage caused to the brain. But for accidents or injuries that result in a significant impact to the head, parents should be ready to recognize the most common physical signs.

## **Here are Typical Signs Observed Following a Concussion Incident:**

- Cannot remember what happened before, during or after the injury
- Confused or disoriented; unaware of time, place, activity, opposing team or score
- Brief loss of consciousness (knocked out) however this is not common
- Easily distracted
- Not playing as well
- Slurred speech
- Blank stare and/or glassy eyed
- Slow to answer questions or follow directions
- Strange or inappropriate emotions (i.e. laughing, crying, getting angry easily)

## **Keep in Mind Following a Concussion as Some Children Will Experience Symptoms for Weeks After Which May Include:**

- A brief period of confusion or memory loss
- Headache, vomiting and dizziness
- Losing consciousness for even a brief time
- Light and noise sensitivity
- Feeling or acting dazed
- Seeing stars or flashing lights
- Drowsiness
- Ringing in the ears
- Memory problems
- Double or blurry vision
- Poor coordination and/or impaired balance
- Behavioural changes

**Quite simply the common guideline is, “When in doubt sit them out!”** Remember that the signs of concussion may not appear immediately after a concussive incident and there could be a gradual increase in symptoms over time.

## **Parents Should Also be Aware of Some Other Signs or Changes:**

- Check the volume on the iPod or other listening devices. A concussed victim may lower the volume from a 10 to a 1 following a severe hit to the head.
- Behavioural changes can be difficult to discern, depending upon age, but as a parent you should know your child’s behavioural traits better than others.
- Learn about your child’s attention at school to see if teachers notice any abnormal behaviour. It’s fine to let supervising adults know that a concussive incident has taken place.
- Sensitivity to light and noise are warning signs that something may have happened that should cause you to be concerned.

Not all parents have the type of relationship with their children that are open and truthful, especially if the child may have suffered a concussion. Children are likely to withhold information because they are fearful that they may not be able to continue to play. They may also be embarrassed to tell you that something happened and wasn’t dealt with properly by the coach, trainer or teachers. And, of course, peer pressure may exist for fear of being called a “wimp” for not continuing to play after a concussive incident.

When seeking medical attention make sure that the physician is current with their knowledge about concussion signs and symptoms and they have the ability to diagnose and map out an appropriate treatment plan that includes specific guidelines.

If you are simply told that some form of rest is adequate and that it is okay to return to play or return to learn when symptoms disappear, after a week or so, you may want to seek a second opinion or get advice from a more well informed medical practitioner. Better yet, visit a specialized concussion clinic.

With the latest concussion research, It has been suggested by top medical experts that the required treatment for concussed individuals should include complete rest without TV, computer, technical and mobile devices for a period of no less than two or three weeks. However, most concussions if identified with symptoms, properly diagnosed and treated, will clear up within seven to ten days.

If your child is symptom free, without headaches, and able to perform light exercise with little exertion, they should be able to return to play on a gradual basis. It is recommended that they perform to about 80% of their athletic capacity without experiencing any symptoms for an extended period. No contact sports should be permitted until the child has practiced at 100% of their abilities and exertion before re-introducing them. The same rules apply to return to learn.

Depending on the child some may be able to return to learn and play more quickly than others. Remember that, for concussions, the severity and recovery time is different for every individual. Symptoms may last several years for some and in others the symptoms may never disappear. The result of repetitive concussions may have some experiencing memory loss, imbalance and the inability to walk properly.

Learn more and get familiar with the signs and symptoms of concussion and continue to gain more awareness to help everyone who is involved in sport. It is important to treat concussions properly and take symptoms seriously and to evolve sport with better return to learn and play policies, right procedures and guidelines.

Smart play is using your own one brain to make the right decisions towards recognizing and treating concussions. Everyone needs to know and practice, "When in doubt sit 'em out!"

*Sports fundamentalist, blogger, producer and host at [BEYONDtheCheers](#), Dave Ferguson is live on internet radio weekly with conversations inside and outside the world of sports and athletics.*

*Dave interviews high profile athletes and coaches, those who are involved in the game and those ready to confront issues that really matter to everyone -- like, "lack of player safety and respect, the win-at-all-cost mentality, concussion awareness, bullying and violence in play, and the declining interest in sports from kids and parents alike..." to name just a few.*

# Glasgow Coma Scale

Reprinted with permission from [Brainline.org](https://www.brainline.org)

The Glasgow Coma Scale (GCS) is the most common scoring system used to describe the level of consciousness in a person following a traumatic brain injury. Basically, it is used to help gauge the severity of an acute brain injury. The test is simple, reliable, and correlates well with outcome following severe brain injury.

The GCS is a reliable and objective way of recording the initial and subsequent level of consciousness in a person after a brain injury. It is used by trained staff at the site of an injury like a car crash or sports injury, for example, and in the emergency department and intensive care units.

The GCS measures the following functions:

## Eye Opening (E)

- 4 = spontaneous
- 3 = to voice
- 2 = to pain
- 1 = none

## Verbal Response (V)

- 5 = normal conversation
- 4 = disoriented conversation
- 3 = words, but not coherent
- 2 = no words, only sounds
- 1 = none

## Motor Response (M)

- 6 = normal
- 5 = localized to pain
- 4 = withdraws to pain
- 3 = decorticate posture (an abnormal posture that can include rigidity, clenched fists, legs held straight out, and arms bent inward toward the body with the wrists and fingers bent and held on the chest)
- 2 = decerebrate (an abnormal posture that can include rigidity, arms and legs held straight out, toes pointed downward, head and neck arched backwards)
- 1 = none

Clinicians use this scale to rate the best eye opening response, the best verbal response, and the best motor response an individual makes. The final GCS score or grade is the sum of these numbers.



## Using the Glasgow Coma Scale

**Every brain injury is different, but generally, brain injury is classified as:**

- Severe: GCS 3-8 (You cannot score lower than a 3.)
- Moderate: GCS 9-12
- Mild: GCS 13-15

Mild brain injuries can result in temporary or permanent neurological symptoms and a neuro-imaging tests such as CT scan or MRI may or may not show evidence of any damage.

Moderate and severe brain injuries often result in long-term impairments in cognition(thinking skills), physical skills, and/or emotional/behavioral functioning.

## Limitations of the Glasgow Coma Scale

Factors like drug use, alcohol intoxication, shock, or low blood oxygen can alter a patient's level of consciousness. These factors could lead to an inaccurate score on the GCS.

## Children and the Glasgow Coma Scale

The GCS is usually not used with younger children, especially those too young to have reliable language skills. The Pediatric Glasgow Coma Scale, or PGCS, a modification of the scale used on adults, is used instead. The PGCS still uses the three tests — eye, verbal, and motor responses — and the three values are considered separately as well as together.

**Here is the slightly altered grading scale for the PGCS:**

### Eye Opening (E)

- 4 = spontaneous
- 3 = to voice
- 2 = to pain
- 1 = none

### Verbal Response (V)

- 5 = smiles, oriented to sounds, follows objects, interacts
- 4 = cries but consolable, inappropriate interactions
- 3 = inconsistently inconsolable, moaning
- 2 = inconsolable, agitated
- 1 = none

### Motor Response (M)

- 6 = moves spontaneously or purposefully
- 5 = withdraws from touch
- 4 = withdraws to pain
- 3 = decorticate posture (an abnormal posture that can include rigidity, clenched fists, legs held straight out, and arms bent inward toward the body with the wrists and fingers bent and held on the chest)
- 2 = decerebrate (an abnormal posture that can include rigidity, arms and legs held straight out, toes pointed downward, head and neck arched backwards)
- 1 = none

Pediatric brain injuries are classified by severity using the same scoring levels as adults, i.e. 3-8 reflecting the most severe, 9-12 being a moderate injury and 13-15 indicating a mild TBI. As in adults, moderate and severe injuries often result in significant long-term impairments.



## Rancho Los Amigos Scale



We use the Rancho Los Amigos Levels of Cognitive Recovery Scale to describe your child's recovery. This scale has eight levels. Your child will change levels at his or her own rate. He or she may also fit into more than one level at a time.

Rancho Los Amigos Scale	
<b>Level I</b>	No response to stimuli. Appears in deep sleep.
<b>Level II</b>	Generalized Response. First reaction may be to deep pain. Has delayed, inconsistent responses.
<b>Level III</b>	Localized Response. Inconsistent responses, but reacts in a more specific manner to stimulus. Might follow simple command "squeeze my hand."
<b>Level IV</b>	Confused, Agitated. Reacts to own inner confusion, fear, disorientation. Excitable behaviour, may appear abusive.
<b>Level V</b>	Non-agitated, Confused, Inappropriate. Usually disoriented. Follows tasks for 2 to 3 minutes, but easily distracted by environment, frustrated.
<b>Level VI</b>	Confused, Appropriate. Follows simple directions consistently. Memory and attention increasing. Self-care tasks preformed without help
<b>Level VII</b>	Automatic Appropriate. If physically able, can carry out routine activities. Appears normal. Needs supervision for safety.
<b>Level VIII</b>	Purposeful, Alert, Oriented. May have decreased abilities relative to pre-injury state.

# What Tests will My Child Need?

Here are some possible tests that your child might undergo after a brain injury:

## **Magnetic Resonance Imaging (MRI):**

- Powerful magnets and radio waves are used to create a clear, detailed picture of the brain and spinal cord.
- Sedation or anesthesia may be needed to help your child remain still

## **Computerized Axial Tomography (CT Scan):**

- A special computer uses xrays to create a clear, detailed picture.
- No special medical preparation is needed for this test

## **Electroencephalogram (EEG):**

- This machine records your child's brain electrical activity from electrodes placed on your child's head.
- This test shows how the brain is working and if seizures are likely.

## **Arteriogram and Angiogram:**

- These tests show the blood vessels of the brain.
- A special dye is, given through an intravenous (IV), shows the blood flowing through the brain.

## **Intracranial Pressure Monitor:**

- A device used to measure pressure in the brain.
- To have this monitor, your child will go to operating room and have a general anesthetic.

## **Neuropsychological Exam:**

- A series of tests to help your doctor find out how a brain injury is affecting your child's ability to reason, concentrate, problem solve or remember.
- Most tests involve answering questions or performing tasks.

# The Modern MRI – A Room With A View

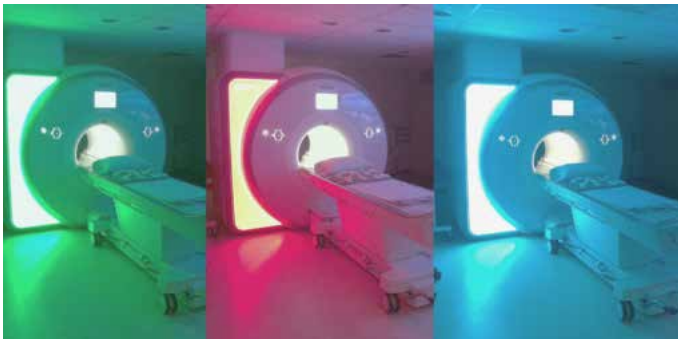
Submitted by Jean-Marie Fiala, President, [MRIappointments.com](http://MRIappointments.com)

Bob Dylan wrote, “The times they are a-changing”. That is a truism that extends to the world of MRI where technology is changing at a rapid pace. Not only are MRI scanners becoming more common-place in Canada, so too are they getting faster and the multiple images they take are sharper and much more detailed. MRI has become the tool of choice for physicians as witnessed by the ever-increasing demands placed on existing MRI installations.

What hasn't changed is the ever present spectrum of claustrophobic anxiety. It is estimated that claustrophobia related to MRI affects 15% of the population, some to the point where they require help getting through their scan. Despite misconceptions from some people that going into an MRI scanner “is like a pimento being stuffed into an olive” the reality is truly just the opposite. It's time to set the record straight. Patient comfort and roominess in the MRI scanner is foremost in the minds of the scientists and engineers that design modern MRI systems.

MRI machines have improved vastly since their introduction in 1983. The newer ones, as found at London Health Sciences Centre, Victoria Hospital and also at St. Joseph's Healthcare, London, are bright, spacious, comfortable and much quieter than their ancestors. The new machines have a wide 70 cm opening featuring soft contours that make the shallow 145 centimeter tunnel seem even bigger and more comforting. What this means is that patients have lots of elbow room and lots of face space too. Studies have shown that these wide-bore machines reduce the incidence of claustrophobia by over 50%.

It doesn't stop there. Designers have created a more relaxed experience for patients by toning down the noise to the point that patients can listen to music during their scan. What about atmosphere, you ask? Do you like the color red? Or maybe blue? Imagine a space where you can choose from a palate of colors to create any pleasing ambience that you like. That's what you will find when you have your scan on the new MRI scanner at St. Joseph's Health Care, London.



**MRI Scanner showing color ambience change from Green to Red to Blue. Photos taken by author**



There is yet another technological innovation, the stand-up, open-design MRI. This is a truly revolutionary machine that allows the patient to stand or sit while having their MRI. Partly, due to their tremendous cost there are very few of these. This scanner is of real benefit to low back-pain sufferers because it can take images with the spine under load.

### **Stand-up open-design MRI scanner**

### **Still Feeling Anxious? There are Number of Things You Can do to Help Yourself.**

- Bring a CD of your favorite music to listen to while having your scan. Many facilities have MRI compatible sound equipment. Call ahead to find out if your centre does.
- The person conducting your test is a Technologist, well versed in the art of making you comfortable. Ask for their suggestions at the time of your test.
- Use a relaxation technique or use guided mental imagery. Imagine yourself at a favorite beach or engaging in some other soothing activity.
- Ask the Technologist if you can go in feet first. Although not always possible, it may prove helpful because your head doesn't have to slide through the scanner.
- Drugs. Ask your physician beforehand to prescribe something to help relax you. If you choose this route, you must bring someone to drive you.
- Bring a friend or family member and ask if they can go into the scanner suite with you. This anxiety reducing strategy actually works well but is at the discretion of the Technologist conducting your scan.

There is another misconception: patients once in the MRI scanner are left alone. The technologist console is positioned so that the Technologist is looking straight at the patient. During the course of the test the Technologist and patient communicate back and forth via a two-way microphone built into the scanner. The patient is never truly "alone".

Thanks to increases in computing power, test times have gotten progressively shorter and shorter. What used to take an hour now takes 30 minutes and what used to take 30 minutes now takes about 15 minutes. MRI is sensitive to patient motion. That was one of the biggest barriers for years. Trying to lie very still for an hour at a time is very challenging. The faster the scan the smaller are the chances for the need to repeat a part of the study because of motion-degraded images.

Although the scan time might be shorter, patients are told to come in a half hour early for their MRI because the Technologist has to review a safety questionnaire. Despite all the advances, patients with pacemakers, cochlear implants, neurostimulators or other implanted devices are not eligible for an MRI. The Technologist is required to review the checklist that patients have completed with their doctor prior to booking the MRI before the test can begin. (See [MRIsafety.com](http://MRIsafety.com) for more information.)

Patients who would like to learn more can visit their local hospital website. It is common now to see hospital websites populated with valuable patient information about MRI and they usually tell patients how to prepare for the test and also what to expect. Look under "Radiology" or "Diagnostic Imaging" on a hospital website to find this.



**Photo of standard imaging suite setup. Technologist able to see patient directly.**  
**Courtesy of Philips Health Care**

# Epilepsy: A Guide For Parents

This article is composed of excerpts from **Epilepsy A Guide for Parents** produced by the **Edmonton Epilepsy Association**. To get a copy of the full guide, please contact the local **Epilepsy Association**. All content was used with the permission of the **Edmonton Epilepsy Association**.

## What Causes Epilepsy and Seizures?

Epilepsy is caused by a number of factors that affect the brain. The cause of epilepsy is sometimes genetic and sometimes acquired but often the cause includes both genetic and acquired factors.

The causes vary according to the age of the onset of epilepsy.

Seizures are classified as **symptomatic** in which the defined cause is known or **idiopathic** in which the cause is unknown. In approximately 60 to 75 percent of epilepsy cases, no specific cause of the seizures can be identified. In the remaining 25 to 40 percent, some of the identifiable causes include:

- Genetic
- Birth injury (e.g. lack of oxygen to the baby's brain at birth)
- Development disorder (brain damage to the fetus during pregnancy)
- Brain trauma (e.g. from car accidents, sports injuries)
- Infection (e.g. meningitis, encephalitis, AIDS)
- Brain tumor

## Seizure Record

Carefully observing your child's seizures is important.

As your doctor may not view one of your child's seizures personally, providing detailed descriptions of the seizures will assist the doctor. Asking others who were with your child during a seizure (e.g. teachers or caregivers) for detailed descriptions is useful. Often a person who has had a seizure does not remember the seizure.

Seizure record charts are available from most epilepsy associations or you could use a notebook or create your own chart.

In addition to detailing the characteristics of the seizures, a record will also provide information regarding the frequency and duration of the seizures. It may also help to identify any consistent seizure triggers.

Certain medical terms are used to refer to the **stages of a seizure**.

An **aura** results in an unusual sensation, feeling, or movement. An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure. If the aura indicates the onset of a complex partial or generalized seizure, it can sometimes be used as a warning signal to allow a person to take the necessary precautions to avoid injury.

The **ictus** refers to the seizure itself.

The **postictal** period follows the seizure. A child may temporarily experience confusion (**postictal confusion**), weakness (**postictal paralysis**), or sleepiness (**postictal state**).

**In the seizure record**, it is important to record information such as:

- the time the seizure occurred
- the date the seizure occurred
- how long the seizure lasted



**Include any information that describes your child's behavior before, during, or after the seizure such as:**

### **Before the Seizure:**

- What was your child doing before the seizure?
- Were there any provoking factors (e.g. lack of sleep, exposure to flickering lights from television, strobe lights, etc., recent illness, stroke drug or alcohol abuse, missed medication, missed meals)?
- Did your child experience symptoms that preceded the seizure by many hours or days (known as prodrome) such as mood changes, dizziness, anxiety, restlessness?

### **During the Seizure:**

- How did the seizure begin?
- Did your child experience an aura?
- Was there unusual or involuntary body movement? What part of the body moved first? Next?
- Was your child responsive during the seizure?
- Did your child experience automatisms (e.g. lip smacking, chewing movements, rapid blinking, head turning, pulling at clothing, random walking)?
- Did your child appear to be daydreaming?
- Did your child stare blankly?
- Did your child's eyelids flutter or eyes roll?
- Did your child's body become rigid?
- Did your child cry out or yell?
- Was there jerking and if so, did it occur on one side of your child's body more than on the other?
- Did your child's skin change color?
- Did your child's breathing change?
- Did your child fall?
- Did your child bite his or her tongue or lip?
- Did your child lose bowel or bladder control?

### **After the Seizure:**

- Did your child experience temporary weakness in any part of the body, fatigue, confusion, and/or headache?
- How long did this period last?
- Was there injury as a result of the seizure?





## Seizure Medication

Seizure medication is the primary treatment for epilepsy. In most children with epilepsy, seizure medication is effective in controlling seizures. Medicine does not cure epilepsy, but it often reduces or even stops seizures from occurring by altering the activity of neurons in the brain. As many children who have had a first seizure do not have a second one, medication is not typically prescribed after one seizure.

## Seizure Medication Tips

1. Assure that your child always takes seizure medication as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus.
2. It is sometimes recommended that if a single dose of seizure medication is missed, the dose should be taken as soon as it is remembered. It is important to ask your doctor what you should do if your child forgets to take a single prescribed dose of medication.
3. Discuss the use of any other medications or vitamins with your doctor or pharmacist. Decongestants, acetylsalicylic acid products (ASA) such as Aspirin, and herbal medications can all interact with seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your child's seizure medication.
4. Avoid running out of medication by keeping a two-week supply.
5. Don't change from a brand name drug to a generic drug without first consulting your doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.
6. Children should wear a medical identification bracelet.
7. If medication must be taken during the day, contact the school regarding the handling of medication.
8. Keep medication out of reach of young children.
9. For older children, a watch with a timer and a weekly pillbox may be helpful.
10. Some pharmacies will bubble pack medications dividing them into doses for usage at the appropriate times of day. This may be helpful when the child is at a camp or sleepover.

## How Can Parents Help?

### Learn About Epilepsy

When a child is diagnosed with epilepsy, parents sometimes react with a range of emotions including anger, fear, or grief. Parents may know very little about the condition and may feel confused and helpless. Learning about epilepsy can empower you and help you to make decisions regarding issues such as medical treatment, care, and safety.

Your local epilepsy association is an invaluable resource. Associations often have libraries with resource material on epilepsy and a staff committed to answering questions and providing helpful information. Associations may also be able to assist in linking you with counseling services, support groups, or with other parents experiencing similar changes.

### Encourage and Support Your Child

#### Feelings

Be straightforward about epilepsy with your child. A diagnosis of epilepsy may result in your child experiencing low self-esteem, anxiety, anger, or a feeling of powerlessness. In some cases, a child may even develop a fear of dying. Encouraging openness and discussing these reactions with your child may help to build your child's self-esteem. By assuring that your child knows that the seizures are not anyone's fault and that it is extremely rare for a child to die of epilepsy, parents may also help to alleviate some of the child's concerns.

There is an increased risk of depression in people with epilepsy. Depression may be a side effect of medication, or it may occur just before, just after, or between seizures. Depression may also be a reaction to the insensitivity of others or living with the constant fear of having a seizure.

Even if seizures are being effectively controlled by medication, children may be concerned about having a seizure in public. Children are often afraid of being different. They may be reluctant to take medication while with others.

Explaining to your child that other children may also have conditions (e.g. food allergies or asthma) that could require medication and/or lifestyle changes may help your child to understand.

Talking with your child about his or her feelings is important. If depression is ongoing, or is hindering your child's enjoyment of life, discuss this with your child's doctor.



### Developing Independence

Being too overprotective with your child can hinder your child's emotional development. If a child learns to be fearful or is continually being restricted, he or she may develop a dependency that will continue into adulthood. By encouraging a child to view seizures as a temporary inconvenience and, by encouraging participation in activities, you may help your child to develop the confidence to become an independent adult.

### Sharing with Others

Depending on the type and frequency of your child's seizures, it may be important to inform others about your child's condition.

Informing caregivers, teachers, or neighbors who are responsible for your child is advised, as it is essential that they know how to help should your child have a seizure.

People who are often with your child such as relatives, good friends, and their parents should also be told.

Sharing with others should be discussed with older children and adolescents and they should be allowed to be involved in decisions regarding who should be told and how.

As with any child, try not to use labels when talking about your child (e.g. epileptic). Your child has epilepsy but the condition is only one facet of your child's life.

## Tips on Sharing

If your child has uncontrolled seizures, then providing information to others may be important. You may want to:

- Describe any seizure triggers and/or indicators that a child may soon have a seizure.
- Describe a typical seizure including its usual length.
- Explain what behavior or symptoms would be considered a medical emergency and how to respond.
- Ask the individual to provide you with a detailed description of the seizure especially if the seizure does not take its regular form.

## Create a Safe Environment

### Your Home

Adapting the child's environment to make it safe and positive is important. There is an increased risk of injury in people with epilepsy.

Depending on the type of seizures experienced by your child, carpeting the floors and padding sharp corners on tables and other furniture may be helpful.

Safety in the child's bedroom could include avoiding top bunks, and placing a monitor in the child's room.

Discuss household safety with your child. For example, baths can be hazardous for anyone with epilepsy. Showers are safer than baths for those with epilepsy, but injuries can still occur.

Young children should be supervised while bathing. Older children should not lock bathroom doors and should never bath or shower when home alone. If your child experiences falls during a seizure, a shower seat with a safety strap should be considered.

Stoves and irons can also be hazardous for those with epilepsy. Encouraging your child to use a microwave oven if cooking while alone may be necessary.

Detailed lists of safety tips and information on safety devices are available from most epilepsy associations.

## Safety Aids and Tips

New safety aids are continually being developed. High Tech devices such as seizure-specific alarms triggered by seizure movements in bed, electronic tracking devices, and adapted showers that use infrared technology to shut off the water supply if a person falls are a few.

First aid procedures should be readily accessible in your home and at the child's school. Always provide information to babysitters, and others who will be caring for your child, so they know how to help should your child have a seizure.

## Seizure Triggers

Monitoring seizure triggers is an important part of creating a safe environment for your child. Assuring that your child takes seizure medication as prescribed, gets plenty of sleep, and manages stress levels may all help in controlling seizures. Eating regularly and maintaining a well-balanced and nutritious diet are also important. A poor and irregular diet can affect medication levels.



## Common Seizure Triggers in Children

While some people are not able to identify specific events or circumstances that affect seizures, others are able to recognize definite seizure triggers. It is useful to learn your child's seizure triggers so that seizures can be avoided. Some common seizure triggers in children include:

- Forgetting to take prescribed seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Illness or fever
- Low seizure medication levels
- Flickering lights of computers, television, videos, etc. in those with photosensitive epilepsy

## Seizure Triggers in Teenagers

Some seizure triggers in teenagers include:

- Forgetting to take prescribed seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstrual Cycle/ hormonal changes
- Illness or fever
- Low seizure medication levels
- Medications other than prescribed seizure medications
- Flickering lights of computers, televisions, videos, etc. in those with photosensitive epilepsy
- Excessive alcohol consumption and subsequent withdrawal
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, withdrawal from marijuana)

## First Aid for Seizures

### What To Do If Someone Has A Non-Convulsive Seizure

(Staring blankly, confused, not responding, movements are purposeless)

- 1 Stay with the person. Let the seizure take its course. Speak calmly and explain to others what is happening.
- 2 Move dangerous objects out of the way.
- 3 **DO NOT** restrain the person.
- 4 Gently guide the person away from danger or block access to hazards.
- 5 After the seizure, talk reassuringly to the person. Stay with the person until complete awareness returns.

## What To Do If Someone Has A Convulsive Seizure

(Characterized by stiffening, falling, jerking)

- 1 Stay calm. Let the seizure take its course.
- 2 Time the seizure.
- 3 Protect from injury. If necessary, ease the person to the floor. Move hard or sharp objects out of the way. Place something soft under the head.
- 4 Loosen anything tight around the neck. Check for medical identification.
- 5 **DO NOT** restrain the person.
- 6 **DO NOT** put anything in the mouth. The person will not swallow his or her tongue.
- 7 Gently roll the person onto his or her side as the convulsive seizure subsides to allow saliva or other fluids to drain away and keep the airway clear.
- 8 After the seizure, talk to the person reassuringly. Do not leave until the person is re-oriented. The person may need to rest or sleep.

## Epilepsy Associations

If you have concerns, questions, or ideas to share regarding epilepsy, contact your local epilepsy association. Epilepsy associations can provide you with, or direct you to, up-to-date medical and lifestyle information regarding your child's epilepsy. New information, research, and medical technology are continually improving the understanding of and treatment for epilepsy.

Consider becoming a member of your local epilepsy association. Epilepsy associations have much to offer including support groups, programs, educational forums, public awareness, newsletters, resource libraries, referrals, special events, and advocacy. Becoming a member will give you the opportunity to learn more about epilepsy, to volunteer, to network with others in your community, and to share information.

By volunteering with your local epilepsy association, you can make a difference in helping others to better understand epilepsy and in improving the quality of life of those with epilepsy. Most epilepsy associations require volunteers to assist in areas such as peer-support programs, educational activities, administrative duties, and fundraising events. Volunteers are also needed to serve on committees and Boards of Directors.

Your local epilepsy association can be of assistance to you but you can also be of assistance to others living with epilepsy. By getting involved, you can help to make a difference in your community. Contact your local epilepsy association or call:

1-866-EPILEPSY (374-5377) toll-free to connect directly with the association in your area

# Vision Issues with Children of ABI

Submitted by Dr. Cheryl Letheren



**More children are suffering from ABI than ever before. Children aged 10 to 19 years old account for 70% of ER visits for sports and recreational brain injuries each year and in the last decade; these ER visits have increased by 60%.**

There are many complaints that can occur with ABI in children that are directly or indirectly involved with the visual system. Insults to the cortex of the brain produced by ABI causes stress in the central and peripheral nervous systems. The effect on vision seems to be an interference with the sensory-motor feedback loop where vision matches with other systems like balance. Children may struggle with reading, school performance, have attention and memory issues and seem confused. They may complain of headaches, light sensitivity, movement of words on a page, motion sickness in the car and occasional or constant blurred or double vision. There may also be problems with balance, nausea or dizziness, spatial issues, clumsiness, and there may be problems with riding a bike or other tasks that were easy to accomplish before injury.

Parents may find the variety of symptoms to be overwhelming but there are ways to improve the situation. First, have your child assessed by their optometrist to assess for standard visual issues. If the symptoms continue, an optometrist who has additional training in neuro-optometric rehabilitation, behavioural vision and /or pediatrics should be consulted as well as physiotherapy or occupational therapy.

There are many practical changes that can be made and optometric vision therapy can be prescribed to help combat the variety of symptoms. Neuro-optometric rehabilitation is a therapy that utilizes therapeutic prisms, lenses, filters, and occlusion to help stimulate parts of the brain which are not functioning to their highest potential, due to interruptions caused by the brain injury.



# Roles of Service Providers:



## Coping With Brain Injury - A Team Approach

### Key Messages

- The health care team is dedicated to helping a person following brain injury and their family.
- Patients, families and friends are important members of the team, because they are the true experts. The health care team is an important source of information and support to the injured person and family. The team can recommend a treatment plan and help to learn skills to meet specific needs. Family, friends and the person with brain injury are important members of the health care team. Active participation in treatment and rehabilitation is essential to recovery. The involvement of other family members, caregivers, friends and coworkers also can help the person with brain injury successfully return home and to the community.

Service Provider	Description
Art Therapist	Art Therapists use visual media to help people who may struggle to communicate verbally or to express their feelings. They must ensure they provide a safe and secure environment. Therapy may be carried out in group or one-on-one settings and art therapists may work closely with other health care professionals
Behaviour Consultant	Conduct a functional assessment or functional analysis of any problem behaviour to determine why the problem occurs. Develop an intervention plan, based on the functional assessment or analysis results, that addresses the factors in the person's physical and social environments that contribute to the problem, and aims to change those factors

Brain Injury Coordinators and Case Managers	These are nurses and therapists who help coordinate care of patients with brain injury and support and educate their families about the injury and recovery process
Dietician	Makes sure nutritional needs are met. They provide nutrition teaching in the hospital and will also help make food choices at home
Individual Support Worker	Implements programming suggestions with child in various environments
Music Therapist	Uses music interventions to accomplish individualized goals within a therapeutic relationship
Neurologist	Performs a series of tests to assess whether or not there is any disruption in neurological functioning. Deals with the nervous system and its disorders.
Neuropsychologist	Looks at how a brain injury may have affected the child's thinking skills and behaviour. Can identify what the child's cognitive strengths are and what the child is having difficulties with. Recommendations on how to deal with the child's cognitive and behavioural difficulties.
Nurse Practitioner	A Nurse Practitioner (NP) is an advanced practice nurse who works with the physician team. They are able to assess and treat, including ordering tests and investigations and prescribing medications. The NP works closely with the nurses and therapists and are often the eyes and ears for the physicians.
Nurses	Nurses have training and expertise in brain injury care, rehabilitation and discharge planning. The nurse monitors a person's vital signs and neurological status and performs assessments and interventions. The nurse also assists with daily care such as taking medications, bathing, dressing and using the toilet. Through rehabilitation, they help a person do the things learned in therapy, to increase their independence while in the hospital and prepare for discharge and reintegration into the community.

Nutritionist	Nutritionists specialize in the relationship between food and the human body. They promote individuals and public health by helping people understand the connection between how they feel and what they eat. While nutritionists fill a variety of counselling, teaching and managerial roles in many different settings, they share the common goal of improving and maintaining health through diets based on the science of nutrition.
Occupational Therapists	They are professionals who evaluate and treat thinking and perception problems, and help an injured person maintain or learn independent living skills (for example: eating, dressing, managing money and safety awareness)



Pediatrician	Specializes in the medical care of children
Physiatrist	These are the physicians who specialize in physical medicine and rehabilitation, including brain injury rehabilitation.
Physiotherapists	They are professionals who evaluate and treat changes in physical abilities. Some activities may include strengthening, conditioning, walking and balance training
Primary Care Physician	The doctor is responsible for medical care and treatment. The attending doctor may have residents, fellows, and clerks working with him or her, making up your team of doctors.
Psychologists and Psychiatrists	There are professionals with training and expertise in evaluating and treating, behavioural and emotional changes caused by a brain injury
Recreation Therapists	These are the professionals who help a person with brain injury explore and participate in leisure activities. They help to find new leisure opportunities and learn new ways to do previously enjoyed activities
Social Workers	These are professionals in the hospital and outpatient settings who help guide the adjustment to acquired brain injury. They provide information on discharge planning, assessment of financial resources, and community resource referrals. They may also assist in addressing stress management and the development of effective coping and adjustment strategies.
Specialized Tutors	To make the most of the tutoring, it is essential for the tutor to have some school contract to discuss the school curriculum with the class teacher or the year coordinator. Tutors should work together with Brain Injury staff to develop a consistent approach to managing homework, study and assignments. Usually, it is better that core class work be made the priority. One role of a tutor is to help the student go over class work and complete homework. Revision is very important to assist the student in understanding the curriculum. It is important that the tutor doesn't complete homework for the student but instead assisting them to organize their thoughts so they can do it themselves.

Speech Language Pathologists or Speech Therapists	These are professionals who evaluate and treat communication and swallowing problems. They focus on improving social skills as well, and looks at cognition as it relates to communication
The Survivor, Family and Friends	This is who make decisions about a person's care and rehabilitation including their goals and plans. Family and friends can speak for the survivor if they are not able to speak for themselves about their goals and plans, and feelings and beliefs. Family and friends can give emotional support and can help meet the survivor's needs. The healthcare team meets regularly to discuss healing, progress and make ongoing plans. In addition to regular, informal updates, a family conference can be scheduled to bring everyone together. If you have concerns, speak with any member of the team.
Transition Coordinator or Home Care Coordinator	Nurses who provide information about home care services and other options for supported living. Help may be available for activities for daily living, to assist with rehabilitation and goals to maintain or increase independence and for surveillance. A home care therapist may make a home visit prior to discharge from hospital to identify and organize any equipment or changes in the home that will make it safer and easier.









# Alternative Medicines

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**People often turn to alternative medicines as an answer to issues created by a brain injury.**

Modern medicine often has difficulties answering questions relating to the brain. Emerson M. Pugh quoted in *The Biological Origin of Human Values*:

“If the human brain were so simple that we could understand it, we would be so simple that we couldn’t.”

Many of the rehabilitation techniques, medications and therapies that are offered through conventional medicine do not work for all individuals with brain injuries. Some conventionally used medications can also have quite detrimental side effects, causing the individual discomfort. This can often see people with brain injuries turn to alternative treatments in search of a solution and a better quality of life.

## What is Alternative Medicine?

Alternative Medicine, also referred to as “Complementary and Alternative Medicine” (CAM) or Alternative Therapies, is exactly as it sounds: an alternative to conventional medicine. While conventional medicine is supported by scientists and pharmaceutical companies, alternative medicine is not endorsed in the same way. Most Alternative Therapies have existed for thousands of years, and many have been passed down from various cultural groups the world over.

Many treatments that were once classed as/or considered alternative have now become ‘mainstream’. Putting mouldy bread on wounds was once just a housewife’s remedy until the antibiotic penicillin was identified, cultured, and produced in a pure form. Vitamins were found to cure scurvy and other previously unexplained illnesses, and the acidophilus cultures commonly put into supermarket yoghurt are now recognised as a major component for intestinal health.

People who seek Alternative Medicine are generally those who are opposed to synthetic pharmaceuticals, and who prefer a more natural approach to health and healing. Examples of Alternative Therapies can include, but are not limited to: Meditation, hypnosis, spiritual healing, massage, chiropractic, herbal supplements, homeopathy, naturopathy and acupuncture. Alternative Therapies can also include widely accepted practices such as nutrition, exercise, and relaxation.

Alternative medicine can often be misunderstood on initial presentation. The statement “Tai Chi (also spelt Dai Qi) cures illness” is controversial and unbelievable initially. When you look, however, at the fact that Tai Chi is a very effective way to improve balance, coordination, strength, flexibility and cardio-vascular fitness - you can understand how it may now affect illness. Having a healthy body improves the immune system which in turn fights off illness - so Tai Chi then affects illness in an holistic way.

If you are unable to find research on a particular practice - proceed with caution. Research may not have been done on the therapy because of insufficient research money, a small group of patients that would benefit, or a lack of people who know how to provide the therapy. The research may also be lacking because the therapy is brand new and there simply has not been time to accumulate reasonable evidence. In both situations, it is important to assess the potential risks of the therapy.

The main benefit of Alternative Medicine/ Therapies is that the likelihood of potential side effects is rare. Massage, "green" or nature therapy, and dietary supplements are examples of effective Alternative Therapies for use with children presenting with ADHD; all of which are free from side-effects such as those potentially resulting from conventional medicine i.e. cardiovascular and psychiatric side effects, schizophrenia, insomnia, and even cancer in extreme cases.

## Potential Pitfalls

It is important to understand and research the particular alternative therapy you are looking into. You need to see if it suits your specific needs, and perhaps try to understand why you may be having difficulties. If, for example, you have high stress, but you dislike people touching you - perhaps think twice about massage. The stress of having someone touch you may exacerbate any difficulties you're having, rather than help them. An alternative therapy such as meditation may be more assistive in this case.

Another risk factor to consider is that alternative medicines are not always regulated by the same legislative controls that mainstream medications must go through. There may also not be minimum standards of qualification required for the practitioners. This may result in a physical therapy doing more harm than good, a potentially severe reaction to an herbal treatment, or no reaction to treatment at all. Even the smallest variation in product composition can alter its effectiveness.

The World Health Organisation reports that although 25% of modern medicines are made from plants first used traditionally, there have been many instances of deaths, heart attacks, strokes or other severe internal organ damage due to an overdose of an herbal medication or an incorrect species of plant being used to make the medication.

As always, ensure you research any therapy/substance before you use it. Try to make sure your practitioner is qualified in the area, and where possible seek practitioners recommended by others.

## Contraindications

It is important to advise the therapist of any existing contraindications (existing medical conditions that may affect the therapy). Some therapies may be harmful if performed under certain circumstances (e.g. massage when you have high blood pressure; ingesting certain herbs when you're pregnant). This is why it is also important to choose a therapist who is accredited in their field - as they will understand what the particular contraindications to their therapy are.

Some alternative medicines may interact quite badly with prescription medicines. A good example of this is St John's Wort (*hypericum perforatum*), a common and widely used herbal antidepressant. Effective in assisting with stress and with minor depression, but not moderate or severe depression, *hypericum* has severe interactions with a wide range of prescription medications, including antidepressants and the contraceptive pill, and its usage should be discussed with your GP.

## Evaluating Alternative Medicines

Today many people use alternative medicine for a wide variety of disorders. Medical science is still learning much about how drugs work upon the body, and about herbal and other alternative therapies. Many of these therapies may be of value without yet having been adequately or appropriately researched. It is important, however, that anybody considering an alternative therapy, or an uncommon application of a mainstream therapy, be informed about the risks and any possible costs if it doesn't work.

Do your own research on the topic (Google Scholar can be quite useful here) and look for published research (in literary journals), rather than generic webpages. See to evaluate them using evidence based practice.

## Evidence Based Practices

One method used to help evaluate alternative medical interventions is called Evidence Based Medicine. This approach asks four questions about the data supporting each medicine practice, procedure, or therapy to help decide if they are worth trying. The following list is taken from the Brain Injury Resource Foundation:

1. Validity (believability/objectivity) - Is the supporting evidence unbiased, performed by knowledgeable researchers and published in a well respected journal? For example, if the owner of a bee farm says bee stings will improve attention span, and publishes these claims on the Internet, would they be highly valid?
2. Importance (significant difference/benefit) - Did the results of the treatment produce a benefit that make it worth the risks? Were the "statistics" truthful and significant? For example, if the bee sting medicine was "studied" in only two patients, caused an allergic reactions in one, improved attention span for only 30 minutes, and most of that time the person was in pain from the bee sting, can it really be considered beneficial?
3. Applicability (to put into effect) - Is the treatment performed easily, available to most people, medically possible, and cost effective? For example, if the bee sting medicine costs \$1000 a day, can be kept only in the freezer, can be obtained only from one bee farmer in Alaska, and has to be injected by another person, is it applicable?
4. Purpose (does it help or change something that makes life better) - Does it do what it should, and does it work in all populations? For example, if the bee sting medicine improved attention in one female child without brain injury, will it work in male adults with brain injury? Does a 30 minute improvement once a day mean insurance coverage should support this treatment?
5. If a therapy or medicine does not meet any of these criteria, then ask whether the potential benefit of this treatment is enough to justify the time, money, emotional investment and potential medical complications that could occur.

## In Conclusion...

Claims of a miraculous cure should also be viewed with caution. Seemingly miraculous cures have been known to occur, however usually as a result of enormous amounts of time, effort, money, or unique circumstances which enable this effect to be achieved.

Some interventions do have an effect and are medically safe but may be poor value for money or extremely time-intensive. Families may opt to pursue these if they have the time and money. Families need to consider the effect on their future security, other family members. It is important to understand the emotional impact if the desired results of the therapy are not achieved, as outcomes may vary between individuals.

It is very difficult for science to evaluate quality of life. Even when there is a limited medical benefit from a therapy there may be a very real benefit to the patient from the sense of purpose, satisfaction, or hope that the treatment can provide. So proceed with caution, but don't discredit something before you think about what it can do for you and your family.



## Pets as Therapy - Fact Sheet

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**Man's best friend, the dog, has been portrayed in our culture as a loyal companion.**

The inclusion of pets into hospital and rehabilitation environments has long been considered very therapeutic, and pets continue to be an important part of life long after rehabilitation has ended. This is true for people with Acquired Brain Injuries, and the wider community.

In addition to filling lonely hours with companionship, pets can be trained, much like the more familiar Seeing Eye dogs, to perform tasks and assist persons with disabilities in many different ways. The responsibility for pet care can enhance cognitive functioning in ways that are more subtle and enjoyable than traditional therapies. Fun activities often stimulate individuals with low motivation in ways that are not often achieved by sitting in front of a television set for hours on end.

Pets are very good companions and help people feel less lonely. They also respond with feedback which can negate inappropriate behaviours, and interest in a pet may redirect egocentricity that may arise from frontal lobe deficits. Selecting a pet can be turned into a cognitive exercise of planning. The choice of a pet should be fun, not fraught with discord. It's important to consider all options e.g. a sophisticated set up of aquariums with pumps and filters may be too complex for some.

Pets must be cared for, otherwise they fail to thrive. The needs of the pet can be motivating for a person who may otherwise resist or refuse to actively engage with others. Naturally a responsible adult should intervene if the pet's health or well-being is adversely affected. When limitations arising from the Acquired Brain Injury are barriers to independently caring for a pet of choice, talk with the individual about strategies that will enable more independence and determine what duties will be managed by whom so responsibilities can be monitored.

Almost everyone loves animals. This often enhances social skills building for individuals when encountering others in the park, neighbourhoods and other places people congregate with pets. Have you ever been able to pass without noticing or striking up a conversation with someone sitting on a park bench with a colourful, exotic bird perched on his or her shoulder? Pets are great conversation pieces.

Individuals with severe brain injury and other impairing conditions often have little control over their lives. Owning a pet can provide an opportunity for controlling at least one facet of their lives - their pet! Pets always have time for sharing with their owners and their loyalty is indisputable.

Pet therapy is a well-established routine in many hospitals, nursing homes and rehabilitation centres. Anecdotal accounts tell of the benefits of pets being in the presence of people in all stages of recovery, rehabilitation and even end-stage illnesses. The comforting and calming affect of stroking a furry animal often elicits more relaxing facial expressions and/or postures in persons even thought to be in minimally-responsive states. Nonverbal individuals generally respond with contented smiles when pets are introduced into their environment. Almost all individuals with disabilities can take some responsibility for the care of an animal, even if it's no more than a daily stroking or play session.

Dogs are frequently trained to assist individuals with brain injury, particularly those with mobility impairments. Custom-styled saddlebags can be placed on the dog and used for carrying personal items, wallet, daily journal and other items needed by those using wheelchairs and/or other assisting devices that increase mobility.

Henry David Thoreau writes, "It often happens that a man is more humanely related to a cat or dog than to any human being." Pets are indeed wonderful companions and can frequently impact positively even on those for whom other therapies, exercises and/or future promise for continuing recovery hold little interest.

# Music Therapy - Fact Sheet

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**Music therapy is just one of many therapies available for people who are in post-coma unresponsiveness or a minimally responsive state. It can be helpful during rehabilitation, leisure time and as a means to communicate with a loved one.**

## The Benefits of Music Therapy

Music is a social medium, a way of bringing people together and sharing intimate experiences through activities such as singing, dancing and playing music. The use of music in leisure activities is also emerging as a strong therapeutic force in promoting health through stress management and relaxation.

For a person with restricted movement, compromised cognitive capacity and limited means of communication, music is quite simply one of the most accessible resources, if there is some hearing ability. People with complex needs may have limited opportunities for participating with others in shared leisure pursuits. Families and carers may feel they are left with no meaningful way to communicate and share time with their loved one after a brain injury. Music can be a way to interact and just be with a person who is minimally responsive.

However, we need to manage the auditory environment for people who are in low awareness and minimally responsive states. Music is a form of stimulation in their environment, so they should be given the chance to lead an activity through expression of choice or preference.

## How to Use Music

There are some really practical ways to use music activities as leisure which can be shared between a person with complex needs and their family member, friend or paid carer. Firstly, it is good to gain an understanding of the patient's relationship with music and their musical preferences before the brain injury occurred. For example, did they listen to live or recorded music? Did they take an active role in playing an instrument? Was music used as a means of emotional expression? Using familiar music will optimise recognition of the music which is being played. Being familiar with how the injured person used music previously will assist in awareness of how it might be appropriate to use music now.

Try incorporating music into leisure activities. Play and explore different preferred music with the person in a minimally responsive state. It can help to establish flexible and fun ways of sharing meaningful connections, hope and love.

## Suggested Strategies for Using Music

- Use concrete visual cues such as CD players, pictures of instruments or photos of a musician to orient the patient to the activity before playing the music.
- Listen to a familiar CD together in a quiet location where distractions are minimised.
- Let the person choose to listen to music with a single 'yes/no' response if they can. If they are capable of choosing a type of music, keep choices to a minimum - e.g. a forced choice of two songs/artists. Use brief musical cues such as humming short fragments of each song if this helps.
- Play music which has been special between you and your relative, and reminisce about special memories out loud as the music plays or afterwards.
- Use background music with personal meaning for gentle hand massage or other physical contact.
- Use music when the injured person is alert, then allow them periods of rest - musical activities should last no more than 15-20 minutes before a period of no stimulation.
- Watch for emotional responses which can be expected; consult professional staff if these responses are unusual. Music can evoke tears, smiles and a range of other emotions for all of us, and this is not necessarily a negative experience for the audience.



## Art Therapy

Art therapy combines the creative process and psychotherapy, facilitating self-exploration and understanding. Using imagery, colour and shape as part of this creative therapeutic process, thoughts and feelings can be expressed that would otherwise be difficult to articulate.

Art helps to express these feelings that can often be difficult to share with words alone. Art therapy can increase coping skills, enhance cognitive function, resolve inner conflicts, develop and maintain a peaceful state of mind and integrate life experiences that have been previously cut off from awareness or personal acceptance.

Art therapy is effective for people of any age. An art therapist works with individuals, couples, families or groups in settings such as counselling agencies, schools, treatment centres, rehabilitation facilities, hospitals, correctional institutes and elder care locations.



## Why Use Art Therapy?

- As an art-based therapeutic approach, there are many potential benefits that may derive from the use of Art Therapy. Some of the specific advantages are:
- Does not rely on language or verbal skill
- May provide an accessible modality for persons with certain disabilities
- Offers opportunities to access experiences in a controlled way
- Focuses concentration on a single activity, shutting out intrusive thoughts
- Encourages creative thinking and risk-taking in a safe environment
- Endorses the idea that creativity is inherently therapeutic
- May be less intrusive and yet is capable of releasing strong emotion safely
- Creating art can be fun

## What Should I Know About My Art Therapist?

Art Therapists use a variety of approaches depending on their academic background, their client base, and their therapeutic orientation. Art Therapy as a therapeutic modality is not limited to a single psychological model nor a school of thought, but practitioners may utilize a variety of approaches including Psychodynamic, Cognitive-Behavioral, Humanistic, Educational or other therapeutic approaches.

Ask an Art Therapist the same questions you would ask any other health professional.

### Common questions are:

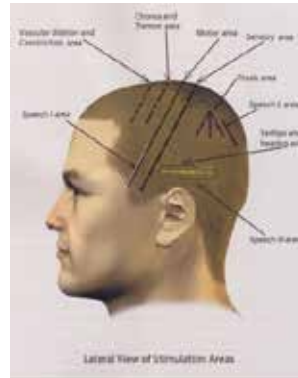
- What is your educational background?
- Where did you receive your Art Therapy training?
- What is your professional/internship experience?
- How long have you been practicing as an Art Therapist?
- What are your fees?
- What therapeutic approach do you use?
- What are your policies on missed appointments?
- What can I expect in a session?
- What professional organizations do you belong to?
- What is your status Registered, Professional, Graduate, Student?

# What is Acupuncture?

**Acupuncture involves inserting thin, flexible, non-hypodermic, usually steel needles, inserted into specific areas in the body.**

Different sizes of needles are used depending on where they are going in the body. A small diameter and length would be used on your face as compared to a longer and greater diameter needle into the thigh muscle. Most needles are inserted into areas where there is a high concentration of nerves. They are inserted quickly and with usually with minimal to no pain. There is nothing on the needle to be injected into the body .

## Scalp acupuncture



**Auricular therapy: the whole body is mapped on the ear.**



## Who Can Provide Acupuncture in Ontario?

Acupuncture is a “regulated treatment procedure” and service that 11 professions can provide legally in Ontario, each within their scope of practice: Chiropractors, Chiropractors, Dentists, Medical Doctors, Naturopathic Doctors, Nurses, Occupational Therapists, Physiotherapists, Registered Acupuncturists, Registered Massage Therapists, and Traditional Chinese Medicine Practitioners. Practitioners with acupuncture in their scope of practice are required to meet the requirements of their own professional regulatory college to practice acupuncture.

## How Does Acupuncture Work?

Acupuncture has a variety of therapeutic effects on the body. It is proposed that acupuncture primarily produces its effects through regulating the nervous system. Regulation of the nervous system aids the activity of pain-killing biochemicals such as endorphins and immune system cells at specific sites in the body. In addition, studies have shown that acupuncture may alter brain chemistry by changing the release of neurotransmitters and neuro-hormones. These affect the parts of the central nervous system related to sensation and involuntary body functions, such as immune reactions and processes that regulate a person’s blood pressure, blood flow, and body temperature.

The ancient Chinese believed that there is a universal life energy called Chi or Qi present in every living creature. This energy is said to circulate throughout the body along specific pathways that are called meridians. As long as this energy flows freely throughout the meridians, health is maintained, but once the flow of energy is blocked, the system is disrupted and pain and illness occur. Imagine rivers that flood and cause disasters or an electrical grid short-circuiting that causes blackouts. Acupuncture works to “re-program” and restore normal functions by stimulating certain points on the meridians in order to free up the Chi energy.

## Different Types of Acupuncture

Body acupuncture involves inserting needles into different areas of the body. The body is traditionally divided into 12 main meridians which cover the entire body. Body acupuncture has been around for 2500 years. Needles may be inserted at the area of your complaint points far away from your complaint may be used.

Scalp acupuncture is a technique that uses traditional needling techniques with the needles inserted over the scalp. Scalp acupuncture is a very modern approach to acupuncture, developing in the last 40 years. The needles are inserted along the scalp overlying the body parts that relate to specific areas in the brain, that the therapist wishes to activate. The needles are then rotated rapidly by the therapist to achieve the most stimulation of the area. The techniques have been shown to have great success with patients with stroke, paralysis, post traumatic stress diseases, post concussion symptoms and other central nervous system disorders.

Ear acupuncture, also known as auricular therapy involves inserting small needles into the ear. The body is represented in the ear in an upside down pattern, where the eye is represented at the ear lobe where traditionally ears are pierced. Auricular therapy is widely used for many conditions, including addiction treatment, mood disorders, obesity, pain, and other conditions. Auricular therapy has a long history of use in China. It was mentioned in the most famous of ancient Chinese medical textbooks, "The Yellow Emperor's Classic of Internal Medicine."

### Things to consider when choosing some-one to administer your acupuncture

- Are the facilities clean?
- Does the therapist wash his/her hands prior to treatment?
- Are pre-sterilized; pre-packaged needles used?
- Can your therapist give you an explanation for each needle that is inserted?
- Is your therapist registered with their respective College?

Acupuncture is an ancient form of treatment with exciting advances happening. More research is showing that acupuncture can have a beneficial affect for a wide range of symptoms and problems including many of the post-concussive symptoms.

*Julia Armstrong is a registered physiotherapist practicing at St. Marys Community Rehabilitation. She completed her AFCI examination in Acupuncture Certification and completed Level 1 with Vital Principles Institute for auricular therapy. She has completed courses in scalp acupuncture. She is rostered with the Physiotherapy College for acupuncture.*

# Hopetherapy

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**Psychology interventions in rehabilitation have traditionally focused on reducing the impact of barriers (i.e. cognitive impairment, chronic pain and depression) on the rehabilitation process. Barrier reduction is effective in enhancing emotional adjustment and functional activities and abilities of daily living. However, this approach focuses on deficits and is reactionary once potential barriers are identified.**

There is growing evidence in the literature for taking a proactive approach. Facilitating positive outcomes by focusing on strengths and fostering positive psychological health has great benefit. Dr. Martin Seligman, described as the father of the Positive Psychology movement, noted the importance of identifying, amplifying, and concentrating on people's positive human traits which aim to both alleviate deficits and increase well-being. Researchers at this cutting-edge of service delivery have shown us that building on an individual's strengths and facilitating positive coping mechanisms at the outset of rehabilitation result in better outcomes than reacting to problems after they arise.

There are a number of positive psychological variables (i.e. courage, faith and honesty) termed facilitators that can play an important role in facilitation of good outcome from rehabilitation. The research points toward hope as being the core element among these facilitators.

## Making Hope Happen

We know the importance of hope – but can it be taught or enhanced? Yes!! The repertoire of hope interventions is rapidly growing. Research has demonstrated that hope can be fostered by using specific strategies. Professionals are in a strategic position to make a difference in clients' hope and clients' lives. At Brainworks we are applying hope theory. By drawing upon this pioneering research, we have assembled a number of tools, strategies and instructional materials into a comprehensive therapeutic platform we call **hopetherapy™**. We are extremely excited to be able to offer this service!!

## Mindfulness Therapy



Originally an ancient Buddhist meditation technique, in recent years mindfulness has evolved into a range of secular therapies and courses, most of them focused on being aware of the present moment and simply noticing feelings and thoughts as they come and go.

It's been accepted as a useful therapy for anxiety and depression for around a decade, and mindfulness websites like [GetSomeHeadSpace.com](http://GetSomeHeadSpace.com) are attracting millions of subscribers. It's being explored by schools, pro sports teams and military units to enhance performance, and is showing promise as a way of helping sufferers of chronic pain, addiction and tinnitus, too. There is even some evidence that mindfulness can help with the symptoms of certain physical conditions, such as irritable bowel syndrome, cancer, and HIV.

Yet until recently little was known about how a few hours of quiet reflection each week could lead to such an intriguing range of mental and physical effects. Now, as the popularity of mindfulness grows, brain imaging techniques are revealing that this ancient practice can profoundly change the way different regions of the brain communicate with each other – and therefore how we think – permanently.

There's still much to discover, especially in terms of what is happening when the brain comprehends the present moment, and what other effects mindfulness might have on people. Research on the technique is still in its infancy, and the imprecision of brain imaging means researchers have to make assumptions about what different regions of the brain are doing.

## Naturopathic Medicine and Brain Injury Support

Naturopathic medicine is a distinct primary health care system that uses modern scientific knowledge with traditional and natural forms of medicine. The naturopathic philosophy is to stimulate the healing power of the body and treat the underlying cause of disease. Symptoms of disease are seen as warning signals of improper functioning. Naturopathic Medicine emphasizes disease prevention through lifestyle modification.

Naturopathic doctors can treat both acute and chronic conditions, including brain and spinal cord injuries. Treatments are chosen based on the individual patient – their neurological function, physiological, structural, psychological, social, environment and lifestyle needs are assessed and treated accordingly. In addition to diet and lifestyle changes, natural therapies that have much success in treating brain injuries include: botanical medicine, clinical nutrition, hydrotherapy, homeopathy, naturopathic manipulation and traditional Chinese medicine including acupuncture. One of the main goals in treating brain injuries is to reduce inflammation at the neurological level and support superior nutrition for optimal cognitive functioning.

In Canada, naturopathic medicine is regulated and a qualified Naturopathic Doctor may be found through the provincial associations. Additional Information can be found at [www.cand.ca](http://www.cand.ca) (The Canadian Association of Naturopathic Doctors).











## Nutrition for Children with Brain injury



All children are unique in their particular needs; however, after sustaining a brain injury they can often struggle with cognitive, behavioral, emotional and and/or physical challenges. These challenges often impact their daily life activities, including their eating behavior and nutritional consumption. Maintaining proper nutrition is essential for growth and development as a child's nutritional needs are dynamic; changing as they grow from one stage to the next. It is noted that a qualified medical professional should be consulted if any health concerns or nutritional challenges persist.

### **Some common nutritional challenges that can occur after a brain injury include:**

- Appetite, texture and taste changes
- Oral feeding and swallowing difficulties
- Selective eating behavior, picky eating and food jags
- Fear of eating
- Disruptive mealtime behavior
- Gastrointestinal disturbance (bowel changes, nausea, abdominal pain)

### **These nutritional challenges can facilitate the following consequences:**

- Increased mealtime stress and anxiety
- Increased behavioral challenges
- Cognitive/physical fatigue and decreased mood
- Impaired attention, concentration and memory
- Weight gain/loss and impaired growth complications
- Low nutrient intake with increased risk of nutritional deficiencies
- Delayed healing



**Six tips to improve nutritional consumption while experiencing cognitive, behavioural, emotional and/or physical challenges:**

1. Involve your children in the selection of recipes and grocery shopping when possible, as this will encourage their interest in the selection and planning of meals, increasing their association with the food that they eat.
2. Create a calm and supportive environment free from distractions such as television and encourage a family atmosphere when eating.
3. If your child consistently refuses specific healthy foods or food groups because of appearance, taste, texture, smell or even temperature, try to minimize all stress and anxiety related to mealtime by providing small portions of the foods your child likes to eat in combination with the healthier options. Attempt to transition away from any unhealthy food products but do not force foods that are not tolerated. Try to remain neutral on whether your child likes or dislikes a new food as even praise can heighten a child's anxiety around food.
4. If your child experiences a poor appetite, try to develop a feeding schedule that offers meals and snacks approximately three hours apart at the same time each day with no other snack foods in between. Provide water between meals, but do not allow unscheduled snacking between the regular scheduled meals. Encourage eating until full through providing smaller portions more frequently while limiting the duration of time at the table if playing with food persists.
5. If excess body weight is a concern, help your child maintain their weight as they grow taller. Maintain healthy food products within the home as cooking healthier meals and reducing the frequency of eating restaurant meals will promote an environment to support a natural progression toward healthier eating.
6. If there is a fear of consuming solid foods, start slow by offering liquids followed by a gradual progression to purees, soft foods and then regular foods as eaten by the family.

Consistent nutritional consumption throughout the day is important for children as it promotes a healthy and balanced nutritional routine. Three to four food groups should be encouraged at each meal with a properly balanced meal or snack that is high in nutrients every three hours. A proper nutritional routine can improve mood, behavior, cognition and energy.

<b>Nutrient</b>	<b>Why It's Important</b>	<b>Food sources</b>
Protein	Builds muscle, maintains organs and supports immune system.	Lean meats, poultry, fish, eggs, nuts/seeds, beans/legumes and cheese.
Carbohydrate	The body's most important and available source of energy.	Grains, rice, pasta, quinoa, bread, cereals, fruits, starchy vegetables and dairy products.
Healthy Fats	Builds nerve tissue (including the brain) and hormones. The body also stores fats for energy and transporting important vitamins.	Avocados, olive and canola oil, non-hydrogenated margarine, oil-based salad dressings, fatty fish and nuts/seeds such as walnuts, almonds, flax seeds, pumpkin seeds.
Calcium	Building block for strong healthy bones. Also supports muscle/ nerve function and the proper release of hormones and enzymes.	Milk, yogurt, cheese, cottage cheese, almonds, broccoli, bok choy, collard greens and orange juice.
Iron	Supports hemoglobin (part of the red blood cell) that carries and delivers oxygen throughout the body.	Red meat, beans, legumes, iron-fortified breakfast cereals, leafy green vegetables, dried fruits, enriched grains, blackstrap molasses, eggs, tofu, salmon and tuna.
Fiber	Plant source fiber promotes a healthy digestive system and prevents constipation.	Fruits, vegetables, whole grain breads and cereals, beans, legumes and almonds.
Fluid	Every function in the body is dependent on proper hydration including the brain and nervous system.	Consistently consume water throughout the day. Add lemon, lime or frozen fruits to flavor. Fresh fruits and vegetables are also good sources of water.



Certain foods and nutrients can assist with improving symptoms following a brain injury, and have been shown to provide protection for the brain.

<b>Special Brain Foods</b>	<b>Why It's Important</b>	<b>Food Sources</b>
Omega 3 Fatty Acids (DHA)	Essential to good brain health. DHA is found in high levels of brain tissue and the retina of the eye.	Fatty fish, algal oils, Omega 3 Fish Oils (DHA/EPA)
Antioxidants and Flavonoids	Helps protect the brain and improve memory.	Nuts, olive oil, brightly colored vegetables and leafy greens (broccoli, tomatoes, red bell peppers, kale, spinach, etc.) and colorful fruits (berries, red grapes, pink grapefruit, oranges, pomegranate, etc.).
Choline (B Vitamin)	Increases alertness, memory and reduces stress on the brain while helping minimize fatigue.	Eggs, collard greens, broccoli, cauliflower, fish, shrimp, chicken
Curcumin (Turmeric)	Beneficial for cognition, reduces stress on the brain and is protective.	Naturally occurring compound found in turmeric spice (yellow curry spice).

Some foods have been shown to worsen the symptoms of a brain injury and impede rehabilitation:

<b>Foods to Avoid</b>	<b>Harmful Effects</b>	<b>Food Sources</b>
Refined Sugar	High levels of refined sugar can be harmful to brain structure/ function and has been linked to memory impairments; as well as, worsening hyperactivity and difficulties with concentrating.	Pop, cookies, cake, doughnuts, syrups, fruit punch drinks and candy with the following ingredients on the food label (corn sweetener, high-fructose corn syrup, fruit juice concentrates and malt sugar).
Saturated Fat	Leads to increased stress on the brain and can negatively influence cognitive function.	Fatty beef, poultry with skin on, lard, high fat dairy products, and bakery pies, pastries and doughnuts.

# Exercise After Brain Injury for Children

Submitted by Stephanie Hutton



**Exercise can become very important to your child's recovery after brain injury. Research shows that individuals with TBI who exercised had fewer physical, emotional and cognitive complaints and symptoms, such as sleep problems, irritability, forgetting, and being disorganized.**

However each brain injury is as different as the child himself, therefore careful thought must be placed around getting your child active after their injury. Consider the following:

- Start slowly. Have your child do 5-10 minutes of movement and then stop for the day. Do it again the next day slowly adding on just a minute at a time if the movement isn't increasing symptoms.
- Track your child's progress. There may be times your child is discouraged by limitations, a clear record can illustrate how far they have come.
- Focus on what your child *can* do after the injury. If standing is prohibited work with chair or floor exercise or seek out a community pool. Consider starting with breath work, empower your child by showing them how to control their breathing. Your child's physical therapist is a great resource for specific moves for your child. \*Use the resource guide in this book to find experts in brain injury and activity.
- Find a place with as little distraction as possible. Your child may be tempted to push too far or become frustrated in environments with other unrestricted children running wild. Talk to your health club or community pool manager when lowest attendance is or to request some private time.
- Make it fun! Exercise can seem like a snooze for a child who is already restricted, make it into a game and it can become valuable bonding time as well as great for the body. Example: have child hold a ball with both hands, moving it when direction is announced; up, down, right, left; switching up speed and direction
- Role model active behavior. Getting active yourself with your child will be beneficial to both of your brains.
- Most importantly, know your child. Be on the lookout signs of fatigue beyond physical exertion and be prepared to wrap up the session in a positive way at any time.

# Quick in Home Caregivers 10 Minute Workout Plan

Submitted by Stephanie Hutton

Think you have no time for exercise? Here is a 10 minute routine that you can do in your home when you have time. Do each exercise for 10 to 12 repetitions, rotating through the list 3 times total a few times a week.

**Chair Dips** Sit on the edge of a sturdy chair, with hands next to hips. Slide your bottom off the edge and bend elbows to 90 degrees. Be sure to keep your back close to the chair, then push back up.

**Chair Squats** Stand in front of chair, feet hip-distance apart, toes forward. Lean chest slightly forward. Bend knees, tap (don't sit!) bottom on chair, then stand up. Keep your weight in your heels and keep knees over toes.

**Butterfly Abs** Lie on back and place soles of feet together; relax knees out to the side. Place hands behind head, with elbows out. Tightening abs, lift chest and shoulders up, then release back down.

**Oblique Crunches** Lie on back, with knees bent. Cross left ankle over opposite knee. Place right hand behind head and lift right shoulder toward left knee. Release down, after 10 - 12 switch sides.

**Modified Push-Ups** Get down on all fours, knees together. Walk hands out and lift feet; move hands slightly wider than chest. Head, neck, back and butt should be in alignment. Keeping your abs tight, bend elbows and lower chest toward the floor. Press back up.

**Standing Hip Extension** Stand with feet hip-distance apart. Shift weight to right foot, and extend left leg behind; lift and lower left foot, squeezing your butt. Use a chair for balance. Do 12 to 15 reps, then switch.

**Step-Ups** Place entire right foot on a stair or a sturdy platform, and step up with left leg following. Step down with left leg, reaching back about 12 inches; follow with right. Do 12 times, keeping chest lifted, then switch sides and repeat. As you get stronger, try this move with weights.

**\*Always consult a physician before beginning any exercise regime.**

For addition in the self care article, under the bullet point about exercise, maybe something like:

*Fit physical activity in when you can wherever you are. Go up and down your stairs 10 xs a few times a day or march in place while heating up food or while waiting on hold on the phone. Do one of those for 2 minutes five times a day and you will have worked over an hour of exercise into your week.*







## Challenging Behaviours and Strategies to Try

Submitted by Frank Nitra B.A. (Psych), Board Certified Assistant Behaviour Analyst

There are some common challenges experienced by children with brain injuries. Following is a list of some behaviours, an example of what you might see, and some strategies to prevent and manage the behaviours. Remember, a strategy may not work the first time, you may need to try it many times before you'll know if it's effective. Also, strategies may not work every time - try to find some that work well most of the time.

Behaviour	Example	Prevent it by
<b>Aggression</b>	Physically harming others or destroying property.	<p>Supervise the child closely when they're in a situation that may cause problems</p> <p>Discuss how to manage situations that may come up and who they can turn to for help and support (i.e. a parent or teacher)</p> <p><b>Afterwards:</b> Give a reasonable punishment such as a loss of privileges for a short period of time.</p> <p>Provide clearly outlined tasks that need to be completed to earn the privilege back</p>
<b>Uncooperativeness</b>	Ignoring a parent's or teacher's requests	<p>Give child some decision-making ability by providing 2 options and letting them choose one</p> <p>Collaborate with the child to solve the problem- they may be feeling or thinking something that is getting in the way of cooperating. Remain open-minded and flexible</p>

<b>Lack of Initiation/Motivation</b>	Challenges beginning a task. Not doing anything until asked.	<p>Use a datebook or calendar to help schedule activities</p> <p>Sequence activities i.e. “when getting dressed for school, put on your underwear first, then your pants, then your...” and set out the clothes for the child in order</p> <p>Use alarms, make phone calls to your child to remind them of tasks to be done</p>
<b>Problems with Social Skills</b>	Child isn't accepted by peers because child acts differently than they do	<p>Practice some role plays with your child. Make them as realistic as possible with situations your child is likely to encounter</p> <p>Give detailed suggestions of what to say, how to say it, use of body language, personal space (how complex your suggestions will be depends on what your child can comprehend)</p>
<b>Impulsiveness</b>	Acting without consideration of possible consequences	<p>At first, avoid situations that you know are difficult for your child</p> <p>When you think they're ready to learn some strategies, review with your child how to manage an upcoming situation</p> <p>Have a detailed plan for managing specific situations, let them know what to expect</p>
<b>Irritability/Frustration</b>		<p>Provide breaks when you see your child's frustration beginning</p> <p>Learn what relaxes your child (i.e. certain songs, breathing deeply, a stuffed animal) and provide when needed</p> <p>Help them learn how to problem-solve the things that frustrate them</p>



# Behaviour Management Tips

Submitted by Frank Nitra, B.A. (Psych), Board Certified Assist and Behaviour Analyst

**When a child incurs a brain injury, it's not only the child, but the entire family that is affected. Changes in the child's behaviour are often the most stressful for family members to deal with, and it will take work from the entire family to make a positive difference. Below are some tips for family members that may be helpful when supporting a child with a brain injury:**

1. Provide schedules and structure- develop routines for completing morning hygiene, school prep and bedtime routines. Have specific days and times for completion of household chores and homework. Develop these routines with your child's input. Give them choices as to how they're going to complete these tasks, give choices as to which tasks they may or may not complete
2. Model positive behaviours- if you want your child to speak calmly and respectfully, make sure that you are doing the same. If you want them to keep their items organized, show them how you organize your items.
3. Provide a quiet, neat, and organized environment- children with brain injuries can be easily overwhelmed by messy environments. Minimize distractions during tasks- children with brain injuries can have trouble focussing on tasks and ignoring what's going on around them. Turn off the TV and avoid loud discussions during homework or chores.
4. Don't criticize, help them problem solve and patiently teach them skills to do better next time.
5. Learn to use POSITIVE REINFORCEMENT- give children something they like for appropriate behaviour; they'll be more likely to repeat those behaviours in the future. Too often, parents think I mean tangible reinforcers (new toys and candy) for children every time they do something positive. But remember non-tangible reinforcers (sincere praise, compliments, smiles, hugs) are often more powerful without being expensive or unhealthy. Other options include spending time playing with them or letting a child choose what dinner will be made that night.

**Just a few tips regarding the use of positive reinforcement:**

- a) Use mostly non-tangible reinforcers- aside from benefits already mentioned, they help to build communication, trust, and mutual respect. No behaviour strategies will be successful unless those traits are present. Children always try their best when those traits are present.
- b) Provide reinforcers promptly- don't make a child work all month to earn a new video game. Most children with a brain injury can't even wait a week. Instead, reinforce doing their chore by spending 15 minutes playing a game with them that night. Praise immediately and often.
- c) There is a place for the occasional tangible reinforcer. Make it commensurate with the amount of work it took them to perform the behaviour i.e. don't give a huge item for a minor task (they will expect it every time) but don't give an insignificant item for a lot of hard work (it's not worth it for the child)



# Documenting Behaviour - Fact Sheet

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**Mental health professionals in white coats are not the only ones who can observe human behaviour and record the results! Keeping a record of incidents is a crucial part of Positive Behaviour Support.**

## Documenting Each Incident

It might sound very clinical to write the details of the latest challenging behaviour, especially when it's about a family member or partner. But keeping records of each incident greatly increases the chances of appropriate behaviours in the future. Why? Documenting each incident can:

- identify possible triggers by comparing various incidents
- show which strategies are working best over time, and the ones that don't work
- provide vital information for the rehab team or support workers
- keep a record of overall progress.

## What Sort of Information Can be Recorded?

Behaviour consultants will often recommend a report be filled out on each incident, which could include:

- when the behaviour occurred
- where the behaviour occurred
- with whom the behaviour occurred
- how long the behaviour lasted (duration)
- the severity of the behaviour (intensity)
- what could have triggered the behaviour
- what was occurring before the incident
- what occurred after the incident
- strategies used and their effectiveness.





## Identifying Triggers

Identifying triggers can be tricky; sometimes you just need to write down all the possible causes and look for patterns that emerge over time. Remember the trigger may have been something that happened well before the actual behaviour emerged. For example, Julie gets anxious very easily after her brain injury, and she doesn't get along well with her mother who visits each month. Julie often starts screaming at the slightest provocation the day before her mother visits, and it took her support workers a few months to join the dots and realize what the trigger was!

This is why it is so important to look at all these questions, and record what happened after each episode of challenging behaviour. The key is to look for patterns emerging over the weeks or months. Is the trigger due to eating a particular food? Does the behaviour occur at a certain time of the day? In a particular environment? The process has been likened to being a behaviour detective!

# Communication Disorders - Fact Sheet

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A brain injury can result in impairment of communication abilities by impairing hearing, the muscle movements of speech or even the cognitive processes that put words to thoughts.

Communication problems that result from acquired brain injury vary, and depend on many factors which include an individual's personality, pre-injury abilities, and the severity of the brain damage. Typical effects may include slow or slurred speech, difficulty swallowing, drooling or a nasal tone. Communication problems can be a mixture of both receptive and expressive problems.

## Receptive Skills

Receptive skills are the skills involved in receiving and understanding language. Indicators of receptive difficulties may include lack of understanding or attention, problems with quickly given complex information and requests for repetition. It should be remembered that hearing loss can also occur following a brain injury and lead to the same effects. Ideally a hearing test by an audiologist should occur first before assessing receptive skills.

### Behaviours that may indicate problems with receptive language include:

- Poor recognition of vocabulary;
- Continually asking for things to be repeated;
- Difficulty with the speed, complexity or amount of information said;
- Not paying attention in conversations;
- Not understanding what is said;
- Difficulty remembering instructions given.
- Expressive Skills ( expressive skills are the skills required to form coherent sentences, find the right words, and then produce the appropriate sounds).

**The ability to use verbal or written skills to express oneself may appear unaffected, but often there are subtle problems that emerge over time. Often communication tests during rehabilitation will not detect problems as these formal testing situations will not trigger many of these subtle issues. Some of these can include:**

- Non-stop talking, rambling explanations or very rapid speech
- Difficulty remembering particular words
- Incorrect use of language
- Talking about/interrupting about unrelated topics
- Not observing the usual norms and customs in social situations
- Making up stories
- Minimal responses when detail is required in an answer
- Difficulty with abstract skills in understanding humour, puns, sarcasm and metaphors
- Hyperverbal or rapid, non-stop talking
- Poor spelling and difficulty in learning new words
- Saying the same thing over and over (perseveration)
- Trouble with writing long sentences.
- Anomia - Trouble with Finding Words

Some people with a brain injury will know the word they want to say but just can't come up with it. This is called "anomia," which means "can't name". Everyone has an occasional anomia; those with a brain injury may have it frequently. It can be particularly frustrating if you are dealing with people all day long, and can lead to poor self esteem.

A variation on this problem is saying the wrong word. Instead of saying, "pass me the spoon", you might say "pass me the noon." Or, instead of using a similar sounding word, you may use an entirely wrong word. Instead of "pass me the spoon," you may say, "pass me the car."

A speech/language pathologist is a professional who commonly works with this type of problem. This person can teach you techniques to decrease this problem. For example, you can use a technique called "circumlocution." Basically, you "talk around" the word. If you can't come up with the word "telephone," you might say "you dial it, you can call people." People eventually get what you were trying to say. Another technique that people sometimes use is to go through the alphabet and try to get the first letter of the word. Or you can visualise spelling the word-picture a blackboard and try to "see" someone writing the word on the blackboard. Then read the word off the blackboard.

## Dysarthria

Dysarthria results in slow, slurred, and difficult to understand speech as the areas of the brain that control the muscles of the speech mechanism are damaged. A speech pathologist may help with strengthening muscles, increasing movement of mouth and tongue, breathing exercises and slower rate of speech. In extreme cases alternative means of communicating may be looked at.

A person with dysarthria should concentrate on slow clear speech with frequent pauses. It may be an idea to commence a topic with a single word first, and to check frequently that the other person is understanding you. Conversations should be finished as you become tired as speech will deteriorate quickly with fatigue.

## Apraxia of Speech

This is a condition in which strength and coordination of the speech muscles are unaffected but the individual experiences difficulty saying words correctly in a consistent way. For example, someone may repeatedly stumble on the word “yesterday” when asked to repeat it, but then be able to say it in a statement such as, “I tried to say it yesterday.”

The type of treatment depends on the severity of apraxia. In mild cases, therapy may start by saying individual sounds and contrasting them and thinking about how the lips and tongue should be placed. Sometimes the timing of rhythm of speech to tapping or clapping helps to speak more clearly. Contrastive stress drills use the natural rhythm of speech to increase intelligibility. In this exercise, the same sentence is repeated with a different stress patterns, changing the meaning of the sentence. Individuals with mild apraxia learn strategies they can use to produce words which give them trouble. For very severe apraxia, alternative and augmentative systems, such as physical communication via gestures and facial expressions or written communication using a board, pre-printed cards or a notebook, are often employed.

## Confabulation

Confabulation is a memory disorder that may occur in patients who have sustained damage to both the basal forebrain and the frontal lobes. Confabulation is defined as the spontaneous production of false memories - either memories for events which never occurred, or memories of actual events which are displaced in space or time. These memories may be elaborate and detailed. Some may be obviously bizarre, such as a memory of a ride in an alien spaceship; others are quite mundane, such as a memory of having eggs for breakfast, so that only a close family member can confirm that the memory is in fact false.

It is important to stress that confabulators are not lying. They are not deliberately trying to mislead. In fact, the patients are generally quite unaware that their memories are inaccurate, and they may argue strenuously that they have been telling the truth.

## **Pressure of Speech**

Pressure of speech is a tendency to speak rapidly and frenziedly, as if motivated by an urgency not apparent to the listener. The speech produced, sometimes called pressured speech, is difficult to interrupt and may be too fast or too tangential for the listener to understand—it is an example of cluttered speech.

It is a hallmark of mania and is often seen in bipolar people during manic periods, and is also seen in people suffering from severe anxiety.

## **Neologisms**

Neologisms are newly coined words or phrases that may or may not express a clear idea. They are most often associated with people suffering a psychotic illness like schizophrenia but are also seen in people with aphasia.

## **Cognitive Problems**

In some cases the person may not appear to have communication difficulties until they are in stressful situations such as returning to work or study. These cognitive problems will usually stem from inability to maintain attention, difficulty with abstract language, poor organisation of language and a slower rate of processing information.

## **How Professionals Can Help**

Following a brain injury, these cognitive issues can make it harder to learn and apply knowledge to specific situations. A speech language pathologist can assess and treat communication problems, and provide advice to rehabilitation teams. They can help the individual with a brain injury to cope in given social situations, using compensatory strategies and treatment to help the individual be more competent in social situations. Often the individual can learn to compensate for a disability by learning a new and different skill or by using assistive technology such as a hearing aid or augmentative communication device (e.g. speech synthesisers or communication boards).

## **How Families and Friends can Help**

Families, co-workers, teachers and friends can play an important role in helping a person improve communication skills or learn new compensatory strategies, particularly when they work with the speech therapist to provide consistent support in the strategies being taught. Family members should ask questions and expect to be involved in the process of rehabilitation. Not only will this greatly improve the prognosis for the person with the brain injury, by increasing the amount of rehabilitation which will be offered, but can greatly assist the family to understand the injury and reassure the person with the injury that they are being supported.



### **Approaches to use when communicating with someone with acquired brain injury and a communication disorder.**

- Acknowledge the injury and be supportive
- Allow people to take extra time to finish their sentence or to find the word
- Prompt the person to evaluate their own speech and be aware of issues
- Speak clearly and simply when there is a receptive communication deficit
- Work with the person to find out what techniques assist them to communicate

### **Approaches to avoid:**

- False reassurance
- Finishing sentences for people who lose track of what they were saying or who take longer than you are used to
- Speaking excessively loudly or slowly
- Using jargon or lengthy explanations that the individual cannot understand or follow

### **General considerations for communication:**

- Try to avoid too many distractions
- Find out what techniques or aids the person may benefit from
- Use active listening:
  - Meaningful eye contact and supportive body language
  - Reflection of feeling e.g. "This sounds really distressing for you"
  - Reflection of content e.g. "It sounds like you want is ..."
- Use paraphrasing and summarising to ensure understanding
- Use verbal tracking to remind people of previous comments or topics of conversation
- Use redirection to assist people who are overly talkative or easily distracted

# ABC Approaches to Behaviour

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**Despite its simplicity, the ABC model for understanding and managing behaviour is at the core of many effective behavioural strategies.**

This is an effective technique for taking the emotions away from challenging behaviours, analyzing these behaviours, then creating effective responses. When creating a behaviour support plan, it will be important to work out which strategies you will use. These strategies are not to be used occasionally, but will need to be applied consistently by everyone who encounters the targeted behaviours. While they may be difficult at first, your chosen techniques will eventually become second nature.

## Antecedents

What occurs before the behaviour (and may have triggered it)?

The antecedents are simply all the relevant things that happened before the behaviour occurred. They can also be considered as triggers for the behaviour, such as:

- Things that other people did or said
- Emotional state (e.g. depressed, tired, anxious etc.)
- The environment (e.g. hot, noisy, cramped, smell, bright lights).

Managing these antecedents, or triggers, is a proactive way to avoid behaviours occurring in the first place. Here are some useful strategies:

- Build and maintain good rapport
- Avoid or minimise known triggers
- Sometimes a distraction or redirection away from the trigger may be all that is necessary
- Involve the brain-injured person in discussing triggers
- Work together on possible coping strategies in dealing with triggers
- Suggest and encourage these strategies when a trigger occurs

## Graduated Exposure to the Antecedent

This is useful when antecedents can't or shouldn't be avoided. With time and patience, it can be a powerful technique. For example, Kirsten starts screaming in supermarkets due to sensory overstimulation. Her mother says they will just stand outside the supermarket for 30 seconds then go home. The next time, they go in for 30 seconds then go home. This is gradually lengthened until Kirsten has adapted to this difficult environment.



## Preparing for the Antecedent

An inability to cope with chaos, unpredictability and lack of routine is common after a brain injury. For example, if Chris finds the activity and noise of a supermarket unpleasant, it can help to talk about expected reactions and ways to cope before the event.

## Behaviour

- What happens during the behaviour (what does it look like?)  
Before you respond to an actual behaviour, the key is to understand the purpose of the behaviour and what it may be expressing about unmet needs. Although emotions can be running high, there are still strategies that can prove useful during the behaviour itself:
- Stay calm and speak in an even tone
- Give simple directions and prompts about coping mechanisms
- Use non-threatening hand gestures
- Manage your personal safety and remember the strategies agreed on for dangerous incidents
- Recognise when it's time for disengagement/exit strategies for crisis situations.
- Ignoring the behavior

In some cases, behaviour occurs to get attention, so the best strategy may be to ignore it. As with many of these techniques, tactical ignoring is best linked with positive reinforcement. For example, a child is ignored during a tantrum, but is rewarded with praise, a treat or favourite activity once the tantrum is over.

## Consequences

What are the immediate and delayed reactions from everyone involved?

Consequences can be pleasant or unpleasant. A pleasant consequence will reinforce the behaviour (e.g. "When I yell everyone gives me what I want") while a negative consequence will discourage a behaviour (e.g. "When I yell everyone ignores me completely"). A consistent response from everyone to challenging behaviour can have a very strong effect.



## Positive reinforcement

This is generally the most effective behavior management strategy. An incentive is given immediately when a desired behavior occurs. For example, Glen usually becomes quiet when anxious then suddenly starts shouting at everyone. He is learning to tell family members when he is getting anxious and do his deep breathing exercises. Every time he remembers to do this, his actions are praised.

The difference between reinforcement and bribery is that reinforcement comes after a task is completed, whereas bribery is offered before. If you offered a treat before even making a request, you would be using bribery.

When choosing reinforcers, remember that each individual will respond to different things. Remember to:

- Look at what has provided motivation in the past
- Ask about likes and dislikes
- Look at the person's deprivation state - what do they want, that they cannot easily get?
- Try to make sure the reinforcer is practical, ethical and valid for the behaviour being targeted.

Timing is critical to the effectiveness of positive reinforcement, and that the person feels that the goal is achievable.









# Back to School Survival Guide for Students with an ABI

**Submitted By: Angie Blazkowski, Occupational Therapist**

There are many challenges faced by students with acquired brain injury when returning to school. These include:

- Change in routine
- New information overload
- Multiple classroom distractions
- Exposure to fluorescent lights causing eyestrain and headaches
- Fatigue
- Too much information presented at the same time
- Switching tasks frequently
- Complicated social interactions

There are several strategies parents can use to help their child successfully transition back into the school environment:

- Help your child mentally prepare for going back to school by talking about it. Let your child ask questions and discuss concerns.
- Practice walking to school or the bus stop.
- Help your child remember and reinforce all the positive things from previous years
- Identify a regular time and space for homework. An alarm clock may be helpful as a reminder of homework time.
- Keep the regular sleep routine (even on weekends)
- Avoid shopping for supplies all at once. It is too much information and stimulation for your child.
- Organize supplies and space at home for school things.
- Use checklists and post them in appropriate areas. A checklist at the closet door, exit door, and inside a notebook or binder is a good idea.
- Use gentle prompts giving only one direction at a time.
- Design systems, strategies, and routines that can be used in the classroom and at home.
- Support your child with consistent use of a planner or calendar to record events, homework, chores, and responsibilities.
- Encourage your child to use a computer and develop keyboarding skills.
- Develop a good working relationship with the teacher and other support personnel to provide your child with consistency, support, reinforcement, and praise.
- Communicate regularly with the teacher and school staff to identify skills that can be reinforced at home.
- Become aware of all community supports, programs, and services available, and work to ensure all are available to your child.

Remember consistency, routine, patience, and positive reinforcement can help minimize problems and builds new positive behaviours over time.

# PARENT ADVOCACY 101

*Supporting your child's success in school*



## **What is "Advocacy"?**

The act of supporting a cause and trying to get others to support it too.

As a parent advocate, you assume the role of negotiator, school liaison, a specialist in your child's acquired brain injury, teacher and mom or dad. Parent advocates speak for their children and are willing to work with service providers and the school to defend the rights of their children.

## **Steps to Effective Advocacy**

### **Know Your Rights**

In Ontario, the Education Act, along with other regulations and policies, define the education rights of children and youth as well as parents and guardians. These rights include:

- the right to public education
- the right to participate in some decisions made about your child's education
- the right to request a review of IPRC decisions and suspensions
- the right to appeal special education and school discipline decisions

[www.schooladvocacy.ca](http://www.schooladvocacy.ca)

### **Document, Document, Document!**

Documentation is critically important when advocating. Medical documents, IEP's, letters to/from the school or any other professional or service provider should be organized and accessible should it be required to support your case. Where possible, email contact is helpful to allow for a 'paper trail' and always ask to have decisions in writing.

### **Talk to the Right People**

Following the chain of command may feel frustrating, but it is the best approach to finding a resolution to the problem. Work with the Principal of your child's school along with any existing support staff (teachers, EA's, resource) to try to manage the problem. If your child's needs are not addressed, connecting with the Superintendent of Education for that school is the next step in the chain. If at the School Board level the problem is not resolved, then you would contact the Ministry of Education.

## Keep Your Cool

As a parent of a child who requires advocacy, it sometimes can be difficult to approach a situation calmly. Anger and frustration can cloud the mind and keep you from analyzing the situation and responding clearly. You have the right to ask for a break or to re-schedule a meeting if needed. Being prepared with the questions you intend to ask before any meeting helps to keep the conversation on track and maintain focus during the discussion.

## When to Seek Professional Help

Establishing strong communication and collaboration with your child's teachers and Principal from the onset is the ideal way of working together with the school to achieve success. If this collaboration is never established or begins to deteriorate and you feel as though your efforts are not being heard or acted upon, seeking a professional advocate may be an option. Professional advocates can help in many ways including helping to plan and prepare for the meeting or advocating on your child's behalf.

### NAVIGATING THE SYSTEM

School Principals	School Boards	Ministry of Education
<b>Responsible for:</b> <ul style="list-style-type: none"><li>• direct decisions made regarding delivery of services within the school</li><li>• management of the school's individual budget</li><li>• quality of instruction</li><li>• maintaining student records</li></ul>	<b>Responsible for:</b> <ul style="list-style-type: none"><li>• delivery of services across the school board</li><li>• supervising the operation of schools and their teaching programs</li><li>• assigning budgets to individual schools</li></ul>	<b>Responsible for:</b> <ul style="list-style-type: none"><li>• giving direction through legislation, regulations, Policy/Program Memorandum (PPM)</li><li>• funding management</li><li>• policy and resource documents</li><li>• setting requirements for student diplomas/certificates and developing programs and curriculum</li></ul>



*For more information on how OBIA can help advocate,  
contact us at  
[support@obia.ca](mailto:support@obia.ca)*

**Resources:**  
[www.schooladvocacy.ca](http://www.schooladvocacy.ca)  
[www.provincialadvocate.on.ca](http://www.provincialadvocate.on.ca)  
[www.communitylivingontario.ca/advocacy-rights-law](http://www.communitylivingontario.ca/advocacy-rights-law)  
[www.eduge.won.ca/eng/parents/faq-parents.html](http://www.eduge.won.ca/eng/parents/faq-parents.html)  
[www.peopleforeducation.ca](http://www.peopleforeducation.ca)

# Back to School after an Acquired Brain Injury – Children

**This article was submitted by the Paediatric Acquired Brain Injury Community Outreach Program (PABICOP).**

When your child has received a brain injury you may feel overwhelmed and unprepared for what lies ahead. Returning to school requires preparation and planning. This step-by-step guide is designed to support you and your child during this transition.

Communication is key. Contact your child's school and tell them about your child's injury.

## Complications of an Acquired Brain Injury

- The following are typical complications of an injury. Your child may experience any combination of these. They may be temporary, may reoccur, or may be permanent:
- Difficulty learning new information
- Headaches
- Problems with attention and memory
- Being tired
- Reading, writing and language difficulties
- Depression
- Visual problems
- Movement problems
- Seizures
- Behaviour problems such as: impulsivity, aggression
- Decreases motivation, repetitive behaviour or thoughts

## Returning to School

It is important to consider your child's energy level. Many children experience exhaustion after a brain injury and may not be physically able to attend a full day of school at first. The following are some suggestions for a gradual return to school.

- If your child's exhaustion, pain or other injuries make attending school impossible, speak to your Principal about getting 'Home Instruction'. This means your child would receive one-on-one instruction while recovering at home. This will require a letter from your doctor.
- Start with a return to school for a morning or afternoon only. It is important to make the most of the time of day when your child's energy is the highest. If your child attends school while tired, it may disrupt learning and socializing.
- Return to school during the lunch period. This way your child may reconnect with friends and be part of the school environment.
- Return to school for a shorter week. Schedule every other day or a few days followed by a longer weekend.



- If your child is secondary school age, you may consider reducing the number of courses he or she is taking. You may also think about replacing a credit course with a resource period so that he or she may receive support for individual subjects

Changing your child's school schedule should be temporary. It is better for your child to return to his or her normal school schedule gradually. Regularly speak to your child's teacher to see how things are going.

## **The Team Conference**

Your child will experience some challenges temporarily – others may be ongoing. You can speak to the Principal or Learning Support Teacher and request a team conference to discuss your child's needs. Write down all your concerns and questions before the meeting.

Bring any reports/updates about your child's injury. You may wish to invite members of your child's team, and a friend or family member. It is a good idea to ask a friend or relative to take notes so that you are free to be fully involved in the discussion. If a member of the school takes minutes, ask for a copy.

## **Addressing Long Term**

Your child may need extra support when he/she first returns. The effects of brain injury may be long term. While the more obvious physical injuries may heal, there may be ongoing learning, behavioural, social or language problems.

Because a child's brain continues to grow, the impact of an injury can become more noticeable as the child develops. When you are planning educational supports, it is important to consider periods such as primary to junior, junior to intermediate, and intermediate to secondary school grades.

## **The Identification Placement and Review Committee (IPRC)**

This process identifies student's needs and initiates appropriate supports. You can contact your School Board or Principal for more information. School board websites often have parent friendly information on IPRC and special education. *Also see IPRC in the Glossary section of this publication.*

## **Safety Considerations**

When your child has a brain injury, it is important that they avoid any activity that would put them at risk of re-injury. Because the effects of brain injury are cumulative, additional injury may cause recovery to be slower and the damage more permanent. Your child may need to stay inside for recess or have extra supervision indoor recess or one-on-one supervision in the school yard during the early return to school. Participation in sport or physical education classes should be considered carefully for risk of re-injury. A helmet will reduce the risk of re-injury.

# Returning to School after a Brain Injury - Young Adult

Submitted by Stephanie Ellis and Dennis Radman

Returning to school after a brain injury can be both an exciting and stressful experience for students and their families. In this article, we'd like to share some ideas to help the back-to-school transition go smoothly.

## Contact the school and request a school meeting

Often, meetings will include the Principal and/or Vice Principal, Learning Support Teacher, and Classroom Teacher. Meetings provide a platform to discuss the child's strengths and challenges, share relevant medical and rehabilitation information, and to map out a plan for successful school re-integration. If your child is receiving services from a rehabilitation team (e.g., case management, occupational therapy, physiotherapy, social work, psychology, speech-language pathology, etc.), it is often beneficial for those members to attend the school meeting, since they will have information to share about the child's strengths and needs from their respective scopes of practice.

Discussion might focus on topics such as:

- Whether special transportation is required (e.g., if the child has problems with mobility)
- What time of day the child should attend (depending on factors such as fatigue, it may be best for the child to attend in the morning, midday, or afternoon)
- The specific class or classes the child should participate in (based on their strengths, needs, and interests. Attending at lunchtime may be an important consideration for social reintegration)
- Whether specific academic accommodations and additional classroom supports are required to facilitate academic and social success (see below)
- Ongoing communication between family, team and school staff is very important, and therefore it's beneficial to identify an individual or individuals who will be the main points of contact

## What are some of the challenges students face after a brain injury, and what types of accommodations may be required?

Academic accommodations are adjustments or supports that maximize the student's opportunity for success. Although not exhaustive, the table below identifies some common difficulties after a brain injury, and accommodations that might be considered:

<b>COMMON CHALLENGES</b>	<b>POSSIBLE ACCOMMODATIONS &amp; STRATEGIES</b>
<b>PHYSICAL:</b>	
Fatigue / reduced tolerance for activity	Gradual return to school
Pain (including headache)	Opportunity to go rest in a quiet place
Visual disturbances / sensitivity to light	Consult with a Neuro-Optometrist
Hearing impairment / sensitivity to noise	Use of ear plugs or specialized noise filters (prescribed by an Audiologist when appropriate) Use of an FM system
Mobility (e.g., problems with walking, balance, and coordination)	Leave class 5 minutes early to avoid the risk of being jostled in the hallway Identify a buddy who can carry books
<b>COGNITIVE AND COMMUNICATION:</b>	
Attention and concentration	Preferential seating (e.g., close to verbal instruction) Use of an FM system Verbal or non-verbal cues from the teacher to ensure that the student is paying attention
Memory and new learning	Present information in smaller chunks Allow for repetition and rehearsal of information (see below)
Organization	Provide assistance with organizing notebooks Use of graphic organizers to assist with organization of information
Information processing	Opportunity to write tests or do schoolwork in a quiet, distraction-free environment More time to write tests and complete assignments
Reading and writing	Access to the teacher's notes/handouts Use of assistive software (e.g., text-to-speech software that reads text aloud while the student follows along, and/or dictation software that allows the student to dictate their ideas rather than having to write or type them) Use of a laptop or tablet
Social interaction and behaviour	Identifying a peer who may be able to help the child reintegrate into social activities Model and positively reinforce appropriate behaviour and social interaction Identify 'triggers' that lead to inappropriate behaviour

## The Importance of a Growth Mindset

Researchers and educators have seen that students fall into roughly two mindsets about their skills and potential. The first is what is called fixed mindset. Students with a fixed mindset see their capabilities as unchangeable. The second belief is called a growth mindset. Students with a growth mindset view their skills and potential as something that can be developed. Which belief students have turns out to have important consequences. The table below summarizes the main differences between a fixed mindset and a growth mindset.

	<b>Fixed Mindset</b>	<b>Growth Mindset</b>
<b>Belief</b>	Nothing will change, I can't get better at this	I can and will improve; I can develop skills and I can use strategies
<b>Tendency</b>	I try to appear as capable as much as possible	I will try to learn and improve as much as possible
<b>Challenges</b>	I avoid challenges, I give up quickly	I will take on challenges because I can learn from them and grow
<b>Effort</b>	I won't put in any effort because nothing will change	I will give this all the effort I can because it's needed for growth
<b>Criticism</b>	I ignore feedback – it's not useful and I get defensive	I will be open to feedback – I am eager to learn and grow
<b>Interactions</b>	I will not ask for help	I will cooperate and work with others; asking for help helps me grow

(Adapted from Carol Dweck, 2006)

## Fostering a Growth Mindset for a Successful Return to School

- A growth mindset can indeed be taught. You can find some tips below:
- Use 'Growth Mindset' language and scripts: use the table above to develop and consistently frame conversations and give feedback to foster a growth mindset
- Encourage students to identify and analyze their own 'growth' experience: You can ask a student to describe how they have managed to become better in something which they used to not be so good at
- Learning from someone else's 'growth': students can be asked to think of and find examples of situations in which someone else had learned something that they did not think they could

Dennis Radman is a Manager at Brainworks and Stephanie Ellis is a Speech-Language Pathologist at Cognitive & Communication Services.

# Returning to Studies - Fact Sheet

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Survivors of a brain injury who have done very well in their recovery still face a major hurdle in returning to their studies.

A number of head injury factors will make this difficult. First of all, short-term memory will make it very hard to learn new material. School is nothing but learning new things. Second, school has a fair amount of fatigue associated with it. With a brain injury, people have limited energy and may be good in the morning, but fade early in the afternoon. Third, returning to school involves a social dimension-people very desperately want to fit in with their peers. For some people, having some friends that you can hang out with is their number one priority in college or high school.

## Impaired Concentration

An injured brain may never be restored to pre-injury capabilities but performance can generally be improved. Difficulties are often experienced in the areas of attention and concentration. It will be necessary to gradually build up tolerance for concentration daily but this is not as simple as it sounds. Keep periods of concentration short by allowing regular breaks. Start with ten minutes and build up gradually with a few extra minutes daily.

## Lack of Insight

Many students with an acquired brain injury have a lack of insight regarding their level of ability, unable to recognize that their performance and capabilities are functioning at a reduced level. They may respond to negative feedback by believing that teachers are against them, or other ways that allow them to believe their performance is still normal.

## Lack of Planning and Organizational Skills

Planning and organizational skills can be impaired to the extent that the student knows what he or she wants to do, but has difficulty getting started. This means that the person will need a very clear plan of how to go about carrying out a task. The first step will be to stop and think - he or she will need time and support to work out a plan by identifying the task, keeping it simple and addressing one task at a time:

- Write down all the steps required to complete the task
- Sort out the list of steps in the order they are to be achieved
- Treat steps as a self-contained goals and tackle them one at a time
- As each step is completed, reinforce it as an achievement of success
- Create a distinct break between each step
- Review each preceding step before moving onto the next.

## Short - Term Memory Problems

Most brain injuries will result in impairment of short-term memory and the ability to retain or process new information. Students will lose books and equipment, forget appointments and arrangements, ask the same questions again and again, or forget which classroom they are supposed to be in. Fortunately, there are ways to assist memory and it can be an exciting challenge to work out new avenues to compensate for problems. However, it is important that the students are aided but not rescued from their own failing memory.

Common memory aids include:

- A diary to note all class times, appointments and instructions
- A notebook to list common times and protocols
- A map of the school showing classrooms, toilets, offices, bus stop etc.
- Clearly marked exercise books and equipment
- Thong necklace for keys
- Wristwatch with an alarm.

Students with poor memory will need to become familiar with using memory aids and will need constant reinforcement. Other helpful aids are clocks, calendars, blackboards, whiteboards, signs, notices, photos, post-it notes, or anything that provides a compensation to memory deficits.



## Confusion

Normally, people use their planning and organizing skills to work their way through confusion. However, because acquired brain injury often results in some loss of these skills, it may be difficult for a student with an acquired brain injury to deal with confusion. Confusion usually comes about through:

- Unrealistic self-expectations e.g. the student may have a memory of achievement that is inconsistent with their impaired ability
- The student's inability to recognize that a disability exists
- Others having too high an expectation of the student
- The student attempting to achieve too much at once
- Interruptions, noise, clutter or visual distractions around the student
- Too many instructions being given to the student at the one time.
- Students should make their teacher aware of these issues and see what changes can be made to minimize confusion.

## Stress, Frustrations and Anger

A common trigger to personal stress is the feeling of helplessness or being trapped in a situation over which we have no control. Disciplined or authoritarian environments can add to students' beliefs that they are deprived of alternatives. The student should be able to choose from a number of options in dealing with these emotions.

The 'triggers' for these emotions should be identified, and where possible, avoided. When this isn't possible, relaxation and meditation can act as good insurance policies. When high levels of anger or aggression are imminent, the student should be able to take time-out, having planned for this already with teachers. This needs to be seen as an opportunity to restore balance and perspective, not punishment.

## Impulsive Behaviour

Students with an acquired brain injury often do things on impulse. Behaviours displayed are often a genuine case of innocently doing what seemed to be a good idea at the time. Strategies should be discussed with teachers so that undesirable behaviour can be replaced with an agreed alternative. It is also helpful to agree on a signal that the teacher can give as a sign for the student to stop and think about what they are doing. It could be a word, or a sign (e.g. arm up in the air). In time it will become an automatic process.

## Allowances

All educational institutions now have policies that make allowances for people with disabilities in terms of time given for tests and assignments. These institutions are frequently unaware of the multiple impacts on a student's abilities such as short term memory difficulties, mental fatigue, lack of concentration, susceptibility to stress and lowered organizational ability. Students should contact their Disabilities Officer to make suitable arrangements for tests and assignments.

Many schools and universities will help you learn new material if you let them know that you have a disability or send emails to [www.braininjurylondon.on.ca](http://www.braininjurylondon.on.ca) disability. There is still little awareness of brain injury in many organizations so you may need to present this information to them to acquaint them with this particular disability. It may help if your doctor or neuropsychologist writes a letter to document that you have a valid disability.

You will need to explain the accommodations or special help you require, such as:

- Extra time assignments and examinations
- Exams in a quiet room without distractions
- Copies of teacher's notes if your concentration and attention are affected.

## Some Study Strategies

Organizing yourself will be crucial. Some useful suggestions to try are:

- Have a balanced diet, good sleep and regular exercise
- Avoiding alcohol, cigarettes and other drugs
- Structure your days and week with a daily planner, diary or electronic organizer
- Use memory prompts such as notepads, alarms, post-it notes, and a large notice board
- Experiment on study times, most do better in mornings than evenings
- Structure your study times and stick to them no matter how you feel
- Make use of study groups or a 'study buddy'.

## Patience and Endurance

There are many resources available on good study techniques which will be useful to students. Students who have acquired a brain injury may take longer to learn these strategies but the same benefits are available as the skills are acquired. Most survivors say that learning compensatory strategies is one of the hardest challenges in their lives, but one that has made them better people when they did not give up.



# When Accommodations Are Not Being Met, What Then?

Submitted By: Katie Muirhead, Advocacy Specialist, OBIA



## What is Advocacy?

Actively supporting a cause and trying to get others to support it to. Speaking up, drawing attention to an important issue and directing decision makers toward a solution.

## Elementary/Secondary vs. Post Secondary

Elementary/Secondary Options:

- IPRC/IEP
- EA's
- Direct Communication
- More options for support
- Class structure and environment

Post Secondary Options:

- Arrange educational accommodations
- Use of assistive devices/technology
- Develop learning strategies/plans
- Course Registration
- Connect with on-campus resources
- Liaise with faculty

## Accommodations vs. Modifications

“Educational modifications are not available in college or university. Instead, you may receive an educational accommodation. Accommodations are available for students in elementary, secondary and post-secondary education. *Accommodations don't change the level or amount of work you are expected to complete.* Instead, they are resources or services to provide you with an equal opportunity to complete the work, should you require them.”

*-Ministry of Training Colleges and Universities*

## How Do I Set Up Accommodations?

- Connect with your student disability office
- Complete an intake
- Documentation of disability
- Neuropsychological Assessment
- IEP/Letter from your school
- Transition plans or existing documents from OSR

## Barriers to Accessing Post Secondary Education

- Cost
- Admissions criteria
- Medical documentation/assessments

## Case Example

“Dan” is a high school graduate who has been accepted to University. He sustained an ABI while in elementary school and was able to rehabilitate himself to a point where he could return to school and with accommodations and modifications graduate.

“Dan” contacted OBIA when a few months into his classes at University when the accommodations were not being met.

“Dan” and I met to discuss needs and strengths along with strategies tried to this point. Joint meetings were had with the student disabilities department where we were able to set up a schedule, modify his calendar, arrange for scribes, and clarify the role of the departments and faculty.





# Sexual Development of Young Children - Fact Sheet

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From the time we are born, we are sexual beings, deriving enormous satisfaction from our own bodies and from our interactions with others, particularly the warm embraces of our mother and father. Most infants delight in being stroked, rocked, held, and touched. Research shows that the amount of intimate and loving care we receive as infants "is essential to the development of healthy human sexuality"

Unfortunately, there are many misconceptions about the sexuality of children with disabilities. The most common myth is that children and youth with disabilities are asexual and consequently do not need education about their sexuality. The truth is that all children are social and sexual beings from the day they are born. They grow and become adolescents with physically maturing bodies and a host of emerging social and sexual feelings and needs. This is true for the vast majority of young people, including those with disabilities.

Some people also think that individuals with disabilities will not marry or have children, so they have no need to learn about sexuality. This is not true either. With increased realization of their rights, more independence and self-sufficiency, people with disabilities are choosing to marry and/or become sexually involved. As a consequence of increased choice and wider opportunity, children and youth with disabilities do have a genuine need to learn about sexuality - what sexuality is, its meaning in adolescent and adult life, and the responsibilities that go along with exploring and experiencing one's own sexuality. They need information about values, morals, and the subtleties of friendship, dating, love, and intimacy. They also need to know how to protect themselves against unwanted pregnancies, sexually transmitted diseases, and sexual exploitation.



## Talking to Your Children

So when do you start talking to your child about sex and sexuality?

The answer is that it's never too early to start talking to your children about sexual matters. Openness, even with young children, will show that sex is an acceptable topic of conversation. Teach your child that you are available to discuss sexual issues, and establish a comfort level - for both of you - with the topic.

What you tell your child about sex is obviously a personal decision, influenced by your own values, morals and religious beliefs, however here are some suggestions:

- Don't make the common mistake of confusing sex education with reproductive education.
- Children will at some stage be curious about where babies come from and it is appropriate for parents to answer their questions truthfully.
- Reproductive education, sometimes described by the euphemism 'the birds and the bees' can be used by embarrassed parents as a more comfortable substitute for a discussion about human sexuality

In early childhood (ages 3 to 6) normal sexual development of children includes the following:

- Children are often curious about where babies come from.
- Children may explore other children's and adults' bodies out of curiosity.
- By age four, children may show significant attachment to the opposite-sex parent.
- Children begin to have a sense of modesty and of the difference between private and public behaviour.
- For many children, genital touching increases, especially when they are tired or upset

Some generally-accepted rules are that during this period children should learn:

- That touching their sex organs is normal, and to seek privacy when they want to touch their sex organs for pleasure.
- The biological differences between males and females, and how babies are made.
- That the child's body belongs to himself or herself, and how to say "no" to unwanted touching.
- The correct terms for sexual body parts, and how to talk about all their body parts without feeling "naughty".
- To learn and understand how to accept their appearances and their desires.



As the child grows it is appropriate to introduce more complex topics such as:

- The fact that sexual thought and fantasies are normal.
- That people can experience sexual pleasure in different ways; some people are heterosexual, some homosexual and some are bisexual.
- And very importantly, about sexual abuse and its dangers - that sexual predators may seem kind, giving, and loving, and may be friends or family members; and to protect themselves from potential sexual abuse

Sexual development should be explained to children before significant sexual maturation begins. Girls in particular should be taught about menstruation well before they enter puberty. Children should be taught that sex is pleasurable and nothing to feel guilty or embarrassed about. It is also important that children learn about contraception, sexually transmitted diseases and pregnancy before they become sexually active.

## **Precocious Puberty**

It is important for parents and carers to be aware that not only does a brain injury not mean that a child is asexual; in fact a brain injury may result in precocious puberty.

Precocious or early puberty may occur at 5 years of age or even earlier and can be a source of great distress for both the affected child and parents. Puberty happens when the hypothalamus, which is responsible for managing the way your body runs, signals the pituitary gland to signal the ovaries or testes to make sex hormones. Precocious puberty can happen for no known reason (or even be inherited), but when a brain injury is involved the hypothalamus or pituitary gland can malfunction in many different ways, one of which is early signalling of puberty.

If your child's doctor suspects that your child has precocious puberty, he or she may refer you to a paediatric endocrinologist (a doctor who specializes in growth and hormonal disorders in children) for further evaluation and treatment.

Treatment usually consists of hormone therapy that stops sexual development until a more appropriate age.

# Assisting your Child's Development - Fact Sheet

Reprinted with permission from [Synapse.org.au](http://Synapse.org.au)

**A brain injury can disrupt the long and complicated process to move from childhood through to being a mature adult.**

At each stage of development a child needs to master a particular range of new skills in physical, intellectual and social skills. Over time, these developmental changes should include:

- Increasing ability to handle complex ideas
- Growing ability to concentrate and to remember what is learned
- Increasing physical and social independence-for example, coming to rely increasingly on peers as well as family members for opinions and social contact
- Growing physical abilities, stamina, strength and coordination
- Increasing self-awareness and a growing sense of who they are as an individual person (a sense of identity)
- Growing ability to express negative feelings and frustrations in words, rather than physically.

These general trends are all important, but there is plenty of 'normal' variation in how they occur.

Changes seem rapid during some periods and slow at other times and at any age, a young person may switch between more and less mature behaviours. 'Transition' times place extra stresses on children. These are times of major change. Some are imposed from outside: starting school, moving from primary to secondary school, leaving school. The most important 'internal' transition is puberty.

## How Acquired Brain Injury Affects Development

Acquired Brain Injury may disrupt development to a greater or lesser extent in areas like language and speech, learning, memory, thinking, behaviour, and physical functioning.

For children and adolescents with an Acquired Brain Injury, the situation is further complicated because their development isn't yet complete. They still have many things to learn and tasks to accomplish to reach mature adulthood.

Acquired Brain Injury ranges from very mild to very severe, with everything in between. A mild Acquired Brain Injury may produce few observable effects, but with increasing severity, more areas of life are usually involved and effects tend to be more obvious



## Direct and Indirect Effects

Direct effects of an Acquired Brain Injury often involve social, intellectual and language development. They might, for example, affect abilities such as getting organized, controlling impulses, learning new skills or remembering things. Many young people with Acquired Brain Injury also have slowed reactions and weakness in some parts of the body, which may affect what they can do and take part in, and their self-image. People with a severe injury may also have major physical problems that affect their ability to move about, care for themselves, and communicate.

Indirect effects result from the way the young person and others respond to the direct effects. These can include loss of confidence, changes in behaviour, social isolation, frustration, emotional problems and low self-esteem. Acquired Brain Injury is not widely understood and some people may confuse it with mental illness or intellectual disability.

If there are no visible signs of having acquired a brain injury then a child's behaviour can be easily misunderstood.

## Cognition

Generally, 'cognitive' (that is, thinking or intellectual) skills are most affected. It is often harder for young people with Acquired Brain Injury to remember things, harder to concentrate, work logically through a process that involves a number of steps, or manage several things at the same time. They may also have some physical issues, for example, slower reaction times and poorer coordination than before the Acquired Brain Injury.

These difficulties don't just affect school work. Because thinking skills play a large part in getting along with others, social interactions can be changed. People with Acquired Brain Injury may also have a tendency to be impulsive, irritable, even aggressive, and this can affect relationships.

### The myth of the resilient brain

It used to be thought that younger children were more resilient and 'bounced back' after a brain injury. But as children develop and grow, they build up an ever-increasing 'bank' of memory, learning, knowledge, language and life skills - the younger the child when the Acquired Brain Injury occurs, the smaller is the bank of stored learning. The young child has less to draw on.

This makes good recovery and adjustment more challenging. Effects of the injury may continue to appear over years, as the child's brain matures and is challenged to learn new and more complex tasks and skills.

## How to Assist Your Child's Development

If children with Acquired Brain Injury are to achieve the best results possible - in overcoming and/or adjusting to their difficulties - it is essential that they have assistance and support designed to meet their particular needs. Helping the young person to deal with and/or overcome these effects can involve:

Taking special care to teach him or her the necessary skills; and/or  
Concentrating on finding ways around the problem - 'compensating' for it.

The best approach will vary from person to person, and problem to problem. Professionals with experience working young people with Acquired Brain Injury can provide advice. The key to success is to identify the nature of the difficulties, and to deal with them before the young person becomes discouraged and loses confidence. Young people with Acquired Brain Injury need lots of opportunities to practise skills that others learn more easily.

## Assessment

The first and essential step is to obtain a clear and accurate assessment of all the young person's abilities and difficulties-whether the brain injury has just occurred, or there are worrying symptoms months or years after the event. Assessment is the basis for planning a specific program to build on the young person's strengths and address their particular needs, and set short-term and longer-term goals.

## Setting Goals

This planning and goal-setting should always be a team effort, with the young person, the family, and the professionals involved - a partnership that works to find the best ways of meeting each young person's needs, and the needs of the family as a whole.

The program needs to be tailored to your child's and your family's priorities and circumstances, to build on your particular strengths and skills. It needs to help you and your child adapt positively to the way things are now, and to foster your child's learning and independence.

In the first six months after an Acquired Brain Injury, recovery is at its fastest although progress may continue for years in cognition, language, physical skills, behaviour, emotional and social skills.

Re-assessment and planning, both formal and informal, therefore need to continue often over years, to track the young person's development and progress, and map out the path ahead. Remember that predictions made by professionals-even the most competent-may not always turn out to be accurate. This simply reflects the difficulty of making accurate long-term predictions with something as complex as Acquired Brain Injury.



## Some General Strategies

Individualized plans are important, but some general strategies may also help:

- Pitch your expectations at a level where success is likely
- Praise or reward small but significant steps toward a goal
- Break larger tasks (be they physical or cognitive tasks) down into small steps that can be learned and practised separately
- Practice how to deal with difficult situations, recognizing that it may be hard to apply existing skills to new situations
- Focus on tapping into the young person's strengths, and changing the surroundings to compensate for things he or she finds difficult
- Respect the young person's dignity, help them achieve their goals for themselves and aim continually to build self-esteem and confidence
- Be consistent in your expectations and approach - don't chop and change the ground rules for the young person.
- Use a 'problem-solving' approach to difficulties, to find the solution that best suits the needs of everyone involved.
- Think about building informal supports for your child - for example, contact with other young people who have had similar experiences.

Try to give yourselves time off from rehabilitation every now and then, and just be together for a bit. Don't expect to change everything at once. It's easy to feel impatient when the young person is struggling to learn or re-learn skills.

# Online Safety for Children with LD

Written by the National Center for Technology Innovation, reprinted with the permission of [brainline.org](http://brainline.org)

NCTI's material does not address traumatic brain injury specifically; however, it can be applicable and useful for people with brain injury.

## Bullying Among Children with Learning Disabilities

All children are at risk for being bullied or harassed, but studies show that children with LD, ADHD, and emotional/behavioral disorders are more likely than their peers to be bullied or become bullies themselves (Snyder, 2003; HRSA, 2007). Many parents and teachers of children with disabilities are well aware of the potential for in-class bullying of kids seen as different and make efforts to stop bullying before it starts; but what about bullying and harassment that teachers and parents don't see? With young people's increasing presence online, much of the inappropriate behaviour, language, and material they may come in contact with is beyond the immediate view of parents, teachers, and guardians.

Preparing all students for safe interactions online is therefore important, and it is all the more critical to examine the special risks and concerns that students with disabilities face online. This Information Brief, prepared by the Center for Implementing Technology in Education, examines Internet safety issues for students with LD and ADHD and provides practical guidance for parents, teachers, and students seeking to navigate the brave new online world safely.

## Special Considerations for Students with Disabilities Online

Though some research has shown that young people with disabilities are at a greater risk of being victims of bullying and harassment, there is little research about how these risks extend to online behaviour. However, it is safe to assume that many of the same issues exist online as they do offline.

Many kids with LD, ADHD, and/or emotional/behavioural disorders struggle with social interactions and appropriate behavior. They may have difficulty reading social cues, regulating their behaviour, determining the accuracy of information, or judging if someone is trustworthy. Because of these social challenges, kids with LD may be at a higher risk for bullying, harassment, and victimization when interacting with peers and adults online.

Social interactions are complex; the social skills needed for basic conversations are different than those needed for resolving conflicts and determining appropriate behavior in social situations. For example, basic social skills include the ability to maintain eye contact, understand facial expressions, and recognize appropriate personal space (Canney & Byrne, 2006; Waltz, 1999). Participating in more complex social

situations, on the other hand, requires interaction (resolving conflicts, taking turns, interacting with authority figures), affective skills (identifying feelings, understanding the feelings of others, recognizing whether someone is to be trusted), and cognitive social skills (making choices, self-monitoring, understanding community norms).

These skills, which are certainly important in face-to-face communication, are essential to healthy and safe online interactions as well. This places children who have difficulties with complex social skills at a potentially higher risk for dangers online. For example, a student who is challenged by making appropriate choices or recognizing strangers' trustworthiness may more easily become an online victim of a sexual predator, an email phishing scheme, or cyberbullying.

Any child may inadvertently develop a relationship online with someone who seems friendly - someone who takes an interest in his or her life and asks superficially harmless questions about his or her home, school, or friends. However, a tween or teen with LD may not recognize that this seemingly friendly adult is asking inappropriate questions or that certain types of information may be dangerous to share with a stranger (phone number, school, real name, etc.). Since children with LD are more prone to loneliness (Margalit & Al-Yagon, 2002), they may be especially vulnerable to the harmful advances of online users who show seemingly benign interest in their lives.

The anonymity of the Internet can also present a number of difficulties for students with LD. While online, people can take on any identity or personality they choose, which makes some people feel that social norms do not apply and leads them to act in malicious ways that they normally would not.

Take online forums and chat rooms for example. These are popular locations for discussing everything from celebrity gossip to politics to a love of dogs, and can be a great place for kids and adults to find and engage in lively discussions with others with similar interests. However, because these forums are generally anonymous, they can rapidly devolve into online shouting matches and name-calling. Many online communities are moderated and make efforts to eliminate negative comments from their boards.

But some online communities relish the cruel jokes, the insults, and the "trolls." A child who is particularly vulnerable or doesn't recognize the community norms and malicious intent of a forum like this may easily grow distraught over online harassment. Many members of online communities recognize this immature behavior for what it is and ignore it; a child with low self-esteem, anxiety, or depression, however, may feel devastated and bewildered when a group of online so-called friends suddenly turns on her or uses her personal information for humiliation.

## **Talk About the Risks and Responsibilities**

This is not to say that children with disabilities should not go online, or that there is nothing of value online for children. In fact, research has suggested that the opposite is true. The MacArthur Foundation's recent study of teens' online behavior indicates that online activity helps teens learn important social and technical skills, develop and extend friendships, and explore new and familiar educational topics (Ito, Horst, Bittanti, Boyd, Herr-Stephenson, & Lange et al., 2008). The same anonymity that may present challenges for children who struggle with social skills can also give them the opportunity to practice interactions with others in a more structured environment, the freedom to explore different aspects of their identities, and the confidence to request help with less fear of rejection (Raskind, Margalit, & Higgins, 2006).

However, the challenges that children with LD face on the Internet do mean that it is important to be aware of children's online activities and to talk with them openly and directly about what they may encounter. These conversations are essential with any child, but of particular importance for students with disabilities.

A recent study on teens' use of social networking sites found that over half of the adolescents whose social networking pages they reviewed posted private content and information about risky behavior including sexual activity, drug use, and violence (Children's Hospital and Regional Medical Center of Seattle, 2009). Encouragingly, when a physician in the study sent teens messages through MySpace warning them about the private content they were posting online, many teens either removed the information or set their profile to private (allowing only friends to see the information). As this example demonstrates, in many cases an explicit conversation with a trusted authority figure, like a parent, a teacher, or the child's doctor, is enough to help kids think more carefully about the personal information they make available online.

While threats to LD children's safety may make it tempting to ban Internet use entirely, experts agree that educating children about the risks and responsibilities of online communities is the best way to keep them safe. Completely blocking access or using scare tactics are methods that simply do not work (Ash, 2009). Instead, stay involved with children's lives and help them develop the skills they need to safely reap the benefits of the online world.

**For References Please Visit [brainline.org](http://brainline.org)**







## Parent's Guide - Emerging Sexuality - Fact Sheet

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Surging hormones and the wish for a successful social life both fuel teenagers' interest in sex. For parents, adolescence can be challenging. For young people, it is exciting and potentially risky, and ABI can increase these risks.

For example, where judgement, planning skills, social skills and self-esteem are all affected, a young person is at higher risk of unplanned pregnancy, sexually transmitted disease and sexual assault. These young people may be vulnerable to being exploited and manipulated, and sexual activity may be a response to feeling isolated. Impulsiveness can further increase the risk.

Reduced self-esteem and self-confidence, and decreased social skills, can affect a young person's ability to develop relationships and be accepted by others. In addition, some people with ABI lose the normal inhibitions we place on our behaviour. They may do and say inappropriate things - for example, use sexually explicit language or masturbate in public - and this inevitably affects the way others relate to them.

Physical disability following brain injury can affect a young person's ability to engage in sexual or self-pleasuring activity, and an injury during adolescence-a time when acceptance by peers is so important-can have a devastating effect on self-image and self-esteem.

## Sex Education and Guidance

To negotiate these years safely and successfully, all young people need to learn about their sexuality. They need to know how to avoid risks to their health and their social and emotional development, and find positive and healthy ways to express their sexuality.

The risks involved in sexual behaviour have changed over time. Unplanned pregnancies have decreased-but the risks of sexually transmitted disease, including HIV/AIDS, are real. Attitudes towards homosexuality are more positive-but young people can still feel shame, guilt and regret about their sexuality.

Having information is a good first step. It doesn't prevent all problems-adolescents aren't always able to put theory into practice. However, research shows that teenagers who receive appropriate sex education tend to delay first intercourse, use contraception and avoid pregnancy. Of course, family input is crucial, too.

Like their peers, young people with ABI need:

- Informal education, at all ages, on sex and self care-such as having their questions answered by trusted adults
- Formal sex education, such as that provided by schools.

Young people with ABI often need extra time to absorb information and learn self-care - for example, managing monthly periods for a young woman. And a young person with ABI who thinks concretely may need to practice skills in a variety of specific situations - it may be very difficult for them to generalize from one situation to others.

Young people with ABI are also more likely to need very firm, clear guidelines about what's appropriate. A degree of tolerance is needed - if they do or say inappropriate things, shaming or punishment doesn't help. The issue needs to be dealt with quietly and firmly, without condemning the person.

Sometimes a trusted adult or young person outside the immediate family is in a better position to provide information, support and advice.

Good relationships and social skills, and good self-esteem, provide a strong foundation for a safe passage through the turmoils of adolescence, and this needs to be the central focus in assisting and supporting young people with ABI. It also helps to address many parent's biggest concern: that their child with ABI may not have satisfying social relationships or be able to find a partner.

For an extensive catalogue of information and services relating to relationships, sex, sexuality and sexual health when someone has a disability, contact your local Health Unit.

## When Young People are Sexually Active

Young people with ABI who are sexually active may be at risk because of poor judgement, planning and follow-through, and/or of social awareness and skills. For example:

- They may be less likely to use 'safe sex' methods to prevent infection or unwanted pregnancy
- They may be more likely to deny symptoms of infection.
- If they have an infection, they may delay seeking treatment or not complete a course of treatment, especially if symptoms decrease.
- They may not inform their sexual partners about any diagnosed infection they have.

Even when they see a health professional, diagnosis may not be correct, and relevant health and education issues may not be discussed. This may be because the young person has difficulty communicating or because the health professional is unfamiliar with the effects of ABI.

These are difficult issues for parents to address at the same time as respecting their young person's privacy. You may be able to go with your young person to the doctor, or get a friend to go, or rehearse with the young person what they will say to the doctor.



# Balancing Risk and Independence - Fact Sheet

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Growing up involves taking risks - this is normal as young people 'test the waters' and move towards independence and adulthood.

Risks are of many types. Some are social - for example, inviting someone on a date for the first time; and some are emotional, such as talking about fears. The risks that most concern parents are usually those that might cause physical harm. Sometimes young people do dangerous things deliberately; sometimes they just don't see the risks.

One of the important things parents do is to help young people learn to manage and judge risk. As parents, you need to judge what risks are acceptable and make sure your young person has the necessary skills to avoid danger. Parents who encourage independence and allow a manageable element of risk are showing optimism and confidence in their child.

Decisions about risk crop up all the time-your child, maybe, wants to go to the store alone, go to a party where you don't know the parents, cook something on the gas stove. Ask yourself:

- Does he/she have the necessary skills?
- Can I trust him/her to follow the rules?
- What are the likely risks, including risks to others?
- Are there dangers outside his or her control?
- What would make it safe?

It may be tempting to put physical safety above all else, but saying 'no' too often can have a cost. Kids lose confidence, or rebel, or simply miss out.

## Acquired Brain Injury and Risk

The pitfalls and dilemmas faced by all parents can be magnified when the young person has an acquired brain injury (Acquired Brain Injury). The young person may be less capable of anticipating danger, judging risk, or showing self-control. It may be harder to learn the skills needed to be safely independent. These might be physical skills, and/or skills related to behaviour, judgement, memory and perception.

Impulsive behaviour can place the young person at risk. Loss of confidence, self-esteem and friendship networks may make the young person more susceptible to the influence of peer groups, as he/she tries to impress, fit in, and make friends.

At the same time, if you try to protect your young person by restricting them more than others of their age, this can also affect their self-esteem and relationships with other young people.

## What Protects Young People From Risk?

Research has shown that some of the most important factors that protect young people from getting involved in some of the riskier activities of adolescence are a strong and caring family and school, and a sense of connection to family and school, coupled with personal skills that enable the young person to develop self-esteem and confidence. Other things that help are a stable family structure, open lines of communication, a pro-active approach to solving problems, and having a good relationship with an adult outside the family-someone who believes in the young person.

## Managing Risks

It is always important to equip young people with the skills, knowledge and confidence to say 'no' to things they do not want to do. At the same time, risky activities are a normal part of growing up, and it is imperative to try to minimize any harm that may result.

Where Acquired Brain Injury is present, there are further considerations. For example:

- Can the young person understand and remember instructions, rules or laws and apply general rules to specific situations?
- Are impulsiveness and poor judgement issues?
- What sort of training or instruction does the young person need to maximize the chances that he/she will act responsibly and safely?

The following strategies may help:

- Set sensible and firm limits based on your family's values and respect for laws and regulations.
- Be a good example and role model.
- Try to keep the communication lines open within the family-listen to what your children have to say, respect their point of view (even if you don't agree with it).

Provide a 'safety net' of appropriate supervision - be aware of your child's friendships, know where they are at night, be awake when they get home.

## Everyday Risks

For young people with Acquired Brain Injury, the small steps toward independence that their peers manage easily may require extra training or supervision. If they lack foresight or are impulsive, some activities possibly should be avoided, controlled or prohibited.

## **'Getting around'**

Very young children are generally under adult supervision when they walk to shops or cross the road. Sometime during primary school, many children begin to do these things without assistance. Throughout secondary school, young people are generally expected to get themselves to school and other places. With increasing independence, children and young people might, for example, want to walk to local shops alone, ride a bike around the local neighbourhood or take public transport to social events as well as to school.

A young person will usually want to do what others their age are allowed to do. However, parents need to decide whether their child with Acquired Brain Injury has, for example:

- The necessary skills for traffic safety
- A good enough memory to remember rules, how to get where they are going and home again, and what to do if they have problems
- The necessary physical skills and reflexes for a bicycle or roller blades
- The ability to organize what they need to do, including things such as handling transport timetables and buying tickets.

If your child does not have the skills needed, then a structured learning program - combined with an appropriate 'safety net' - may help.

Some children and young people with Acquired Brain Injury may be worryingly ready to trust and be friends with anyone and everyone. Younger children may not have the separation anxiety that most of their peers experience, because they are so used to seeing many different people in hospital. All age groups can be very trusting. This openness can have positive aspects, but it also exposes the young person to risk of danger. Rules need to be very specific and structured, about how to behave in particular situations. They need to be practiced over and over, in social situations.

## **Other Everyday Risks**

If the young person wants to play a contact sport, a neurosurgeon (if one has been involved) can say whether it's safe and what precautions are necessary (for example, a helmet). Otherwise, ask your paediatrician or general practitioner to advise. The young person may need coaching to learn the rules of the game or to manage any frustration they may feel.

Using household equipment like stoves and knives can be risky if, for example, memory difficulties make it hard to learn a sequence of steps. Again, set very specific rules and practice and rehearse them repeatedly. Where necessary, you may need to put some activities off limits, or install protective devices around, for example, stoves. Talk to an occupational therapist about managing risks of this nature.

Some kids always seem to be looking for something ambitious-and possibly forbidden-to do. Try to step back and ask yourself what you would do for a child who didn't have Acquired Brain Injury. Make sure lines of communication remain open, boost the young person's self-esteem, encourage more positive friendships and provide appropriate supervision-for example, have friends visit your house, rather than letting your child go out with them.

## Driving

Obtaining a driving license will not be possible for some young people with Acquired Brain Injury, but it will be an option for many others.

Problems that may affect a young person's ability to drive include:

- Physical weakness and/or poor coordination
- Altered sensation - for instance, lack of awareness of one side of the body
- Difficulties in perception - for instance, difficulty judging distances
- Slowed reaction time
- Changed vision - for instance, a restricted visual field
- Difficulty concentrating
- Impulsive behaviour
- Confusion between left and right, difficulty in understanding maps and directions
- Risk of epilepsy

Even if the effects of the Acquired Brain Injury appear minor, it is crucial that you find out the requirements to be met if someone is applying for a driver's license and has an Acquired Brain Injury. It is important to get this done, as it provides you, your child and others with legal protection should an accident occur. Failure to disclose a medical matter may be an offence, and any license or permit obtained by false statement could be rendered null and void.

**An assessment by an occupational therapist and/or a neuropsychologist is recommended.**



# Adolescent Self-Regulation

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**Despite their age, adolescents with self-regulation difficulties require the amount of supervision and structure typically provided for younger children.**

## Use Everyday Activities:

- Use videos, daily situations, and real life experiences to illustrate other's points of view. Engage in discussions in which you and your adolescent each "take a side," and then switch sides. Avoid topics that are likely to start a fight.
- Find ways to talk about what is really going on at school and with friends. Discussions need to be non-judgmental.
- Make a habit of starting off a conversation on a positive or neutral topic. Do not let yourself get immediately pulled in to controversy or negativism. Schedule a daily time for discussion about problems and review of household rules and expectations. Avoid these topics during other conversations.
- Set a curfew for your adolescent and expect him to call you if plans change. Reinforce your expectations by making the privilege of going out contingent on his follow through.

## Change the Environment:

- Use and enforce clear rules and consequences for inappropriate verbal behavior, drug use, and alcohol use. Do not accept these activities as part of "a phase." Instead, address and deal with them directly.
- Provide clear and concrete information about the ramifications of sexual activity. Teach your teenager how to deal with social situations that may lead to sexual activity. Identify specific situations (for example, he is at a large party or an unsupervised get-together, and alcohol and drugs are being used) and plan a course of action. Support your adolescent in developing a detailed and realistic plan of escape from such situations. Discourage unrealistic solutions (for example, "I'll just be cool").
- Acquire detailed knowledge about your adolescent's peer group. Ask directly about what goes on at the parties he attends, and reward him for telling you the truth, even if it is upsetting. Encourage your teen to invite friends to get together at your house. Limit interaction with peers who are involved with drugs, alcohol, or other dangerous activities.



### Teach New Skills:

- An adolescent who has poor self-regulation abilities should be involved in individual therapy with a therapist knowledgeable in working with both adolescents and brain injury. Therapy should include a family component to help guide discussions about appropriate limits, expectations, and punishments, and to brainstorm ideas for appropriate family activities.
- In order to avoid poor choices, your adolescent must be involved in other structured activities that fill time and provide opportunities to meet well-behaved peers. Examples include volunteer work, jobs, community recreation activities, hobby-related courses, and community service.
- Verbal abuse may be a symptom of difficulty with expressive language. If your adolescent has this problem, teach him how to appropriately express himself in language and behavior, by discussing acceptable alternatives and modeling them yourself. Participation in a social skills group may be necessary to offer your teenager a reasonable forum for problem-solving better behavior in a group of his peers.
- Adolescents with judgement difficulties experience widespread interpersonal and social failure. Teachers and parents must persist in their efforts to create opportunities for success and improved self-esteem.









## Federal Financial Resources

Name	Description	Eligibility	Applying
<b>Universal Child Care Benefit (UCCB)</b>	The UCCB is designed to help Canadian families, as they try to balance work and family life, by supporting their child care choices through direct financial support. The UCCB is for children under the age of 6 years and is paid in installments of \$100 per month per child.	<ul style="list-style-type: none"> <li>- you must live with the child, and the child must be under the age of 6;</li> <li>- you must be the person who is primarily responsible for the upbringing and for the care of the child</li> <li>- you must be a resident of Canada;</li> <li>- You or your spouse or common-law partner must be: Canadian citizen, permanent resident, protected person, or temporary resident</li> </ul>	Canada child benefits application or by applying online on My Account by using the <i>Apply for child benefits</i> service.
<b>Canada Child Tax Benefit (CCTB)</b>	The CCTB is a tax-free monthly payment made to eligible families to help them with the cost of raising children under age 18. It may include the National child benefit supplement, a monthly benefit for low-income families with children, and the Child disability benefit, a monthly benefit providing financial assistance for qualified families caring for children with severe and prolonged mental or physical impairments.	<ul style="list-style-type: none"> <li>- you must live with the child, and the child must be under the age of 18;</li> <li>- you must be primarily responsible for the care and upbringing of the child;</li> <li>- you must be a resident of Canada; and</li> <li>- you or your spouse or common-law partner must be a Canadian citizen, a permanent resident, a protected person, or a temporary resident who has lived in Canada for the previous 18 months, and who has a valid permit in the 19<sup>th</sup> month.</li> </ul>	Automated Benefits Application service or complete Form RC66, Canada Child Benefits Application or online on My Account by using the <i>Apply for child benefits</i> service.
<b>Child Care Expenses Deduction</b>	A tax deduction may be available to you at income tax time through the Child Care Expenses Deduction. If you have paid for childcare to a caregiver, daycare, day nursery, day or overnight camps, etc., to earn income from employment, carry on a business or attend school, you may be eligible	<a href="http://www.cra-arc.gc.ca/tx/ndvds/tpcs/ncm-tx/rtrn/cm-pltng/ddctns/lns206-236/214/wh/menu-eng.html">http://www.cra-arc.gc.ca/tx/ndvds/tpcs/ncm-tx/rtrn/cm-pltng/ddctns/lns206-236/214/wh/menu-eng.html</a>	Apply using Form T778, Child Care Expenses Deduction

<b>Medical Expenses Deduction</b>	<p>Medical expenses for your child can be claimed through your income tax for eligible expenses within a 12-month period. It is important to hold on to all receipts that are medically related throughout the year. The total expenses have to be more than 3% of your net income or \$1,884 but whichever is less.</p>	<p><a href="http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html">http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html</a></p>	<p><a href="http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html">http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html</a> Find the correct expense and click to see certification needed</p>
<b>Child Disability Benefit (CDB)</b>	<p>The Child Disability Benefit is a tax-free benefit for families who care for a child under age 18 with a severe and prolonged impairment in mental or physical functions. A benefit of up to \$2,455 per year (\$205.58 per month) is available for children who qualify.</p>	<p>Recipients must be the primary caregivers of a child under age 18 with a severe and prolonged impairment in mental or physical functions. Other criteria may apply.</p>	<p>To apply for this benefit, you will need to have your child's doctor fill out Form T2201-Disability Tax Credit Certificate</p>
<b>Registered Disability Savings Plan (RDSP)</b>	<p>A registered disability savings plan (RDSP) is a savings plan that is intended to help parents and others save for the long-term financial security of a person who is eligible for the Disability Tax Credit. Contributions to an RDSP are not tax deductible and can be made until the end of the year in which the beneficiary turns 59 years of age. Contributions that are withdrawn are not to be included as income for the beneficiary when paid out of a RDSP. However, the Canada disability savings grant (CDSG), Canada disability savings bond (CDSB) and investment income earned in the plan will be included in the beneficiary's income for tax purposes when paid out of the RDSP.</p>	<p>You can designate an individual as beneficiary if the individual:</p> <ul style="list-style-type: none"> <li>- is eligible for the disability tax credit</li> <li>- has a valid social insurance number;</li> <li>- is a resident in Canada when the plan is entered into; and</li> <li>- is under the age of 60 ( a plan can be opened for an individual until the end of the year in which they turn 59).</li> </ul> <p>The age limit does not apply when the beneficiary's RDSP is opened as a result of a transfer from the beneficiary's former RDSP.</p> <p>A <a href="#">beneficiary</a> can <b>only have</b> one RDSP at any given time, although this RDSP can have several <a href="#">plan holders</a> throughout its existence, and it can have more than one plan holder at any given time.</p>	<p>To open an RDSP, a person who qualifies to be a holder of the plan must contact a participating financial institution that offers RDSPs. These financial institutions are known as <b>issuers</b>.</p>

<b>Canada Disability Savings Grant (CDSG)</b>	<p>The Canada Disability Savings Grant is a matching Grant the Government will deposit into your RDSP to help you save. The Government provides matching grants of up to 300 percent, depending on the amount contributed and the <b><u>beneficiary's family income</u></b>. The maximum Grant is \$3,500 each year, with a limit of \$70,000 over your lifetime. Grants are paid into the RDSP until the end of the calendar year in which you turn 49 years of age.</p>	<p>After opening an RDSP, if you meet the following requirements, you may apply for a Grant:</p> <ul style="list-style-type: none"> <li>- be 49 years of age or under (if you are 49, you must apply before the end of the calendar year in which you turned 49);</li> <li>- be a Canadian resident;</li> <li>- have a <u>Social Insurance Number (SIN)</u>;</li> <li>- be eligible for the Disability Tax Credit (<u>disability amount</u>);</li> <li>- make contributions to your RDSP; and</li> <li>- for beneficiaries <b>over 18 years of age</b>: <ul style="list-style-type: none"> <li>- file your personal income tax returns for the past two years and all future taxation years to qualify for the 200 percent and 300 percent matching Grant;</li> <li>- for beneficiaries <b>under 18 years of age</b>: <ul style="list-style-type: none"> <li>parents or guardians must file their income tax returns for the past two years and all future taxation years, and apply for the <u>Canada Child Tax Benefit</u> to qualify for the 200 percent and 300 percent matching Grant.</li> </ul> </li> </ul> </li> </ul>	<p>You must apply for the Grant through the <u>financial organization</u> where you have your RDSP. For your convenience, you can download, complete and print the <u>application form</u> found at <a href="http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml">http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml</a> before meeting with your financial organization.</p>
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<p><b>Canada Disability Savings Bond (CDSB)</b></p>	<p>The Canada Disability Savings Bond is <a href="#">money</a> the Government will deposit into the <a href="#">Registered Disability Savings Plans (RDSPs)</a> of low-income and modest-income Canadians. If you qualify for the Bond, you will receive up to \$1,000 a year depending on your family income (see <a href="#">beneficiary's family income</a>). There is a limit of \$20,000 over your lifetime. Bonds are paid into the RDSP until the end of the calendar year in which you turn 49 years of age. You do not need to make any contributions to your RDSP to receive the Bond.</p>	<p>After opening an RDSP, if you meet the following requirements, you may apply for a Bond:</p> <ul style="list-style-type: none"> <li>- be 49 years of age or under (if you are 49, you must apply before the end of the calendar year in which you turned 49);</li> <li>- be a Canadian resident;</li> <li>- have a <a href="#">Social Insurance Number (SIN)</a>;</li> <li>- be eligible for the Disability Tax Credit (<a href="#">disability amount</a>);</li> <li>- have a family income of less than \$43,561 (this amount is updated each year based on the rate of inflation);</li> <li>- for beneficiaries <b>over 18 years of age</b>: file your personal income taxes for the past two years and all future taxation years;</li> <li>- for beneficiaries <b>under 18 years of age</b>: parents or guardians must file their taxes and apply for the <a href="#">Canada Child Tax Benefit</a> for the past two years and all future taxation years.</li> </ul>	<p>You must apply for the Bond through the <a href="#">financial organization</a> where you have your RDSP. For your convenience, you can download, complete and print the <a href="#">application form</a> found at <a href="http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml">http://www.esdc.gc.ca/eng/disability/savings/grants_bonds.shtml</a> before meeting with your financial organization.</p>
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## Provincial Financial Resources

<b>Assistance for Children with Severe Disabilities – Ontario</b>	A program that provides financial assistance to parents to help with extraordinary cost related to their child's severe disability. It is a direct funding program for low and moderate income families.	A parent or legal guardian whose child: - is under 18 years of age - lives at home - and has a severe disability	Contact your local regional office and ask for an application form.
<b>Special Services at Home Program - Ontario</b>	The Special Services at Home program helps families who are caring for a child with a developmental or physical disability. It is funded and managed by the Ministry of Community and Social Services. The program helps families pay for special services in or outside the family home as long as the child is not receiving support from a residential program. For example, the family can hire someone to: help the child learn new skills and abilities, such as improving their communications skills and becoming more independent provide respite support to the family - families can get money to pay for services that will give them a break (or "respite") from the day-to-day care of their child	Children with a developmental or physical disability (or their families) can apply if they: - live in Ontario - need more support than most families can provide - are living at home with their family, or - if they are not living at home with their family and are not being helped by other residential services	<a href="http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx">http://www.children.gov.on.ca/htdocs/English/topics/specialneeds/specialservices/index.aspx</a>

<b>Ontario Drug Benefits (Trillium Drug Program)</b>	<p>The TDP helps people who have high prescription drug costs relative to their household income. It covers all drugs approved under the <a href="#">Ontario Drug Benefit (ODB) program</a>. For drug products that are not on the list of approved ODB products, your doctor may apply for special approval through the <a href="#">Exceptional Access Program (EAP)</a>.</p>	<p>You may qualify for the Trillium Drug Program if:</p> <ul style="list-style-type: none"> <li>- You have a valid <a href="#">Ontario health card</a></li> <li>- You live in Ontario</li> </ul> <p><b>AND</b></p> <p>You are <b>not</b> covered under ODB as:</p> <ul style="list-style-type: none"> <li>- a <a href="#">senior over 65 years of age</a></li> <li>- someone who receives financial help through <a href="#">Ontario Works</a> or the <a href="#">Ontario Disability Support Program</a></li> <li>- a resident of a Long-Term Care home or Home for Special Care or</li> <li>- someone who receives <a href="#">Home Care Services</a> <b>OR</b></li> <li>- You don't have private health insurance or your private insurance does not cover 100% of your prescription drug costs.</li> </ul>	<p>To get an application kit:</p> <ul style="list-style-type: none"> <li>- ask at your local pharmacy OR</li> <li>- call 1-800-575-5386 OR</li> <li>- download the Application for Ontario Drug Benefits and A Guide to Your Application (Ontario Drug Benefit) at <a href="http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx">http://www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx</a></li> </ul>
<b>Assistive Devices Program – Ontario (ADP)</b>	<p>The objective of the Assistive Devices Program (ADP) is to provide consumer centered support and funding to Ontario residents who have long-term physical disabilities and to provide access to personalized assistive devices appropriate for the individual's basic needs.</p> <p>Devices covered by the program are intended to enable people with physical disabilities to increase their independence through access to assistive devices responsive to their individual needs.</p>	<p>Eligibility includes any Ontario resident who has a valid <a href="#">Ontario Health card</a> issued in their name and has a physical disability of six months or longer. Equipment cannot be required exclusively for sports, work or school. ADP does not pay for equipment available under the Workplace Safety and Insurance Board or to Group "A" veterans for their pensioned benefits.. There are specific eligibility criteria which apply to each device category.</p> <p>An individual who has a chronic illness or dysfunction that requires long-term oxygen therapy may be eligible for home oxygen funding.</p>	<p>All forms can be found at:</p> <p><a href="http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/MinistryResults?Openform&amp;SRT=T&amp;MAX=5&amp;ENV=W&amp;WE&amp;STR=1&amp;TAB=PRO-FILE&amp;MIN=014&amp;BR-N=67&amp;PRG=67">http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/MinistryResults?Openform&amp;SRT=T&amp;MAX=5&amp;ENV=W&amp;WE&amp;STR=1&amp;TAB=PRO-FILE&amp;MIN=014&amp;BR-N=67&amp;PRG=67</a></p>

## Non-Government Financial Resources

Name	Description	Eligibility	Applying
<b>Helping Acquired Brain Injury Treatment H.A.B.I.T.</b>	The Helping Acquired Brain Injury Treatment assists in funding medical healthcare and supportive services for individuals, charitable organizations and medical facilities with special emphasis on the needs of children and youth with brain injury.	For more information: Phone: 519-672-4942 Email: <a href="mailto:habit@rogers.com">habit@rogers.com</a>	<a href="http://www.habit-braininjury.ca/pdf/Application.pdf">http://www.habit-braininjury.ca/pdf/Application.pdf</a>
<b>The Jennifer Ashleigh Foundation</b>	Assists children who are seriously ill, have a permanent disability and are 21 years of age or under and whose permanent residence is in Ontario, funding exists to provide emergency financial relief, respite for medical treatments not covered by government health plans or insurance	The Jennifer Ashleigh Children's Charity assists children who are: seriously ill; have a permanent disability; 21 years of age or under; permanent residents of Ontario or Landed Immigrant status	You may call the Charity office at 905.852.1799 Ext. 22 or 23 or toll free at 1.866.268.9187 and ask for a Request for Assistance form or go to " <a href="http://www.jenash.org/about-us/what-we-do/">Get Help Now</a> " to print off an application form. The form may be completed by the child's parent, physician, therapist, social worker, teacher or community liaison. <a href="http://www.jenash.org/about-us/what-we-do/">http://www.jenash.org/about-us/what-we-do/</a>

## Accommodations Financial Resources

Name	Description	Eligibility	Applying
<b>Ronald McDonald House</b>	<p>Ronald McDonald House of Southwestern Ontario provides a home away from home where guest families can focus their attention on their ill or injured child and family.</p> <p>It offers safe, low-cost accommodations in a welcoming atmosphere for families residing outside of London who have children receiving treatment from any of the area's health care centres. The first priority is to provide a secure and stable environment for families during this stressful time.</p>		<p>Tel: (519) 685 – 3232  Toll Free: 1-877-848-8188  E-Mail: <a href="mailto:info@rmhswo.ca">info@rmhswo.ca</a></p>
<b>Home Modifications</b>	<p>The <a href="#"><u>Residential Rehabilitation Assistance Program - RRAP for Persons with Disabilities</u></a> offers financial assistance to allow homeowners and landlords to pay for modifications to make their property more accessible to persons with disabilities. These modifications are intended to eliminate physical barriers, imminent safety risks and improve the ability to meet the demands of daily living within the home.</p>	<p>Homeowners and landlords may qualify for assistance if the property is eligible. Your property may be eligible for RRAP-D if the property:</p> <ul style="list-style-type: none"> <li>- is occupied, or is intended to be occupied, by a low-income person with a disability;</li> <li>- is rented and the rents are less than established levels for the area; or</li> <li>- is owned and the house is valued below a certain amount; and</li> <li>- does not have major deficiencies to the structure and systems.</li> </ul> <p>Other criteria may apply.</p>	<p>Tel: 1-800-668-2642</p>

## Scholarships, Bursaries, and Student Loans

### Financial Resources

Name	Description	Eligibility	Applying
<b>Mattison Endowment Fund Scholarship for Disabled Students</b>	<p>Deadline Date: May 15<sup>th</sup>, 2014</p> <p>Value: \$2,500</p> <p>Number Available: 6</p> <p>Duration: One year; may be renewed upon re-application.</p>	<p>Candidates must be Canadian citizens or have lived in Canada for at least 2 years as permanent residents.</p> <p>Candidates must be diagnosed with a documented permanent disability that is the primary disability for which they are applying.</p> <p>Candidates must have a minimum average of 85%.</p>	<a href="https://juno.aucc.ca">https://juno.aucc.ca</a>
<b>Bursary for Students with Disabilities (BSWD) - Ontario</b>	<p>This bursary provides up to \$2,000 per academic year for students with permanent or temporary disabilities who require education-related services or equipment, such as tutors, note-takers, interpreters, brailers or technical aids, that are directly related to their disability.</p>	<p>To be eligible for the BSWD, you must:</p> <ul style="list-style-type: none"> <li>- Have applied and are eligible for OSAP for Full-Time Students and have at least \$1 in calculated Ontario need; or</li> <li>- Have applied and are eligible for OSAP for Part-Time Students and are receiving an Ontario Part-Time Grant; or</li> <li>- Have applied and are eligible for an Institution-Funded Special Bursary.</li> </ul> <p>AND,</p> <ul style="list-style-type: none"> <li>- Have a permanent or temporary disability; and</li> <li>- Have disability-related educational costs (e.g. note-takers, vision/learning aids) that result from your disability and are not covered by another agency.</li> </ul>	<p>Use the Application for Bursary for Students with Disabilities and Canada Student Grant for Services and Equipment for Persons with Permanent Disabilities (CSG-PDSE), available on the Forms section of the OSAP website. The CSG-PDSE provides up to \$8,000 of federal assistance for disability-related educational services and equipment for students with permanent disabilities. You will be considered for both programs through a single application. For more information on the CSG-PDSE visit <a href="http://www.canlearn.ca">www.canlearn.ca</a></p> <p>Deadline: Submit your application 60 days before the end of your study period.</p>

<b>Canada Student Loans</b>	<p>The <a href="#">Canada Student Loans Program</a> provides financial assistance in the form of loans and grants to post-secondary students who demonstrate financial need.</p>	<p>Students must give loan providers proof of enrolment within six months of finishing their last study period in order to maintain interest-free status while studying. Confirmation of Enrolment forms are issued by educational institutions.</p>	<ul style="list-style-type: none"> <li>- Students must first apply for a provincial or territorial student loan. Students are automatically considered for a Canada Student Loan when they apply for a provincial or territorial student loan.</li> <li>- Loan application forms are available from provincial and territorial student assistance offices and at financial aid offices in educational institutions.</li> <li>- Students must apply every year in order to receive funding.</li> </ul>
<b>Canada Student Grant for Students with Permanent Disabilities</b>	<p>Under this grant, students with permanent disabilities may receive \$2,000 per academic year to help cover the costs of accommodation, tuition, and books.</p>	<p>You are eligible if you:</p> <ul style="list-style-type: none"> <li>- apply and qualify for a <a href="#">Canada Student Loan</a></li> <li>- attend a <a href="#">designated post-secondary institution</a> on a part-time or full-time basis; and</li> <li>- meet the criteria for students with <a href="#">permanent disabilities</a> (You must be able to provide proof of your disability in the form of a medical certificate, a psycho-educational assessment, or documentation proving receipt of federal or provincial disability assistance, as outlined in the <a href="#">Canada Student Financial Assistance Regulations</a>)</li> </ul>	<p>When you apply for a Canada Student Loan in your province or territory of permanent residence, you will also have to provide proof of your disability in the form of a medical certificate, a psycho-educational assessment, or documentation proving receipt of federal or provincial disability assistance. If you qualify for a Canada Student Loan you will automatically be assessed for the grant. Eligibility for this grant is determined during the assessment of the student loan process.</p> <p>Loan application forms are available from provincial and territorial student financial aid offices in educational institutions.</p>

<p><b>Canada Student Grant for Services and Equipment for Students with Permanent Disabilities</b></p>	<p>If you require exceptional education-related services or equipment, you may be eligible to receive the Canada Student Grant for Services and Equipment for Students with Permanent Disabilities. This grant offers:</p> <ul style="list-style-type: none"> <li>- up to \$8,000 per academic year (August 1 to July 31) for each year of studies after high school (including undergraduate and graduate levels), provided you continue to meet the eligibility criteria. The assistance provided under this grant is determined apart from your assessed need.</li> </ul>	<p>You are eligible if you:</p> <ul style="list-style-type: none"> <li>-apply and qualify for student financial assistance (have at least a \$1 of assessed need)</li> <li>-are in a full-time or part-time program at a designated post-secondary institution</li> <li>-meet the criteria for students with permanent disabilities</li> <li>-include one of the following with your loan application as proof of your permanent disability: a medical certificate, a psycho-educational assessment, or documents that prove you've received federal or provincial permanent disability assistance</li> <li>-provide written confirmation that you are in need of exceptional education-related services or equipment from a person qualified to determine such need</li> <li>-show, in writing, the exact cost of the equipment and services.</li> </ul>	<p>If you want to apply for either the Canada Student Grant for Students with Permanent Disabilities and/or the Canada Student Grant for Services and Equipment for Students with Permanent Disabilities, please contact your province or territory's <a href="#">student financial assistance office</a>.</p> <p>Note: A separate application form is required to apply for the Canada Student Grant for Services and Equipment for Students with Permanent Disabilities.</p>
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<p><b>www.scholarshipscanada.com</b></p>	<p>ScholarshipsCanada.com is one of Canada's largest and most comprehensive databases for students looking for scholarships, bursaries, grants and student awards. With over 77,744 scholarships, bursaries and awards worth over \$167,627,971, we offer unique opportunities for students across all schools, levels of study, fields of study, extracurricular activities and much, much more.</p>		<p>www.scholarshipscanada.com</p>
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## SIBLINGS AND PEERS: UNDERSTANDING TBI IN THEIR OWN WAY

### Joel's Diary

**June 2:** My Dad told me I should keep a diary to help me. Ever since my brother got injured it has been awful. My parents are at the hospital all the time. I have to stay at Joey's house. School is a bunch of crap. And I don't know anything that is going on. I just hope my brother lives.

**June 7:** Dad said my brother is not in a coma anymore. But he still can't move or talk. They said I could see him on Saturday. I'm pretty scared. Dad said they had to shave his head and he has lots of tubes and things in him.

**June 10:** I finally saw my brother and I almost threw up. He looks so bad. I tried to cry but nothing would come out. Dad told me to speak to him normally so I told him about school stuff and his friends. He didn't move or anything. I don't know if he heard me. I feel so sick.

**June 14:** I'm not doing well in school. I flunked my math test today. I know my teacher is going to call my parents. Mom and Dad are arguing a lot lately. I try to sleep but I hear them fighting. Dad is sleeping in my brother's room.

**June 17:** I'm going to go see my brother again. I hope he's looking better. I hope he still knows who I am. I hope he doesn't die.

**June 18:** Dad told me tonight that my Mom is going to live with Grandma for a while. Mom is really stressed Dad said. Ever since this accident happened everything has been awful. Now my Mom is leaving. I hate school. I hate everything.

The excerpts from the diary above are from a 9 year old boy whose 15 year old brother was injured and sustained a severe traumatic brain injury (TBI). Siblings also find it extremely difficult to deal with an injury to their brother or sister and often cannot understand the "injury" itself and how devastating a TBI is to the entire family constellation. Siblings are shuttled to school, to a friend's or relative's

home, sometimes to the hospital and end up on an emotional roller coaster that makes no sense to them. Much of the information they receive is second-hand or overheard from adults. While they may understand the need for their parent(s) to be with their brother or sister, they still have their own needs.

A number of questions surface in their minds: Will my brother or sister live? If they do live, will they be the same as before? What does it mean to have a "traumatic brain injury"? How long is all this going to go on? Why are my parents so stressed or why are they arguing so much? Who will help me with my school work? How will I get to my baseball game this weekend? How come nobody tells me anything????

Friends as well need support and understanding. Too often the injury is left "out-of-sight, out-of-mind." Their friend's accident and injury is not discussed with them and they only receive information that is overheard from phone calls and adult conversations. They begin to question: Will my friend come back to school? Will they be retarded? Will they be able to walk?

Siblings and peers need to be part of the information loop concerning their brother/sister/friend. The ideas that follow will help parents, relatives, friends and teachers enable the sibling or peers understand TBI and the injury itself and provide continuity as their brother/sister/friend recovers and returns home.

At the time of the accident and during the hospital/rehabilitation stay:

1. Explain exactly what happened to the sibling/peer in language and ideas they can understand. "Your brother/sister/friend was in an accident. They were hurt and taken to the hospital so the doctors and nurses could help them." Oftentimes it is upsetting for siblings/peers to see their loved one in the hospital, but it may help to drive by the hospital so that they know exactly where their sibling/peer is. When children ask whether their sibling/peer will live, answer them directly. Tell them it is still too soon to know in cases of severe brain injury, but assure them that the doctors are doing all they can and when you know you will tell them. Continually let them know that their sibling/peer is in good care.
2. Explain words like "coma" and "traumatic brain injury." Medical terms are frightening to children and often do not make any sense. Tell them that "coma" is when you are unconsciousness because your brain has been hurt. Just like when you twist an ankle and it swells up and gets black and blue, your brain swells and bleeds and that can make you unconscious. The doctors are trying to stop the swelling and bleeding, but people just don't wake up from a coma like we wake up from sleep. Explain to them how people wake up very slowly from a coma over days and weeks. In addition, tell them that your brain helps you to do 3 things: think, move about and feel (behave). When you have a brain injury, you may have problems with your thinking (memory, language, etc.), your ability to move around and the way you act or feel. Our brain is the most important and most complicated organ in our body. When the brain is injured it takes a long time to heal and while some problems get better, some may stay with us forever. Fortunately, there are ways to help people work around their difficulties.
3. Allow the sibling/peer the opportunity to communicate. Some children need to talk, some need to keep diaries, some need to ask 100 questions a day over and over. The more opportunities we create to help children express their feelings, fears and needs, the better they will understand and feel a part of what is going on. Trying to "protect" children by isolating them or not answering their questions only increases anxiety and misunderstanding. Children fear what they don't know and are wonderfully resilient to the things that they can understand at their level. Schools can

generally provide many kinds of support services to help the sibling/peer. However, some children may require additional professional counselling supports to help them cope with the injury to their sibling or peer.

**At discharge to home, school and community:**

1. When a child returns home from a long stay in the hospital or rehabilitation center, his/her siblings and peers think that their loved one is "all better," that they have been "fixed" or "cured." For many children with TBI, their return home is the real beginning of recovery. Returning to home, school and community presents its own challenges and siblings and peers play a vital and integral part of this period of recovery. Siblings and peers need to know ahead of time that the return to home and school does not mean that everything is OK and will return to normal. They need to know that we are all still working on ways to help their sibling or friend continue to get better. By using words like "better," rather than words like "rehabilitated, cured, recovered, etc.", it will help children understand that "getting better" is something that happens over time. Every one of us is always trying to do "better."
2. Siblings and peers are often the first to recognize that their friend is "not the same as before." Even subtle personality and cognitive changes rarely escape their recognition. However, siblings and peers are also the most accepting of these changes when they know how they can help. Unfortunately, for children who are severely disabled, the effects on their siblings and peers can be devastating. Younger brothers and sisters with an older sibling with TBI may find themselves suddenly as the "older child" in the family and that new roles and responsibilities will fall on their shoulders. Again, counselling, especially for the entire family, may be needed to help the family as a whole and as individuals accept, adjust, modify and redevelop their relationships with each other.
3. Siblings and peers will be a tremendous support for their friend in the school and community. However, along with that support comes tremendous responsibility and guilt if the sibling/friend does not feel they can be the "same" brother/ sister or friend as they were before. The high school years, in particular, can be hard for all adolescents, but life for an adolescent with a TBI can seem like a never ending series of challenges and losses. Siblings and peers who truly understand that their loved one's needs are really the same as their own need (i.e., a supporting family, a good place to live, school/work and friends who care about them) will realize that while life changes, it is in change that growth occurs. While one does not want to burden children and adolescents with having to "care for" their sibling/friend with a disability, part of life is learning how to best handle situations with maturity and understanding.

These guidelines will hopefully help siblings and peers better understand that while life for their brother/sister/friend may change, their own lives change as well. The more the siblings and peers are given opportunities to learn about traumatic brain injury, express their needs and feelings and have their questions and concerns answered honestly, the better they will understand their brother/sister/friend...in their own way.

Author: Ronald C. Savage, Ed.D.



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# Siblings and Acquired Brain Injury - Fact Sheet

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**Because siblings are such a large part of each other's lives, it is not surprising that when one sustains an acquired brain injury, the others can be greatly affected - sometimes for many years.**

Brothers and sisters often share a lifelong relationship. They greatly influence one another's behaviour, personality and identity. The emotional bond that exists is often characterised by such dynamics as love, hate, jealousy, rivalry, companionship, solidarity, loyalty, competition, and affection. Although the onset of a child's brain injury is different for every individual, there are some common experiences that siblings are likely to feel.

## The Sibling Story

Having a brother or sister acquire a brain injury can be devastating for a young person. As shared by one teenage girl, "...The whole situation... Sort of turned our lives upside down which was a real bugger. Probably because everything was going really smoothly and then, Yuk... Lots more stress than usual.... We were tired and freaked out and all that sort of stuff that you have got to expect".

## Emergency, Intensive Care and Hospital

This can be a particularly stressful time for siblings because it is fuelled by a range of thoughts and emotions. Siblings may be present when their brother or sister sustains their injury or becomes ill. Those who witnessed the injury said that they still experienced memories of the accident many years later.

Some of the young people who shared their stories said that they blamed themselves or accepted some form of responsibility for their brother or sister's brain injury, despite having no control over what happened. Seeing their brother or sister in hospital can also be overwhelming and confusing. For some it may also trigger fears of death. Siblings said that talking to someone, particularly their parents, or close

relatives assisted in helping them feel better. In addition to feeling intense worry, some young people may also experience emotional turmoil, such as feeling shock, numbness, isolation, and sadness. Siblings, especially those who are teenagers, may want to spend all their time at the hospital with their brother or sister, which can interrupt their routine or life plans.

If parents are at hospital much of the time siblings may have to look after themselves more and may feel jealousy or abandoned. These feelings may continue after discharge when the parents are concentrating on the injured child. Siblings usually understand and accept this situation but may experience these feelings nonetheless.

One of the most difficult experiences described by the young people who told their stories was seeing their parents upset and distressed, especially when their brother or sister was in hospital and for some time after. As a result siblings may attempt to put on a brave face and act in control.

## **Return Home, Rehabilitation and Onwards**

Siblings also have to adjust to many changes when their brother or sister returns home. Many notice the full impact of the changes when their brother or sister returns home and may be confused and unable to cope, particularly with violence or risk-taking behaviour. There may be a deep sense of loss as a result of the changes in their sibling, grieving for the person they “lost” and the person they could have been. They will frequently be worried for them and become protective even if they are younger chronologically.

Siblings can be frustrated, stressed, angry, and embarrassed about their brother or sisters' behaviour at times. At the same time however, they may feel guilty and ashamed for these feelings. A positive outcome is that siblings often have an increased understanding of disability and become more tolerant, responsible and mature. They may also be able to better accept their situation and realize their own special worth and set and accomplish their own life goals.

## **Strategies for Assisting Siblings**

The type of support given to siblings will often depend on such things as the age of the sibling, their friendship networks, familial support and their living environment. However, there are many complex processes impacting on how young people react to their brother or sisters' brain injury. When assisting siblings one must keep in mind that each person should be listened to carefully and their individual experiences and needs assessed.

## **Encourage Communication**

Many siblings can greatly benefit from debriefing to help them process their thoughts and feelings about the event. Often a staff member at the hospital can arrange for someone experienced to talk to young people about their fears, guilt, anxieties and concerns. Talking to family and close friends also helps siblings enormously, as does someone willing to listen to them about what they are thinking or feeling. Even though it may seem daunting and scary, talking helps young people to get things off their chest and to get appropriate support. It may be that siblings feel the need to talk about this at length and for some time after the accident as the experiences of siblings change over time and may impact on them for many years after the injury. The school which siblings attend must be informed of the siblings' situation so that they can allow concessions and provide support for them, particularly when their brother or sister is first injured.

## **Appropriate Information, Preparation and Inclusion**

Most siblings want as much information as possible about their brother or sister's brain injury, and their condition. Information is usually available in booklets and brochures given out in hospitals or at various interstate associations and hospitals. Nurses and doctors may also be able to help by providing information to the family, including the siblings. It is also important to prepare siblings for the first hospital visit, especially about the medical equipment used to help their brother or sister and its purpose. Some siblings will want to be involved in their brother or sisters' recovery and rehabilitation.

It is important, however, for siblings to be given a choice. Some younger siblings may prefer limited information as more details about their brother or sister could upset them further. Siblings want to be sufficiently briefed and prepared for what to expect when their brother or sister returns home, such as how the acquired brain injury may affect their behaviour and how to handle these changes.

## **Normalize and Validate Feelings**

It is very important that siblings know that their feelings are appropriate and common to experience when their brother or sister sustains an acquired brain injury. It is important to encourage siblings to talk about their concerns and have someone listen to them. Often parents can encourage siblings to talk by talking about their own feelings. This sets up an environment that shows other family members that talking about their feelings is acceptable. Siblings should also be given permission to feel upset and to talk through their concerns and frustrations. For those young people who do not wish to talk to anyone, encourage them to write down their feelings, by either writing themselves a letter, or writing in a journal or diary. Alternatively, reading information and providing them with books and brochures about the impact of acquired brain injury may also help.



## Acknowledge Siblings' Contributions

It is very important that parents acknowledge the difficulties and sacrifices that siblings make when their brother or sister sustains an injury. Many siblings put on a brave face and attempt to be strong for the entire family, sometimes for years after the injury. No matter how unaffected siblings may appear, however, it is important that their contributions, trials and achievements are recognized. Acknowledging their difficulties, responsibilities and understanding is an essential ingredient in supporting siblings. It is also important that siblings are not always expected to provide constant time, attention or care to their brother or sister with acquired brain injury. Siblings sometimes need time to themselves or to be with their friends alone for time out.

## Time-out with Parents and Respite

Siblings still need some time out with their parents alone. They need to know they are still special, even if they don't have much time together. Do not assume that siblings know this, sometimes they need a reminder. Younger children sometimes display changes in their behaviour when they fail to understand the inequity of time - especially when their brother or sister with acquired brain injury looks like they always did. Encourage the siblings to go out with friends on their own and to continue their sport, activities, school, hobbies and goals that interest them. It is important to return to stability and routine as soon as possible.

## Groups

Siblings can gain an enormous amount from hearing other stories of siblings in a similar situation. This helps them to feel supported, by knowing that other people experienced similar things. It is therefore important to encourage children to go to sibling groups when they become available, because support from people in a similar situation can provide great relief and release many of the anxieties and fears they may have. These groups are also fun and provide activities and time out for siblings. Other sibling support networks come in the form of an internet group, whereby siblings of children or adults with special needs can talk over the internet and share their experiences.

## Conclusion

It has been shown that life after brain injury can present many changes, challenges and learning experiences for all of those affected. Like all family members, siblings are also affected in a myriad of ways. The stories shared by the young people who have experienced this situation reflect the strength, resilience, patience and maturity in managing the life change presented to them when their playmate, confidante and life's companion is struck with an acquired brain injury. Siblings mostly cope extraordinarily well, however, they may also experience many underlying fears, anxieties, feelings, thoughts and concerns that they find hard to understand and comprehend. These experiences can be somewhat alleviated when they are provided with support, compassion, understanding and acknowledgment. As one sibling put it, "Don't give up hope because it does come good. Like it might not come good totally, but it does come good - enough so that you can get over it."

## Self Care for Caregivers

**Submitted by Nancy Attrill, Advantage Neuro Balance, Mother and caregiver of a daughter with a severe brain injury**

It is well documented that family caregivers are less likely than non-caregivers to practice preventive healthcare and self-care behaviour. Many problems are reported by caregivers while they are immersed in caring for their children with Acquired Brain Injury. These include:

- sleep deprivation
- poor eating habits
- lack of exercise
- lack of rest while ill
- personal and workplace relationships are compromised
- avoid making medical appointments for themselves

Family caregivers are also at increased risk for depression and forming addictive habits including excessive alcohol and drug use. Caregiving is an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are extremely stressful. This handbook provides many resources, and here are some tips I have learned to maintain good physical and emotional/mental health while providing loving care to your child:

- Ask for help! This could be family members and friends helping with caring for your child, or to come and do laundry, clean the house or cook a meal while you take care of your child. Or, they could entertain the other children in the home. It all helps!
- When someone takes over the care of your child, even for an hour, make good use of it.
- Plan family meals ahead. Refer to "Nutrition for Children".
- Be your child's advocate. Working with a good case manager can save the day!
- Seek medical care when ill.
- Avoid overeating sweets and junk food.
- Exercise whenever possible. ( Review the 10 minute workout plan on page #104 )
- Find joy with your brain injured child. Humour is great medicine!
- Go to bed at a reasonable hour, and take time for deep breathing, positive thought, or meditation.
- Let out emotion in a positive way, either by talking with a friend, or by simply having a good cry. Don't wallow too long, however.
- Share your attention with other family members. If you have other children, schedule quality time for them. That goes for your spouse too!
- Use a daytimer to be organized and use it daily.
- Keep a list of contacts with you such as family, care giving services, therapists, physicians etc.
- Never, never, never give up! Don't just talk positively, BE the positive force. It's difficult some days, but always keep hope in front of you.

It will seem at times there is no time. That's when you ask for help or get respite care to step in. It seems like a juggling act; it is, but as long as you take time out for you on a consistent basis, you will get through it. You are stronger than you think!

# Family Stress and Children with Brain Injury

**Submitted by Cheryl Bunzenmeyer-Rempel MSW, Private Therapist, Woodstock, Ontario.**

The family is the child's primary world and safety zone, where the parents provide support, love and nurturance. When a child sustains a brain injury the balance of that world is challenged and stressed.

## **Parents Face Multiple Stresses:**

- Depending on the injury possible fear for child's life, grief for the child's potential aspirations and future. Grief for the changes in life style and changes in family roles. Guilt at their inability to protect their child from harm and hurt
- Feel overwhelmed with multiple roles i.e./ caretaker, advocating for child in health care, school and legal system.
- Transition times from hospital-to-home, back to school, changing schools are difficult times as transitions take time and energy for advocating and are emotionally ridden for the brain injured child.
- Financial burdens with increased therapeutic and caretaker needs or the need for a parent to reduce employment to accommodate caretaker needs. Often financial burden is related to the complexity of child's needs and severity of brain injury.
- Parents' relationships are often strained with little time to focus on their own intimacy needs

## **Siblings Face Multiple Issues:**

- Siblings may be jealous and resentful of the extra attention given to the brain injured child.
- Siblings may be openly resentful and rebellious with expectations of increased responsibility of housework or care of younger siblings
- They may feel guilty and responsible for the cause of the brain injury to their sibling or that 'they escaped the injury'.
- Siblings may feel embarrassed with how their brain injured sibling behaves.

## **Other Relationships are Affected:**

- The brain injured child's friends will drift away and may have difficulty developing new friends, especially with the nature of the invisible injury.
- Family friends and extended family may not understand the nature of the difficulties, especially with the more subtle cognitive issues, therefore do not understand the time required for care-taking and the emotional and psychological energy required of parents, therefore they drift away.

Despite the many issues facing families dealing with a child with a brain injury there are many families have developed creative and flexible problem solving strategies to deal with these issues. They accessed family and friend support, family support groups within the community, advocacy groups and counseling to normalize their family relationships and family stability.

# Staying Connected: How Couples Maintain Their Relationship During Pediatric Brain Injury Recovery

Submitted by Jill Bowen Parkwood Institute



When your child sustains an acquired brain injury, it evokes a myriad of emotions ranging from sadness, fear, anxiety, and worry to anticipation, guarded optimism, and hopefulness with early signs of recovery and progress. Family life as you once knew it dramatically changes and navigating the rehabilitation process can feel all-consuming. Recovery is etched with highs and lows, and the old adage of one step forward, two steps back seems to best describe the rehabilitation journey you now find yourself on, as you become your child's strongest advocate and cheerleader. As a couple, you must decide together that your marriage/relationship is a priority and worth protecting, regardless of how difficult the journey is, and make a conscious effort to stay connected.

There are many stressors families endure following pediatric brain injury including the emotional stress of witnessing your child seriously injured, appearing vulnerable, and struggling to make gains. Many families endure the financial stress from time lost

from work to be with your child and/or extended leaves of absence to support and care for your child during the recovery phase. Add to this the stress of running and managing your household, caring for and attending to other children, learning to navigate the rehabilitation system and becoming an advocate in a health care system that just never seems to have enough, which often leaves parents feeling like they are hanging on by a thread.

When a child has a brain injury it is a tremendous ordeal for families making it very easy to lose sight of the family that once was and the couple you used to be. As a couple, it is important to realize recovery from acquired brain injury is slow and it may take a few years to resolve the upheaval that creates in a marriage or relationship. It is imperative that as a couple, you maintain your relationship during this difficult and often tenuous time.



Listed below are 5 simple strategies that couples I have worked with have found to be effective and beneficial in staying connected when dealing with pediatric brain injury recovery:

- Schedule a regular “date-night”: Start by booking a reliable babysitter, possibly a family member but most importantly someone you are comfortable and confident in taking care and meeting the needs of your child. It is important that you are able to relax and enjoy you partner when out on your date-night and worrying about the well-being of your child and/or calling or texting home for updates, questions, and reassurance can be counterproductive.

Mark your “date-night” on the family calendar, in each others’ personal schedules, and treat it with the same importance and priority that you would rehabilitation and medical appointments. Even if you are feeling tired, make a point of going out. Set boundaries and limits for conversation in that you may not talk about recovery, doctor’s appointments or new therapy techniques but instead keep the conversation light, enjoyable, and maybe reminisce about special moments you’ve shared in the past. Enjoy each other’s company during a dinner out, a stroll under the stars, a walk on the beach, or holding hands during a movie. It may require you to be creative if you have limited time and resources.

- Protect romance and sexual intimacy: Intimacy is demonstrated in physical touch. When life feels so overwhelming and challenging, I encourage couples to look for opportunities to physically touch one another, perhaps on the shoulder or the small of their back. Offer up hugs and ask for hugs frequently and keep your arms wrapped around your partner for a little longer than you typically do.

Sexual intimacy is often lost in the mist of turmoil and stress and I frequently hear that couples are just too exhausted and find the prospect of sleep more appealing than sex. Sexual intimacy is an important component of staying connected during this difficult time and couples need to find creative ways to protect this part of their relationship.

- Plan “individual time”: Ensure you both find individual time, apart from one another and from your family. Spending time with supportive friends can prove to be very beneficial in bringing some sense of normalcy, if even for a brief time. It is important to participate in activities that are restorative and renewing, such as participating in a yoga class, attending a book club, or joining a pick-up hockey game. It is important to schedule and protect this time, as it is an investment in your “self”.

- Love List of Gratitude Journal: With the countless challenges, frustrations and difficulty this journey of rehabilitation brings, it is important to remind yourself what you love most about your spouse. Purchase a lined journal and start a “love list” or “gratitude journal” of what you enjoy most about your spouse, something he or she may have done that day that caught your eye or something you admire about him or her. On days when you find life really challenging, review the list and remind yourself of the beautiful things that can become clouded by feelings of frustration and discouragement that are felt along the way.
- Create a “Huddle time”: Typically one parent becomes the primary point of contact for communication; however, it is important for the other parent to feel involved and up-to-date on progress and recovery. It is very easy for updates to be long-drawn due to interruptions, questions to be asked during family time and the topics of recovery quickly permeating your shared time together.

I encourage couples to consider scheduling a 30-45 minute daily “huddle time”, as a protected and distraction-free time to sit with one another and discuss updates, medical appointments, and rehabilitation progress and gains. Often the spouse who has worked all day needs time to walk in the door and calm down prior to the evening’s activities so be sensitive to each to each others’ needs and possibly consider “huddle time” after the kids go to bed in the evening.

Acquired brain injury recovery is an often slow and challenging journey. Placing your relationship as a priority during this difficult time and committing to staying connected will prove beneficial to you and your spouse over the long-run.



# Promoting Your Family's Wellbeing - Fact Sheet

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## **In the aftermath of your child acquiring a brain injury it can be easy to neglect your family.**

Caring for a child with Acquired Brain Injury can take a great deal of time and energy. It's easy for everyone else's needs to get side-lined, and difficult to get the balance right.

Let your other children know that you care about them and that you understand that things are tough for them. Try to give each child some time regularly, when he or she is the focus of your attention.

Don't be afraid of feelings - your own or other people's. Let everyone in the family understand that it is OK to express their feelings. Try to maintain as much family structure as possible, to give you all a sense of security and continuity. Keep on doing some of the things you used to do as a family.

Encourage teenagers to get on with their lives and make their own plans (remembering that it's always best to know where your teenagers are and who they are with). Don't sweep con

flicts and problems under the carpet - talk about them openly, and deal with them. Set aside times when the family can discuss responsibilities and problems.

Let teachers or school counsellors know what's happening at home. Keep in contact with the school to make sure things are okay and 'troubleshoot' any problems.

Use respite services or find other ways to give everyone a break (including yourself). Accept offers of help from friends and relatives. Take care of yourself - both for your own sake, and for your family's. Do at least one thing a week that is just for you - pamper yourself occasionally. If your children see you having fun and getting satisfaction out of life, they will tend to see this as a good model to follow, a good way to be. Try to make opportunities to recognize and celebrate what's been achieved. Observe the same special occasions as you did before the injury.



## Responding to Your Other Children

Your child's Acquired Brain Injury will affect any other children in your family. Parents usually see these effects, but professionals may be unaware of what siblings are feeling.

Children's reactions to Acquired Brain Injury in a sibling

Sadness is common and reactions may include both positive and negative elements. Different responses can occur at the same time or in quick succession. It's a challenge to encourage more positive responses without 'putting the lid' on the negative ones.

## Helping Children Express Themselves

The most important thing you can do for your other children is to listen and be there for them. This means making time to be with them-something that is often not easy, either practically or emotionally. Brothers, sisters and other young relatives need opportunities to express their feelings freely. They may believe that some of their normal responses - anger, resentment, rejection - are wrong or abnormal. Let them tell you their worries without judging or trying to change how they're feeling.

Some young people don't talk to parents because they don't want to worry them or be a burden. They may prefer to talk to friends, other relatives or counsellors. This can be a good thing, but if these people have little knowledge of Acquired Brain Injury try to tactfully correct the wrong information if it comes up.

Young children can't take in too much information at one time. Keep explanations simple and respond to questions at the level the child can understand.

Take advantage of the chances you get to be with each of your children - clearing up the kitchen, getting some breakfast together or watching a match. You can't force children to talk, but you can be there when they are ready.

Listening - active listening - is very important. Give the child your attention, and show that you're interested without breaking the flow of the conversation.

Often they don't volunteer how they're feeling - but they may answer direct questions. Sometimes a gentle prompt can help, when the child is ready to talk, such as "How do you think (your brother or sister) has changed?"

When children do talk, try not to jump in too quickly with reassurance or advice. Give them time to talk, to express their feelings. It is important to remember children's behaviour may give clues to how they are feeling, by withdrawing, acting out, sleep disturbances or poor school results.

## Providing Factual Information to Children



Children who are well informed are better able to understand and accept what's happened. They are also usually better able to support and understand the difficulties facing their brother or sister with Acquired Brain Injury. Don't overload your children with information but answer their immediate questions and concerns. Be aware that children vary widely in the amount of information they want, and their ability to take it in.

In the early days after the injury, hospital or rehabilitation staff may help to explain to your children what's happening, or they may have useful pamphlets, books, videos or computer programs. Ask the staff how your other children can be involved with your child with Acquired Brain Injury - maybe helping with care in some way, talking and listening, or simply just being there and being reassuring.

## **Acquired Brain Injury and Mental Health**

Ups and downs are a normal part of life. Teenagers in particular have wide swings of mood as they learn to deal with increasing independence and a changing body. This is to be expected, it's a normal part of growing up, though it can often be demanding to live with.

Sometimes, however, changes in behaviour are the first sign of something more serious. Many children with Acquired Brain Injury can remember how they were before the injury, and adjusting to the changes can be very difficult. Changed abilities, disrupted schooling, loss of friendships can cause great unhappiness, and young people often become depressed as they gradually become aware of the full impact of their Acquired Brain Injury.

If depression is severe or prolonged, it can interfere with a young person's normal development and increase the risk that they will harm themselves in some way. Anyone with depression of this nature (whether or not they have an Acquired Brain Injury) needs treatment for their depression-and depression can be successfully treated.

The young person may find it helpful to talk about what he or she is experiencing. Sometimes it's easier to talk to a friend or professional rather than a family member.

Acquired Brain Injury may cause problems with thinking and speech that make it harder to talk through problems, so it's particularly important to teach concrete ways to help the young person cope. But even if speech and thinking are limited, the young person can often communicate their sadness and distress. It's important to listen to what your young person is saying rather than how he or she is saying it-simply having someone listen and care is a help.

## Can Acquired Brain Injury Lead to Mental Illness?

Mental disorders can occur in anyone, and are common in our society. Most disorders don't have a single cause, but result from a complex combination of events and conditions, including the person's biological and inherited make-up, their psychological make-up and skills, and their family, social and community environment.

Risk factors such as stress increase the likelihood that a person will develop a mental disorder. Protective factors, on the other hand, help people to cope with adversity such as an easy temperament, a strong and supportive family and school environment, and a sense of belonging.

Adolescence- particularly later adolescence- is the time when mental disorders are at their most common. Some of these disorders start in childhood, some during adolescence.

Many young people with an Acquired Brain Injury will not develop a mental disorder, but some inevitably will. Each young person's level of risk and protective factors will be different, but some of the effects of an Acquired Brain Injury do increase the risk of some mental disorders. For example, Acquired Brain Injury can erode a young person's confidence and self esteem, and behavioural problems can put teenagers and young adults at high risk of becoming socially isolated and without friends.

In short, Acquired Brain Injury may both increase stress and decrease the person's ability to cope with stress.

The most common symptom in young people with Acquired Brain Injury is depression - often probably a response to the adjustments necessary after an injury. Young people with Acquired Brain Injury may also experience severe anxiety, sometimes diagnosed as 'post-traumatic stress disorder'.

There is no evidence that Acquired Brain Injury increases the risk of a number of other mental disorders, including schizophrenia and bipolar disorder.

Suicide is always a concern for parents. Remember that only a small number of young people actually take their own lives, though many more attempt suicide, and still more think about it. Mental illness-particularly depression-is one of the main risk factors for suicide, and young people who have previously attempted suicide, or have deliberately harmed themselves in some way, are particularly at risk.

## Symptoms of a mental illness

- Parents are the people most likely to notice signs of a mental illness or emotional disorder. The signs can be difficult to pick, as many resemble the effects of Acquired Brain Injury. They include:
- A drop in school performance
- Rigidity in thinking and behaviour
- Unwarranted worry or anxiety and inability to cope with day-to-day problems
- Changes in sleeping or eating habits
- Aggression (verbal or physical) towards others
- Excessive fear and feelings of persecution, paranoia
- Recurrent nightmares and seeing, hearing or experiencing things that are not there
- Depression or social withdrawal
- Difficulty 'getting going'.

## What to do

If you're worried about your child's emotional health or suspect a mental illness, it's useful to consult a health professional-preferably someone who understands Acquired Brain Injury and its effects on your child, and preferably someone you've worked well with before. Together you could first try some strategies to deal with the problem. Your child's response will provide useful information.

Refusing to go to school may reflect relatively mild anxiety that could be helped changing the child's school environment, or by using carefully chosen strategies to change the child's behaviour. If the anxiety is severe - for example, if the child is having panic attacks - medication may be necessary.

Treatment for mental disorders has improved vastly over recent years. Medication can usually reduce symptoms, and a range of psychological, behavioural and social therapies help people to address the problems in their lives and learn healthy ways of coping and behaving.

If the young person's problems continue, try to see a mental health professional with experience of both Acquired Brain Injury and young people (ask about their experience). If you can't find someone with these skills, make sure the mental health professional knows your child's history. Mental health professionals include psychiatrists and psychologists.

Acquired Brain Injury specialists and mental health specialists must coordinate their care, as treatment needs to take account of both conditions. For example, the dose of medications for mental illness may need to be adjusted for a person with Acquired Brain Injury.

Coordination may not be easy. The Acquired Brain Injury and mental health treatment systems are separate, and experts in one area may know relatively little about the other.

Good case management can help to ensure that services are coordinated and the right treatment identified. Often, though, parents have to be the 'go between' to make sure information is shared.

# Reactions and Responses - Fact Sheet

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**Brain injury in a child causes many different reactions in the family. There is no single, predictable pattern but the ongoing emotional stress can be very difficult.**

Feelings change over time, and finding ways for everyone to adjust and get back on an even keel can take a long time. It can be confusing, chaotic, and difficult at times to work out exactly what you are feeling. Relationships within the family may change. Sometimes people see a pattern in their lives, but often there just seems to be constant stress.

Often, the first reaction is shock and disbelief, particularly if the ABI is sudden and obvious. On the other hand, a diagnosis of brain injury may be a step forward, if you have been concerned for some time about unexplained problems for your child. An explanation may help you to move on and focus on finding the best ways to address the problems.

Gradually, families adjust to what is happening, and become more aware of the implications and the effects on everyone's lives. Some may search far and wide for a cure or a treatment, others rest their faith in the treatment team and concentrate their efforts on simply getting back on track.

## Rebuilding Hope

It takes time to realize that, although everything won't return to the way it was, there are positive ways of adapting and coping, and good things ahead. But parents who have lived for a long time with the changes ABI produces know that things can get better. Their messages of hope for people just beginning this journey include:

- You haven't failed, even though you may feel you're never able to do enough
- It's possible to work with negative responses in positive ways
- Grief doesn't necessarily go away, but over time, it becomes possible to see things from a new and positive perspective All the many different and conflicting emotions you may feel are normal
- Let yourself grow gradually into your own situation
- Find people you can talk to-friends, your partner, family, support groups, people in your community.
- Remember that, first and foremost, you are a mom or dad, even when you're doing the work of an occupational therapist, speech therapist, physiotherapist or counsellor.
- Ask for help, and if you don't get it, ask again and again.

## Professional Help

Many people have found professional help from a psychologist or social worker can provide a positive pathway through these emotions. It can help to prevent difficult emotional patterns from becoming entrenched, and can also help you to keep family relationships on track.

If you or one of your family is struggling with these emotions, consult a mental health professional about appropriate treatment, including medication. Look for a therapist - a psychiatrist or clinical psychologist - who has experience dealing with carers. If medication is needed, it can be prescribed only by a medical practitioner (a psychiatrist or GP).

If mental health professionals are in short supply in your area (for example, in some rural and remote areas), find another health professional in your community whom you trust and can talk to. Social workers are trained to provide families with considerable support, both emotional and practical. Some GPs are very good in this role, and therapists and community nurses also provide emotional support as part of their work.

## Positive Ways to Work Through Negative Emotions

An acquired brain injury in a child is often a devastating event for parents and families. Everyone reacts differently, but parents and families often feel guilt, grief, hopelessness and despair, a sense that the difficulties will never end. Everyone else may seem to know better and have advice for you - often when things are at their most difficult. All these feelings are common and normal - but they don't help you to cope.

### Guilt

When someone has an ABI, other family members often feel guilty in one way or another. This feeling is common, but you need to work through it if you are going to get on with your life productively. The first step is to accept that guilt is normal, and that you can't stop it appearing - you don't need to feel guilty about feeling guilty!

Look carefully at your guilt - how realistic is it? If there is something you really could have changed, try to forgive yourself for not doing it, focus on what you can do now, and move on. If there was nothing you could have changed, recognize that your guilt has no basis in fact. In either case, you'll need time to deal with feelings. Talk to a good friend or consider finding support through a counsellor, for example, at the local Community Health Centre.

## Grief

Grief and anguish are normal, though everyone experiences them differently. It can be a real struggle to adjust to these losses and changed expectations - but there are many positive things you can do. Acknowledge and accept what has happened, and look ahead. Try to treat your child as you always have done-don't let yourself turn your child into someone different, a 'patient'. Retain what you can of the good things you used to have together. Talk to other moms and dads of children with disabilities.

Be kind to yourself. There will be sad moments, but good times are possible, too. Arrange for your child to do different special things when other kids are passing 'normal' milestones (e.g. going to university, getting married).

## Hopelessness

Parents can feel despair and hopelessness-particularly when recovery slows down- as they realize life will never return to its former pattern. These suggestions may provide a starting point to help you work through this despair:

- Don't put arbitrary time limits on your child's recovery, that set you up for disappointment (even if organisations act as if there are time limits).
- Be ready to modify your hopes and expectations. A young person with ABI may not return to their pre-injury self, but they can be happy and achieve in other ways. Take this as your starting point.
- Focus on the things your child can do, rather than dwelling on what they can't do as well as before.
- Find ways to see, and to celebrate, the good things in your child's life. For example, some families find it helps to sit down together regularly (e.g. monthly) to review what's been achieved, celebrate the good things, and set more goals.
- Consider finding support from a professional (psychologist, social worker, etc.) to help work through emotional issues - and consider doing this early on, before problems become entrenched.

## Blame or criticism

Sometimes, it can seem that everyone knows better than you. Family, friends, even people who have little contact with your child, give you advice, pass judgement, or tell you what to do - particularly when things aren't going well. You have less privacy, and everyone is an expert except you.

Such criticisms and remarks may stem from the person's own feelings of frustration and powerlessness in the face of your child's injury - particularly if the person is close to your child. Understanding this may help you to cope better with the comments.

If criticisms come from someone close to you, consider talking openly to that person about the impact on you.

It's also worth listening to comments to see whether they include anything that is actually helpful - even if you feel hurt.

It's not wrong to get frustrated or 'lose your cool'. But you may feel better about yourself and more in control of the situation if you can learn how to manage and express your feelings in ways that don't damage relationships and friendships.

Remind yourself of the positive things you are doing and achieving. You might, for example, make a list and stick it on the fridge door, of "good things we've done this week".

## **Looking After Yourself**

An injured child can place enormous strain on parents. Sometimes the relationship becomes stronger, but couples can also drift apart.

Some things that put strain on relationships are a sense that one or other of you is to blame, differences of opinion about how to handle specific issues and differing views on how family life should change in response to the injured child.

Open communication between a couple (even if they're separated), supportive friendships and the right professional help can all assist. Opportunities to talk to others-and cry-in safe, confidential surroundings give many parents the strength to carry on.

Assistance from carer respite services or disability services can be vital, especially for single parent families.

## **Keeping in Touch with Friends**

When the young person comes home, family members often focus on providing a quiet environment and emotional support, and see less of people outside the home. It's easy to establish a pattern where life revolves around the child with ABI.

Some friends may offer great strength and support. Others may drift away. This can be hurtful, but it usually happens because they can't cope with the situation in some way.

Here are some suggestions to consider:

- Let friends and family know they matter to you
- Let them know how they can support you - for example, doing the washing, baby-sitting other children, coming to an appointment with you, or just having a coffee together
- Try to spend some time talking about issues other than your child and ABI
- Schedule family outings or social activities even if you may not feel like it
- Don't convince yourself that you're the only one who can care for your child
- Involve extended family and close friends in the 'team' working with your child.

Ask for professional help in dealing with emotional upheaval. If there are waiting lists for public services, consider seeking help privately if you can afford it.









# The Office of the Children's Lawyer



## In Brief

The Office of the Children's Lawyer is a law office in the Ministry of the Attorney General which delivers programs in the administration of justice on behalf of children with respect to their personal and property rights.

Lawyers within the office represent children in various areas of law including child custody and access disputes, child protection proceedings and civil litigation.

Clinical investigators prepare reports for the court in custody/access proceedings and may assist lawyers who are representing children in such matters.

## Property Rights Cases

The Office of the Children's Lawyer has lawyers on staff who represent minors (persons under 18 years of age) and unborn persons in property rights cases in the Greater Toronto area. The Office may hire a lawyer outside Metropolitan Toronto. Property rights cases include civil and estate/trust matters.

## Civil Cases

In civil cases minors (persons under the age of 18) cannot sue or be sued in their own name. A Litigation Guardian is necessary. This is a person who makes decisions for a minor in a court proceeding. The Children's Lawyer may be ordered by the court to act as Litigation Guardian for the child in cases where there is no parent, guardian or other adult willing and able to pursue or defend the claim. These cases consist mainly of personal injury actions.

The Office of the Children's Lawyer also reviews proposed settlements referred by the courts in cases involving minors. The Children's Lawyer assesses whether the proposed settlement is in the best interests of the child and reports to the court.

The Children's Lawyer is required to be served with an application for appointment of a guardian of minor's property under the Children's Law Reform Act.

## Estate/Trust Cases

The Children's Lawyer represents minor beneficiaries and unborn beneficiaries in estate and trust cases which include:

- Challenges to the validity of a will;
- Will interpretation applications;
- Applications for removal of executors and trustees;
- Claims for support under the *Succession Law Reform Act*;
- Applications to vary a trust;
- Division of property claims under the *Family Law Act*; and sale or mortgaging of minors' property

Under the *Estates Act*, the Children's Lawyer must be provided with estate and trust accounts that are presented to the court for approval where a minor or unborn person has a vested or future interest in the estate.

The Children's Lawyer does not have the authority to administer estates, nor to act as guardian of property for a minor.

## Personal Rights Cases

The Office of the Children's Lawyer has lawyers, clinical investigators and articling law students on staff who represent children in personal rights cases. There are other lawyers and clinical investigators in private practice available throughout Ontario who work on behalf of the Children's Lawyer and are hired on a case-by-case basis.

Personal rights cases include child protection and custody/access matters.



### Child Protection Cases

Protection proceedings in court occur when children may be in need of protection for many reasons, including abuse and neglect, and therefore may be removed from their families by the Children's Aid Society (or Family and Children's Services) through a court order. The Children's Aid Society, the child's parents or other caretakers usually have their own lawyers to represent them in court. In these cases, the court may request the appointment of an independent legal representative for a child under the *Child and Family Services Act*. This happens when the court believes a lawyer for a child is necessary to represent the child's interests in protection proceedings.

### Child Custody and Access Cases

Court proceedings about child custody and access are usually between the child's mother and father. In most cases, the parents have lawyers who represent them in the case. Where there is a dispute before the court about the child's custody or access, a court may request the appointment of the Children's Lawyer under the *Courts of Justice Act*. This happens when the court requires independent information and representation about the interests, needs and wishes of the child who is the subject of the proceedings.

The Children's Lawyer's involvement in custody/access cases is to provide a legal representative (a lawyer) for the child or to prepare a report, or a combination of both.

The Children's Lawyer does not represent children in child support matters in custody/access cases.

### Clinical Investigator Services

The Office of the Children's Lawyer has some clinical investigators on staff as well as other clinical investigators hired on a fee-for-service basis throughout Ontario, who prepare Children's Lawyer reports in custody and access cases. The clinical investigators use alternative methods of dispute resolution to try to help parents to resolve their dispute. If the dispute is not resolved by the parties, a Children's Lawyer Report is filed with the court.

## Requesting the involvement of the Children's Lawyer in Custody and Access cases

After a court action about custody and access has begun, one or more of the parties (the applicant and respondent in the case) may request the appointment of the Children's Lawyer.

It is not necessary for parties to serve the Office of the Children's Lawyer (OCL) with a Notice of Motion and Pleadings for an order to appoint the Children's Lawyer in Ontario Court of Justice, Superior Court of Justice or Superior Court of Justice, Family Court cases.

Judges will consider the Intake Criteria before requesting, by order, the involvement of the Children's Lawyer in a case.

A printed form of the Order is available to every family law Judge. When the order is signed it will be forwarded immediately by one of the parties set out in the order (or by the court), by facsimile (416-314-8050) or mail to the Office of the Children's Lawyer.

As required in the order, within ten days, each party will complete a separate Intake Form and send it to the Office of the Children's Lawyer. The Intake Form itself is available in all Court Houses.

Within three weeks of the date of the order, the Children's Lawyer will review the order and Intake Forms and notify the parties and the court (by facsimile or mail) whether the Children's Lawyer consents to become involved in the case and, if so, the type of professional service that will be provided.



The types of professional services that may be delivered are:

1. **Legal Representation** - A Lawyer will be assigned.
2. **Children's Lawyer Report** - A clinical investigator will be assigned.
3. **Legal Representation with a Clinical Investigator Assist**

A) Both a lawyer and clinical investigator will be assigned at the beginning if there are serious clinical and legal issues requiring an expeditious response, e.g. murder/suicide, mobility, etc., or,

B) After the case has been assigned to the lawyer, a clinical investigator will be assigned if there are specific serious clinical concerns that need to be addressed in order to assist the lawyer in representing the interests of the child client at any settlement meeting or in court.

4. **“Summary” Legal Representation or Children's Lawyer Report**

The lawyer or clinical investigator will be instructed to deliver, in a summary way, a time limited service and to report to the parties and the court either by way of submissions (lawyer) or by a short Report (social worker) about what, if anything, has been accomplished to advance the interests of the child client towards a resolution or court order.

5. **Lawyer Assisting Clinical Investigator**

A lawyer will be assigned to assist a clinical investigator who is preparing an OCL Report when the social worker needs legal advice and guidance in special circumstances, e.g. evidence, interpretation of documentation, legal procedures, etc. Please note that the lawyer will not be the legal representative of the child under s.89(3.1) of the *Courts of Justice Act*.

**NOTE:** Except in special circumstances, legal representation and a Children's Lawyer report of the OCL will **NOT** be provided simultaneously.

**To find out more information, visit Ontario's Ministry of the Attorney General.**

## What to Ask A Lawyer

1. What is your experience in this field? Have you handled matters like mine?
2. What are possible outcomes?
3. How long do you expect this matter to take?
4. How will you keep me informed as the case progressed?
5. Will anyone else be working on my case?
6. How do you charge?
7. Do you charge by the hour? What is your hourly rate?
8. Will junior attorneys or paralegals in your office be able to handle some of the administrative work at a rate?
9. If you charge a fixed fee, what is it?
10. What happens if something unforeseen occurs?
11. If you charge on contingency, what percentage of a settlement or award will that be?
12. Will that be taken after expenses are deducted?
13. Beyond fees, what kind of expenses will there be and how do you calculate them?
14. What's a ball park figure for my bill?
15. Will you put your estimate in writing?
16. How often will I be billed?
17. If we have a disagreement over billing will I be billed for the time spent disputing the bill?
18. Will you agree to mandatory arbitration if we cannot settle the dispute?
19. How can I help you help me?
20. Can I do some of the work?
21. What other information do you need from me?
22. What are my alternatives?
23. Do you recommend arbitration or mediation?
24. Do you know good arbitrators or mediators?

**P.S. Ask for an explanation when an answer is not clear! If the Lawyer can't explain or treats a request for clarification in a condescending manner – cross his or her NAME OFF YOUR LIST!**



# Who Can Make Decisions for Your Child if They Sustained an ABI

**Submitted by: Nigel Gilby, Lerner LLP, Personal Injury Lawyers**

If you are reading this article then unfortunately, you are likely a loved one of a child that has sustained an acquired brain injury. If you are a loved one and your family member is still in the hospital while you are reading this, then there are likely a number of questions and decisions that are being asked of you by the hospital care providers, possibly insurance companies and others that involve making decisions for your child.

I will provide some general principles surrounding decision making and capacity when dealing with someone who is under the age of 18 and what happens when they turn 18.

## The Injured Child Under the Age of 18

In general, children under the age of 18 may make decisions about their own medical care and treatment if they appear to be competent and understand the decision which they are making.

Generally, if someone is in the hospital and in the acute phases of having sustained an acquired brain injury, then that injury is obviously significant at that point in time and they will not be able to make any decisions about their own medical treatment.

In hospital, it is the parents who make the decisions or where the parents are divorced or separated, the custodial parent.

One always hopes that by the time a child is released from the hospital, things have returned to normal and life goes on the same as it had before that child was admitted to hospital. Unfortunately, when dealing with acquired brain injuries that is not always the case, and the cognitive challenges of a child can continue long after being discharged from hospital.

In the event that your child is going to continue to suffer from ongoing cognitive issues indefinitely and financial decisions need to be made on their behalf, then there may be a need to establish a “substitute decision maker”.

If a child sustains an acquired brain injury and does not have the capacity to make any decisions about their personal care and/or about property, then a substitute decision maker needs to be legally established. The substitute decision maker becomes the person with the authority and responsibility of making decisions over the person’s medical care and/or property and is charged with the responsibility by the Courts to make those decisions appropriately.

When it comes to being a substitute decision maker, there is a legal process that must be followed. More than one person can apply to be the substitute decision maker and again, it is usually a parent or parents who make this application.

At this time it is important to speak to a lawyer to help you through the process of making the application to the Court as this is a legal process.

## **What Happens When my Child Turns 18? Can They Make Their Own Decisions?**

Generally speaking when one turns 18 in the eyes of the law, they are deemed to be an adult. They get to make their own decisions, even though, we as parents may not agree with them. The Court does not regulate poor decisions. What the Court does however is determine whether or not a person has the capacity to make their own decisions.

When a child sustains an acquired brain injury, that injury may prevent them from having the capacity to make certain types of decisions as they get older and take on more responsibility.

Whenever dealing with somebody who has sustained an acquired brain injury, and there are concerns about their ability to make decisions, then a capacity assessment should be done.

A capacity assessment is like a test which is given to the individual who is exhibiting poor decision making skills and/or has cognitive issues that are affecting their day to day living. There are a limited number of capacity assessors that have been certified by the province to do these types of assessments. This assessment is based upon a series of questions and information obtained by the assessor to determine whether or not that individual has the capacity to make certain decisions. There are two types of capacity assessments one for personal care and the other for property.

A person with an acquired brain injury may have a capacity to make certain decisions but not others. They may have the ability to make decisions regarding their personal care but not their property.

When the assessment is completed and the proper questions have been asked by the assessor options may be available to the individual and their family. If an individual can understand the consequences of executing a Power of Attorney, this may be the best option for the individual as it is a less costly and quicker alternative to applying to the Court for a substitute decision maker.

A Power of Attorney is a document wherein an individual can give authority to someone they trust to take care of their finances and/or their medical decisions in the event they cannot do so on their own.

If an individual is deemed not to have the capacity to make a Power of Attorney or manage their finances then those decisions need to be made by a substitute decision maker. This process involves a Court application to appoint the appropriate person.

Depending on how your loved one sustained their brain injury there maybe lawsuits against the person or persons who caused it. This can result in significant amounts of money paid out for the benefit of the child with the acquired brain injury. In that situation, decisions need to be made about how to spend that money. Where an application is made to the Court, it is the Court's job to see that money is spent in the best interest of the person unable to make their own decisions.

If you are reading this article in the early stages of your loved ones acquired brain injury, I can tell you the children that I have encountered with acquired brain injuries, have amazing resilience and ability to do better than we may believe or be told in the early stages of their brain injury.

Don't be afraid to seek out advice from qualified lawyers. They should be prepared to give you an initial consultation without charging you any money and give you a reasonable estimate as to what legal fees may be involved in the legal process of becoming a substitute decision maker for your child.

*Please contact for  
more information*

*Nigel G. Gilby  
Lerners LLP  
Personal Injury Lawyers  
ngilby@lerners.ca  
519-672-4510*







# Tips: How I Can Help My Child Recover

## Synapse

### 1. Challenging Behaviour - Fact Sheet

Parents generally want the best for their children. Despite obstacles presented by Acquired Brain Injury parents can still bring out their strengths, help them to ride out the difficulties, and enable them to develop to their full potential. Ways to understand challenging behavior and managing agitation, frustration and anger are presented in this fact sheet.

### 2. Reactions and Responses - Fact Sheet

Brain injury in a child causes many different reactions in the family. There is no single, predictable pattern but the ongoing emotional stress can be very difficult. Gradually, families adjust to what is happening, and become more aware of the implications and the effects on everyone's lives. Many people have found professional help from a psychologist or social worker can provide a positive pathway through these emotions. There are some positive ways to work through the negative emotions and ways to look after you, which need to be considered as well.

### 3. Building Social Skills - Fact Sheet

Acquired Brain Injury can cause children to interact in ways that aren't socially appropriate - being tactless, poor at 'reading' social cues, talking too much, interrupting, or seeing the world only from their own point of view. Other social skills may be lacking - simple things such as using eye contact appropriately or they may be excessively friendly and accepting, hugging near-strangers and willing to trust and go with anybody. They can be at risk of becoming socially isolated and cut off from friends and the normal things kids do together. Bullying or teasing can sometimes become a problem due to being impulsive and less able to judge social situations. Some strategies to work on this include keeping the communication lines open, following a problem solving approach, and getting help, all presented in this fact sheet.

### 4. Language and Every Day Living Skills - Fact Sheet

Language and every day living skills may need particular attention to ensure that a child with Acquired Brain Injury recovers to the fullest extent possible over the years. Helping your child to listen and understand and other tips on how you can help are included in this fact sheet.

## **5. Assisting Your Child's Development - Fact Sheet**

If children with Acquired Brain Injury are to achieve the best results possible - in overcoming and/or adjusting to their difficulties - it is essential that they have assistance and support designed to meet their particular needs. Helping the young person to deal with and/or overcome these effects can involve:

1. Taking special care to teach him or her the necessary skills; and/or

2. Concentrating on finding ways around the problem - 'compensating' for it.

The best approach will vary from person to person, and problem to problem. Professionals with experience working young people with Acquired Brain Injury can provide advice. The key to success is to identify the nature of the difficulties, and to deal with them before the young person becomes discouraged and loses confidence. Young people with Acquired Brain Injury need lots of opportunities to practice skills that others learn more easily.

## **6. The Early Days - Fact Sheet**

Child rearing brings challenges to all parents, and for parents of a child with an acquired brain injury (ABI), the challenges can be magnified, such as striking a balance between protecting your child from harm, while encouraging self-reliance and independence. This fact sheet touches on some of the challenges faced by parents and some of the concerns while providing tips on what you can do and how to look after yourself and seek help when needed.

## **7. Balancing Risk and Independence - Fact Sheet**

Growing up involves taking risks - this is normal as young people 'test the waters' and move towards independence and adulthood. It may be tempting to put physical safety above all else, but saying 'no' too often can have a cost. Kids lose confidence, or rebel, or simply miss out. There are many different risks involved: social, and emotional. This fact sheet provides tips on how to get make decisions to protect your child, and how to manage everyday risks.



## BrainLine Kids

### 8. **Parental Distress, Parenting Practices, and Child Adaptive Outcomes Following Traumatic Brain Injury.** Jackie L. Micklewright<sup>a1a2 c1</sup>, Tricia Z. King<sup>a2</sup>, Kathleen O'Toole<sup>a3</sup>, Chris Henrich<sup>a2</sup> and Frank J. Floyd<sup>a4</sup>

The researchers in this study examined the relationship between parental psychological distress, parenting practices (authoritarian, permissive, authoritative), and how well a child was functioning 1-3 years after a traumatic brain injury. They found that authoritarian or strict parenting practices were related to higher parental distress and lower adaptive functioning in the children. Study results also suggested that parenting practices are an important factor in the quality of the parent/child relationships following TBI.

### 9. **My Child's Brain Injury: Family Matters**

The whole family feels a child's brain injury. It changes the way a family works and challenges even the strongest relationships. Some common problems — and solutions — that some families use to help them feel supported and strong are mentioned in this article.

### 10. **Concussion Recovery: Parents Play Important Role**

This article focuses on what parents should do during concussion recovery right from the beginning. Some of these include: Regular and close monitoring for the first 24-48 hrs, constant waking up, medication, drug use warning, physical rest, cognitive rest, diet, and further testing.

### 11. **Children with Traumatic Brain Injury: A Parents' Guide – Chapter 4: Helping Your Child Adjust**

Your child's ability to cope with or develop strategies for dealing with these changes will vary depending on many factors. Some of these may include your child's previous coping skills, her intellect and personality, the support available from friends and family, her emotional health, the strength of her relationships, the stage of development she was in when injured, and the extent of the injury. As a parent, you will play a key role in helping others understand your child. Thanks to your unique experience parenting your child, you will be able to provide professionals with valuable information and insight into your child's individual traits. During the rehabilitation process, parents' involvement and commitment are often seen as pivotal to their child's recovery and return to home and school. To help you better help your child, this chapter will examine some of the changes that children with TBI commonly face during the acute, rehabilitation, and back-at-home phases of the recovery process. It will also offer suggestions for helping your child cope with and adjust to these changes.

## Online Resources

<http://braininjury.society.com/information/acquired-brain-injury/children-with-abi/>

- What to expect
- Returning to school

<http://transitions.canchild.ca/en/OurResearch/transitionsexperiencedbychildrenwithABI.asp>

- Transitions experienced by children and families after ABI

<http://synapse.org.au/get-the-facts.aspx?category=Parent's%20Guide>

- Fact Sheets

[http://www.rch.org.au/rehab/abi\\_resources/](http://www.rch.org.au/rehab/abi_resources/)

- Guides for parents and families, info

<http://www.braininjuryhub.co.uk/>

- Info and support for parents and family members drawing on expertise of a clinical team

<http://childbraininjurytrust.org.uk/>

- Child and family support, FAQs, fact sheets

<http://www.brainlink.org.au/page/37/carers-guide>

- Carers and parents guide

[www.brainline.org](http://www.brainline.org)

- BrainLineKids

[http://www.chw.edu.au/kidsrehab/brain\\_injury/about.htm](http://www.chw.edu.au/kidsrehab/brain_injury/about.htm)

- Info sheets

<http://www.helpingkidsbrains.com/abitherapy.html>

- School re-entry, therapy

<http://www.bianj.org/>

- Info for families on support, therapy, education, etc.

# The Identification, Placement and Review Committee

Submitted by Marty Rempel

## What is an IPRC?

[Regulation 181/98](#) requires that all school boards set up an Identification, Placement and Review Committee (IPRC), composed of 3 people , one of whom is likely a principal.

The role of the IPRC will:

- 1 decide whether or not the student should be identified as exceptional;
- 2 identify the areas of the student's exceptionality, according to the categories and definitions of exceptionalities provided by the Ministry of Education;
- 3 decide an appropriate placement for the student; provide or purchase special education programming for their students.
- 4 review the identification and placement at least once in each school year.

## Who is identified as an exceptional pupil?

The Education Act defines an exceptional pupil as “a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program....” (Please search Ministry of Education for further information of categories and definitions of exceptionalities of exceptional students).

## Glossary

Some of the words found in this glossary are not found in the text of this booklet. They are included here as they may be associated with the care of a child with a brain injury.

**Anticonvulsants** - Medications used to treat seizures.

**Ataxia** - Inability to coordinate movements and maintain posture; a tendency to lose balance.

**Cognition** - A generic term involving perceiving, recognizing, conceiving, judging, sensing, reasoning, remembering and imagining.

**Congenital** - Existing before or at birth.

**Craniectomy** - An operation in which the skull is entered by removing small pieces of bone to gain access to the brain. Unlike a craniotomy, the removed pieces of bone are not reinserted into the skull. Following surgery, a soft spot may be left in the area of the scar.

**CT Scan** - A CT Scan is a series of X-rays taken of the body. It is done in the Radiology Department. Using computers, the CT Scanner makes a series of pictures that will help the doctor follow your child's progress.

**Diplopia** - Double vision.

**Dura Mater** - The outer membrane covering the brain.

**Encephalitis** - Is an acute inflammation of the brain.

**EEG Electroencephalogram** - A test that measures electrical activity in the brain. Small electrodes are attached to the scalp. A machine will record the electrical activity as brain cells and signals or messages to one another. Abnormal signals can be detected from the tracings made by the machine. These abnormal signals may indicate that there is seizure activity occurring or that damage has occurred to the brain cells in a particular region of the brain.

**Epilepsy** - Epilepsy is a physical condition characterized by sudden, brief changes in how the brain works. It is a symptom of a neurological disorder - a disorder that affects the brain and shows itself in the form of seizures.

**Fatigue** - A common side effect experienced by many patients as a direct result of swelling and/or treatment. Enough rest, proper nutrition, and moderate exercise can all help to combat this symptom.

**Health Care Professional** - Any medical team member involved in care (e.g. nurse, physician, dietitian, pharmacist, physiotherapist, occupational therapist, social worker, psychologist).

**Hemiparesis** - Muscle weakness on one side of the body; may be permanent or temporary.

**Hemiplegia** - Complete paralysis on one side of the body. This may improve with time.

**Incidence** - The number of new instances of a specific condition occurring during a certain period in a specified population.

**Increased Intracranial Pressure** - Increased pressure within the brain. This can be caused by edema (swelling) in the surrounding brain tissue.

**Meningitis** - is an acute inflammation of the protective membranes covering the brain and spinal cord, known collectively as the meninges. The inflammation may be caused by infection with viruses, bacteria, or other microorganisms, and less commonly by certain drugs. Meningitis can be life-threatening because of the inflammation's proximity to the brain and spinal cord; therefore, the condition is classified as a medical emergency.

**MRI Scan** - Magnetic Resonance Imaging Scan that uses a magnet and radio waves to produce pictures of organs and tissues of the body.

**Neurologist** - A physician specializing in non-surgical diseases of the nervous system.

**Neuropsychologist** - A psychologist who specializes in assessing brain function in persons with central nervous system disorders.

**Neuroophthalmologist** - An ophthalmologist who specializes in the diagnosis and treatment of visual problems related to the central nervous system.

**Neurosurgeon** - A physician who specializes in surgery of the nervous system.

**Nervous System** -The nervous system involves the brain, spinal cord and all of the peripheral nerves that branch off the spinal cord.

**Ophthalmologist** - A physician who specializes in the diagnosis and treatment of eye disorders. Also known as an eye specialist. Brain injuries may affect vision. An ophthalmologist is qualified to conduct eye surgery. An optometrist is a person qualified to prescribe eyeglasses and contact lenses.

**Prevalence** - The total number of cases of a particular disease at a given moment in time, in a given population.

**Cognitive function** - The brain's ability to take information from the environment, think about it, and take action to respond.

**Concussion** - A violent jarring or shaking of the brain which causes a temporary loss of consciousness, confusion and/or vomiting.

**Contrecoup injury** - Occurs when the head collides with a solid object. The blow to the skull causes bruising of the brain at the point of impact (coup) and more bruising when the brain is driven against the opposite side of the skull (contrecoup).

**Contusion** - Bruising of the brain

**Diffuse injury** - Occurs when the head hits an object and stops, but the brain keeps on going. The sharp twisting and shifting movements of the brain causes stretching, shearing and tearing of nerve fibers in the brain, causing widespread damage and loss of function.

**Edema** - Swelling of the brain due to a build-up of fluid in the tissue.

**Glasgow Coma Scale** - A scale to measure the degree of impairment of the person's level of consciousness. Based on a person's ability to open his or her eyes, respond with movements or words.

**Hemorrhage** - Bleeding in the brain.

**Hematoma** - An accumulation of blood in the brain tissue.

**Intracranial pressure (ICP)** - The level of pressure inside the brain.

**Rancho Los Amigos Levels of Cognitive Recovery Scale** - A scale to rate a person's recovery from a brain injury. There are 8 levels, from "no response" to "purposeful and appropriate".

**Level of consciousness (LOC)** - How awake, aware and responsive your child is. The Glasgow Coma Scale (GCS) is used to measure your child's level of consciousness.

**Skull fracture** - A broken bone of the skull caused by a traumatic injury.

**Tracheotomy** - An opening made through the neck into the trachea (windpipe) to place a tube used as an airway for breathing.





## Legal minds. Caring hearts.

If someone in your family has suffered a serious personal injury, our caring lawyers can guide you through this uncertain time. We listen. We speak from experience. And we look out for your family's needs as long as you need us.

When we take your case, we charge no fees unless and until you're compensated. We provide initial consultations for free—even if that's all you need. And we will never charge for hospital or home visits, or things like parking and long-distance calls. That's just not our style.

**We're here to help.**