



The Monarch

June 2008

Brain Injury Happens to the Whole Family

Keeping the Family Together After a Brain Injury

**BRAIN INJURY
ASSOCIATION
OF LONDON
AND REGION**

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Freedom

“If disabled people could focus on all the things they can do, instead of the things they can’t, they will find, just like I did, that life is fantastic.”

Danny McCoy



Danny McCoy was rendered a paraplegic in a terrible car accident at the age of 43. Before the accident he was an avid sailor. After the accident, Danny became one of the top ranked competitive disabled sailors in the world. He’s also the founder of the Disabled Sailing Association of Ontario and one of the sport’s foremost international ambassadors.

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Reminder:

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and the Brain Injury Association
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See Page 4 for Dual Membership
Application

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EXECUTIVE DIRECTOR'S REPORT

Each June across Canada, we commemorate Brain Injury Awareness Month. The Editorial Committee has chosen to focus on family issues for this edition of the Monarch. Anyone that has experienced ABI with one of their loved ones knows first-hand that 'Brain Injury Happens to the Whole Family'. In this issue of the Monarch many readers will identify with the challenges and struggles that family members face after ABI.

We thank all of the contributors to this publication and would like to say a special thank you to Marg Willemse for taking the time to write and having the courage to submit an article about her family's journey following her son Joel's ABI. I am sure that many parents and siblings reading this three part series will find similarities to their own situations in this story. I hope this will help those families who feel isolated to see that they are not alone on their journey.

The Association is planning several activities for the month of June. The Helmets on Kids partnership is gearing up for its 7th Annual Campaign kick-off. I am pleased to announce that several other municipalities across Ontario will be implementing this program, thanks to Barb Legate promoting this initiative to her colleagues at the Ontario Trial Lawyers Association.

The conference committee has planned a wonderful conference featuring Dr. Norman Doidge, best selling author of 'The Brain That Changes Itself', among other esteemed speakers. Our Annual General Meeting will be held immediately following the conference.



Our 3rd Annual Brain Injury Awareness Day is set for the first day of summer vacation for the kids. Many thanks to Alon Shatil at East Park who is giving our Association a tremendous discount for that day. You can find a coupon in this issue of the Monarch or download one from our website.

Our student interns and placements have now moved on and I would like to thank each of them for their contributions to our organization. The office is once again very quiet! I look forward to September for the new group of students.

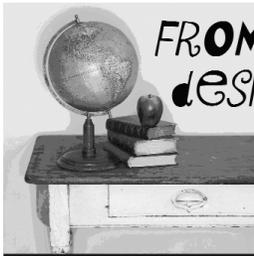
We will be busy over the next couple months with several community events where we will be promoting bike helmet safety and conducting helmet fitting clinics. Recently, we held a training session for several volunteers to assist us.

August marks the end of the Trillium funding for the support & volunteer position. Our board will be participating in a strategic planning session to plan for the future programs and funding needs of the organization. Although many of the support groups have determined that they will not run during the summer, we do plan to continue to offer all the groups in the fall. We have appreciated the opportunity to develop these groups by the funding from the Ontario Trillium Foundation.

Have a safe, happy and healthy summer!

Donna Thomson





FROM THE
desk OF

THE ONTARIO
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LA FONDATION
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Joe Zablocki

Support and Volunteer Coordinator

Thank-you to Our Volunteers

The Brain Injury Association of London and Region depends on the time, efforts, knowledge and experience of our many volunteers who freely give of their time to assist with the many programs offered by our association.

Our volunteers include survivors, family members, professionals, students and persons with an interest in Acquired Brain Injury. Each of our volunteers brings to our association their own personal and professional experiences that contribute to and complement our services.

We would like to take this time to recognize the tremendous impact the efforts of volunteers have in providing support to those living with the affects of an Acquired Brain Injury.

Volunteers provide the network of support that drives our association. With only two part-time paid staff it would be impossible to offer so many varied services to support those living with the affects of ABI.

Volunteers serve as support group leaders, peer mentors, office assistants, helmet fitters,

board members, community representatives, social supports, committee members and fundraisers. Some assist with setting up for special events, preparing mailings and maintaining information systems.

We do not take our volunteers for granted and we recognize that for many, their time given to our association is time taken away from personal, recreational, professional and family activities.

Despite so many so-called "timesaving devices" all of our lives are getting busier and the clock appears to be running faster.

For your many sacrifices and your ongoing commitment we say a heartfelt thank you.

We say thank you for your time, your knowledge, your experiences, your smiles and your contributions to the Brain Injury Association of London and Region and the lives of the many individuals our association serves. The key to our success rests in people like you who embody the spirit of volunteering by saying, "Yes I can!"



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&
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Program Highlights

- ◆ Membership in both the Ontario Brain Injury Association (OBIA) and the Brain Injury Association of London and Region (BIALR). Individual members shall be entitled to one vote at both BIALR and OBIA's Annual General Meeting. Family members shall be entitled to no more than two at both BIALR and OBIA's Annual General Meeting.
- ◆ Membership in Community Support Network/Reseau De Soutien Communautaire (CSN/RSC) is available to individuals and families who support the aims and objectives of participating community associations and OBIA. Corporations, associations, partnerships or other types of organizations are welcome to support participating community associations and OBIA by listing or advertising in the online ABI Directory of Services, but may not hold CSN/RSC membership.
- ◆ Members will receive a one-year subscription to OBIA Review and The Monarch newsletter.
- ◆ Members may participate in the Peer Support Mentoring Program for People Living with ABI.
- ◆ Members will have free access to OBIA's resource library and be eligible for a \$25.00 discount on most of OBIA's training programs.

All membership fees are equally divided between OBIA and BIALR

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The Peer Support Mentoring Program for People Living with ABI

By Jamie Fairles

Since I was given the role of Peer Support Coordinator (PSC) in November of last year, I've been busy recruiting both mentors and partners by promoting the program by way of giving presentations, word of mouth, and through Supporting A.B.I. (Acquired Brain Injury), the Facebook Group I've created.

I run the group with the help of Tammy Baskomb Filiat, the PSC for the Brain Injury Association of Windsor and Essex County. Currently, this Association has 3 active mentors and 7 new possible mentors waiting training later this month.

Initially it was hard to recruit partners to the program, but lately there has been an influx of survivors and family members recognizing that the need to talk about their issues and seek guidance and support is a crucial step in their own or their family member's recovery. We also have 2 cross association partnerships with the possibility of another one or two in the process of being established.

If you are a brain injury survivor, care giver, or family member and are interested in the program, Please call the office at 519 642-4539. I am typically in the office on Wednesdays, but if I am not there, Donna Thomson or Joe Zablocki can talk to you about the program or take a message for me to call you back. This is really a terrific program and it would be a shame to see it not being utilized.



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The Provincial Picture

Report from the January & March meetings of the OBIA Advisory Council

January 26, 2008

The council heard a presentation from Diane Radunsky and Carla Thoms who deliver OBIA's Support Services. Support services are offered through OBIA's 1-800 number and through the internet, and are available to anyone in Ontario. Dianne and Carla provide support and information to families/friends, survivors and professionals and other stakeholders, and provide referral information about services (lawyers, rehab programs, case management, therapists, crisis intervention etc.) located throughout the province. They also offer information about memberships in OBIA, training courses, the resource library and the new online Directory of

Services. Dianne and Carla make referrals to local Brain Injury Associations so that callers can get local information, and find out about group support, social events and peer mentoring in their own community.

They continue to offer advocacy on behalf of survivors/families where needed. Sometimes this can occur with 3rd party funders (WSIB, CPP, ODSP, auto and private insurance). Often they will be called upon by a family to help with advocating for an appropriate rehab facility, funding for rehab and/or appropriate long term acquired brain injury environments.

To help raise awareness of OBIA and its services, they disseminate information packages which



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include when appropriate our Caregiver Information Support Link (CISL). They are actively involved in disseminating OBIA's "You Are Not Alone" throughout Ontario.

To find out more about OBIA's support services, or to speak with Dianne or Carla, call (800)263-5404.

The OAC reviewed the outcome of the 2007 Provincial Conference, which was a huge success. The Council will host another conference in 2009. Having had a sell out crowd this past fall, the council will be looking for a venue for the next conference that will accommodate a minimum of 400 participants. The Provincial Conference Site Selection Committee will begin to visit sites in early March.

After much discussion the OAC decided to discontinue the production and sale of the lottery calendars. While the calendars were a valuable way to showcase the art produced by survivors, sales were not sufficient to support their continued production. Members of the council would like to have a new venue to present the talents of survivors. A committee of OAC reps will look at possible ways to achieve this goal.

March 29, 2008

The OAC held its last meeting on March 29. Representatives from around the province had the opportunity to learn more about the Ontario Disability Supports Program (ODSP). ODSP staff from the Income Support and Employment Supports program gave presentations on these programs, on which so many people with ABI rely. While the staff acknowledged that the level of income is very low, they emphasized the new changes that have helped reduce the barriers to employment. OAC representatives learned that recipients are able to;

- ◆ Maintain the benefits that cover the costs of drugs and essential disability expenses like wheelchair repairs, even after becoming employed
- ◆ There are financial incentives to getting and keeping a job
- ◆ Any competitive employment is encouraged, even one hour/week
- ◆ Get extra funds to help with expenses like moving

The OAC also received updates on some of the activities that are being carried out together around the province, including:

Peer Support:

Peer Support Coordinators from around the province met on March 28 to review the successes and challenges of the past year. All coordinators had wonderful anecdotal stories about the success of the program and how helpful it is for participants. All Coordinators also shared their struggles and concerns about encouraging participation in the program. We are all looking forward to new promotional materials, including a TV commercial that will be aired in June on CBC. Watch for it!

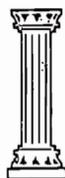
Provincial Conference, 2009:

The Provincial Conference will be hosted by the Brain Injury Association of Niagara. The Steering Committee is already starting the planning process.

OBIA Awards:

At each AGM, OBIA presents awards to various people and companies for their outstanding service and support to persons with ABI. John Kumpf asked the OAC representatives to review the Awards Criteria and nominate qualified individuals in their home community. Contact your local association if you know a person or a company that is making an outstanding contribution to people living with ABI.

The OAC will meet on June 21, which will also be the date of OBIA's Annual General Meeting.



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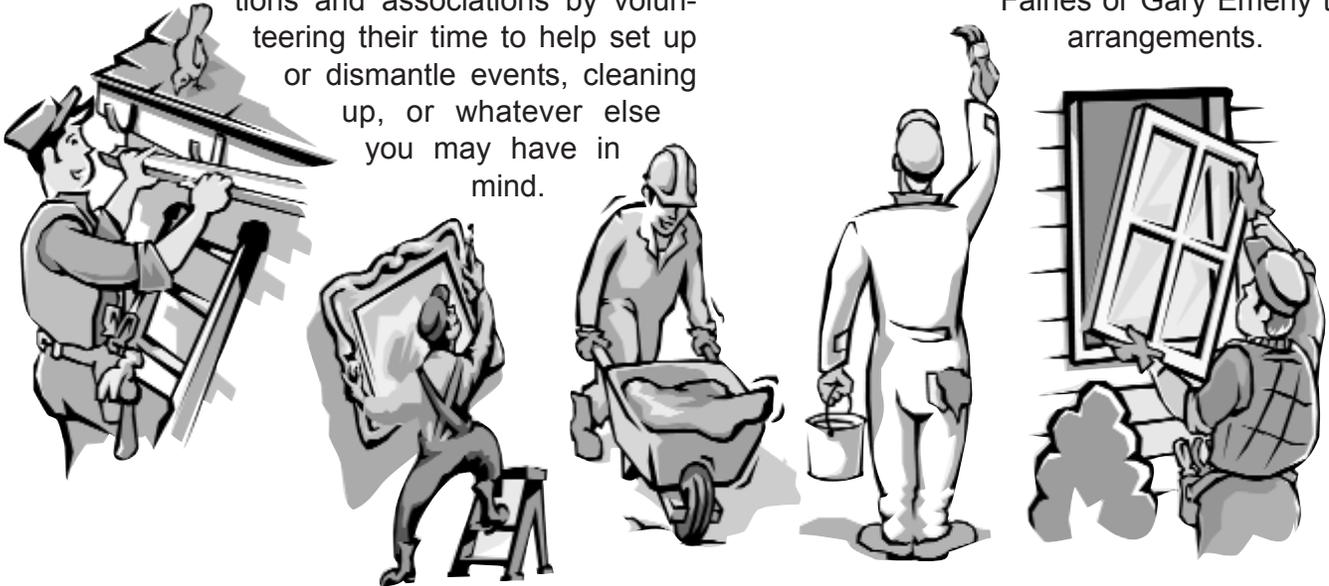


New Men's Group at Cornerstone Clubhouse

Cornerstone Clubhouse is pleased to announce the formation of a men's group that has four main objectives. The **first** aim of the men's group is to build camaraderie within the male membership. The **second** objective is to support one another through shared experiences. The **third** and the **fourth** objectives go hand in hand. They are willing to offer their 'man power' to help out various charities, organizations and associations by volunteering their time to help set up or dismantle events, cleaning up, or whatever else you may have in mind.

The final purpose of the men's group is to gain more recognition for Cornerstone Clubhouse and let people know that at Cornerstone, they are hard workers despite being affected by an Acquired Brain Injury.

If you and your organization have an event or something in mind for the men's group to lend a hand, don't hesitate to call Cornerstone Clubhouse at 519 679-6809 and ask to speak to either Jamie Fairles or Gary Emeny to make arrangements.



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Ask a Lawyer

Sean Mackintosh

Family Members' Lawsuits: *The Impact of Injuries on the Family*

In addition to the lawsuit of an injured individual, the *Family Law Act* of Ontario permits an injured or deceased person's family members to bring their own lawsuits relating to their own losses sustained as a result of the injury or death caused by fault or neglect. These eligible family members can sue even though they themselves were not physically or psychologically injured.

Which Family Members can Sue?

In general, the *Family Law Act* permits the following "non-injured" family members to sue for their losses: the spouse, children, grandchildren, parents, grandparents, and siblings of the injured or deceased person.

For a spouse to qualify where there has been no marriage, there must have been cohabitation for not less than 3 years or there must have been a relationship of some permanence if they are the parents of a natural or adopted child.

There are some cases where a step-parent or step-child may be permitted to sue if there has been a demonstrated settled intention to treat the child as a child of his or her family.

What losses can the eligible Family Members claim?

The *Family Law Act* permits eligible "non-injured" family members to claim for their own pecuniary and non-pecuniary losses.

Pecuniary losses are "economic losses" which may include out of pocket expenses resulting from the injury or death of the family member. It may also include any lost financial support and services that are no longer received from the injured or deceased family member. These damages also can relate to the "non-injured" family member's personal loss of income directly arising from the injury or death of a family member.

Non-pecuniary losses that may be recovered by the "non-injured" family member relate to the loss of care, guidance and companionship. Although money can be recovered in a lawsuit for these damages, the damages are not translatable in terms of money or economic loss so they are called "non-pecuniary". The law will not compensate for grief or sorrow but only where there is evidence of the loss of care, guidance and companionship. These terms have been defined by the courts to include the following:

Care: feeding, clothing, cleaning, transporting, helping and protecting another person and assisting in the creation and strengthening of relationships within a family over time.

Guidance: education, training, discipline, and moral teaching.

Companionship: sharing experiences and spending time together and celebrating achievements, events and landmarks in life.

With regard to these non-pecuniary losses, if the injury or death was caused by the operation of an automobile in Ontario after October 1, 2003, the insurance legislation requires that \$15,000.00 be deducted from these damages awarded to each non-injured family member.

It is therefore important to carefully look at the impact of a family member's injury or death on the other members of the family.



Sean Mackintosh

Legate & Associates Professional Corporation



Living with My Sibling's Brain Injury

By Lesley Fairles

"Jamie has a brain tumour", is what the neurosurgeon told our family in November of 1998. What I interpreted this to mean was that our lives were going to change because my brother had a serious medical complication and no one in our family understood how this story would unfold. At the time I didn't realize how my life would change as well.

Over the past ten years, I have learned what it means to have a sibling who is brain injured and what kind of impact that has on his life, as well as my own. Luckily Jamie's

personality is much the same as it was prior to both brain injuries. His sense of humour, intellect and ability to persevere remain intact. Oddly though, I can't recall a lot of memories of Jamie and I prior to his surgery in 1998. I can only muster up two or three specific memories of what Jamie was like before being brain injured. Over the years, I have attributed this lack of recollection to be a psychological effect where I think somehow, subconsciously, I have blocked out these memories because it would be



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too hard for me to think about how he might have changed.

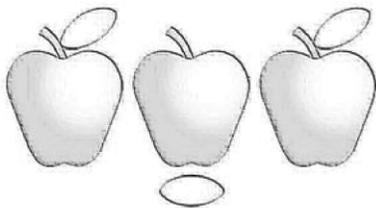
My relationship with my brother has remained strong throughout his brain injuries. We've argued like most siblings do and laughed a lot about life in general. However, when I look back on how I changed in the months during Jamie's recovery from the brain tumour, I realized I started living much more in the moment. I started throwing caution to the wind and only caring about the "now". This decision wasn't a conscious one, it just kind of happened as a result of witnessing my brother's life path change so quickly. It is only now, in my early 30's that I can reflect upon those years and attribute some of my behaviours as my own rebuttal to Jamie's brain injury.

Then, in January of 2006 I moved away to Toronto, only months after Jamie was injured for the second time, and that presented new emotions and new challenges. I decided to move because my life

was propelling forward and yet his life was coming to a very abrupt halt. Through this time, I struggled with feelings of guilt because I left to better myself and my life, leaving my little brother to slowly begin another recovery. In the past couple years instead of feeling guilty or sad, I draw on my brother's constant and incredible strength and his devotion to helping others who have suffered brain injuries. Jamie often says "things can be a lot worse". I try to also live by this mantra and help others too. For the past five years, I have raised money for the Brain Tumour Foundation by participating in the Spring Sprint in London, Ontario. Now, our entire family, including Jamie, completes the walk. Jamie's brain injury has ultimately pulled our family closer together, but it took us a while to realize this and work with each other to understand the large emotional, physical and financial impact brain injuries can have on the family.

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Brain Injury and Emotion Research Study

The human brain is an impressive organ that has the capacity to recover to various extents after injury. However, following brain injury resulting from head trauma or stroke, survivors often experience lasting changes in personality or behaviour. Survivors or their families may notice that they experience stronger feelings of anger, sadness, anxiety or happiness than they did before the injury. In contrast, family and friends of other brain injury survivors may notice that their loved one now rarely shows emotion and seems less sensitive to the feelings of others. Other survivors experience a full recovery without any observable changes in their personality or behaviour following rehabilitation.

Researchers from the Departments of Psychiatry and Clinical Neurological Sciences at the Schulich School of Medicine and Dentistry at University of Western Ontario are seeking the help of volunteers with a history of brain injury to study the links between brain function, emotion, and behaviour. With this knowledge, it is hoped that we may identify targets for future research and treatment for patients who experience changes in their

personality, actions, or emotions following brain injury. We also hope to learn more about how the human brain operates to give rise to different emotions and behaviours, and about how some areas of the brain might compensate for loss of function in other regions.

Principle investigators, Dr. D. Mitchell and Dr. E. Finger, and their research team will be conducting studies that examine problem solving and perception. Some of these studies will involve computerized tasks, and others will involve using non-invasive imaging techniques including Magnetic Resonance Imaging (MRI) to look at the brain activity of volunteers. Participants will be asked to make decisions or solve problems about images or sounds presented to them on a computer or during a functional MRI scan. Volunteers who have experienced head trauma or stroke are needed to take part in this important study. If you are interested in participating or would like more information about this study, please contact members of our research team: Jayna or Betsy at (519) 685-8500 ext. 32006 at the London Health Sciences Centre, University Hospital.

*You are cordially invited
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Brain Injury Association of London & Region

The Brain Injury Association of London & Region is committed to maximizing the quality of life of individuals with brain injuries, their family and friends through: Peer and Community support, Information about available services, Resources and Programs, Public Awareness of the causes, impact and prevention of brain injury, and advocacy on behalf of those affected.

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Living Life with Joel an ABI Survivor - Part 1

This is the beginning of a three part series of one family's journey following a brain injury. We would like to thank Marg Willemse for sharing this very personal story about her family.

June 6, 1980 and July 11, 2004 are two very significant dates in my life and especially in the life of my son Joel. June 6, 1980 was the day I gave birth to Joel Boudewyn Willemse, our third son. July 11, 2004 was the day Joel's life and the lives of his immediate family changed in a way we could never have predicted.

It would be difficult to talk about what it is like to live with a son with ABI (acquired brain injury) without starting from the beginning and explaining what our lives were like prior to Joel's injury. Joel has two older brothers, Keith and Adam, and a younger sister, Aprille. Visiting specialists was not foreign to me or to my husband due to the fact that both of Joel's brothers had been born with clefts which required numerous trips to London for doctor appointments and hospital stays.

When Joel was nine years old he had his first epileptic seizure. It was hoped that as he grew older he would out grow them. Unfortunately, that was not the case. Joel has always been on anti-seizure medication of one kind or another since he was nine. He was never able to go an entire year without having a seizure. Naturally, by the time Joel reached his sixteenth birthday, his friends were all getting their driver's license which of course Joel was not able to do. It was a tough blow at such an important time in a teenager's life. Aprille, who is two years younger than Joel, had her first epileptic seizure at the age of thirteen. When our son Adam was fifteen, he was diagnosed with Type 1 diabetes. As you can imagine our lives were busy, yet amazingly under control. At one point our son Keith said it looked like he was the only "normal" kid we had. I imagine that all the surgeries he had gone through seemed minor compared to what his brothers and sister were dealing with.

After a year of trying different anti-seizure medications, Aprille's seizures were under control, but Joel's were not. Nothing seemed to work for him and it took a toll on Joel's life, especially his self esteem. Yet, Joel managed to get through elementary and high school and went on to college. It wasn't smooth sailing, but it was manageable. After a number of years Joel decided he had had enough of school and wanted to start working. He had been in

a Law & Security course and made the decision to move to London, Ontario where he moved in with a couple of friends. Shortly after, he was hired by a London security company and was to begin his new job the following week. In the mean time he was working part-time as a bouncer at a local club. On Saturday, July 10, 2004 after his friends had left to go out for the evening, Joel was preparing for his shift at the club which would have been around 9:30 P.M. It was 2 A.M. when one of his roommates returned and found Joel seizing in his room. This particular roommate was an old childhood friend of Joel's and had been with Joel more than once when he was having a seizure. As a parent you always dread that phone call that tells you something terrible has happened to your son or daughter. This time, when Cory called me, I could tell by his voice he was really scared and then he told me he had never seen Joel quite this bad before. He was blue, still seizing and had been vomiting. I could hear Joel in the background and asked Cory if he had called 911, which he had. We were instructed to meet them at University Hospital.

Upon our arrival we were allowed to see Joel before he was moved to the ICU. He was not responding and had been given a large dose of medication to stop the seizing. Needless to say it was a long night and we were not getting a lot of answers. Joel had only had one seizure when he was younger that required a hospital visit to stop it. Otherwise, they always stopped on their own, until this time. The doctor's told us that Joel had seized for approximately 4 - 5 hours and due to the vomiting he may have asphyxiated. If so, this may also have cut off the oxygen to his brain, possibly causing brain damage. There were no definite answers and no explanation as to why it happened in the first place.

All we could do was wait. During the first day, we were getting a lot of information coming at us from all directions; he had a temperature of 102, there was an infection in his body they could not explain, he was dehydrated, his brain was swollen, his heart rate was too high, his blood was too thin, and he was also on a respirator. They thought he might have meningitis, so we had to wear gowns, gloves and

continued on page 18



continued from page 17

masks when we went in to see him. The doctors had actually given Joel a drug to paralyze him; it was the only way to stop the seizing. With all this information coming at us, I decided to start keeping a daily log. It was total overload for all of us. When the doctors decided to bring Joel out of the induced paralysis it took 5-6 attempts because he would start to seize each time. On the second day they were able to get him off the medication. They also stopped sedating him, in hopes he would wake up, which he did not. We were told Joel was in a coma. By the end of third day the doctors told us that they had done everything they could, but that Joel's liver and kidneys were failing. He was "very critically ill". Basically, if he did not "turn that corner" soon, it did not look like he would make it.

I have always been strong in my faith, but I can honestly say that I have never prayed as hard or more desperately in my entire life. Fortunately, my husband and I are both from large families and we immediately had their support, love and prayers. Family members and friends sat vigil with us waiting for some good news. My mother, who was 82 at the time, was and still is a huge comfort and support to me and my family. The hospital staff were wonderful in that they would let his Dad and I, Joel's brothers and sister and any extended family or friends who wanted to spend time with him, go in to see Joel any time day or night. It was not until some time later that we realized they did this because they did not expect Joel to survive. He was steadily going downhill. At one point, when the doctors were basically saying there was nothing else they could do, a wonderful neurologist by the name of Dr. Young went in to see Joel a number of times and he was able to discover why Joel was not improving. With a change in medication, came a change in Joel's body and he started to respond to the new

treatment. Although Joel was still in a coma he was managing to hold on. On the sixth day an MRI was done, but the prognosis was grim. Dr. Young had actually stayed late that Friday night just to be there when the results came in as he knew we were waiting.

Dr. Young sat us down and explained that according to the MRI there was considerable brain damage on the right side of the brain. Joel would still have his speech, but he would not be able to walk, meaning he would have to be in a wheelchair. His eye sight



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would be affected in a way that he would see everything “flat”; he would not be able to see three-dimensionally. He would not be able to see depth either, using stairs as an example.

Dr. Young said he was sorry to have to tell us this. At this point, we were happy that Joel was still alive because we felt we could deal with anything.

As we waited for Joel to come out of his coma, numerous tests were being done on a daily basis and with each day came more problems and little improvement. It was on the tenth day that Joel actu-

ally tried to open his eyes. I had just come into the room and the nurse was trying to get a response from him, which they would do on a regular basis through the day. She said to him, “Joel, your Mom is here” and his eyelashes began to quiver and his eyelids started to flutter. I just kept talking to him and he kept trying so hard to open his eyes. By the twelfth day they had to do a tracheotomy. It was the next day, when I was holding Joel's hand, that I asked him to squeeze my fingers, which he did three separate times.

It seems like such a small thing, yet to us it was huge. He was responding to voice commands. Then he started to yawn and as he stopped, he opened his eyes! It only lasted a couple minutes, but he gave us more joy and hope in those few minutes than we had had in almost two weeks.

Over the next few days he continued to give us small signs that he was starting to come out of his coma. Then on the sixteenth day we were told Joel had blood clots in his left leg. The doctors administered Heparin in an effort to dissolve them. The next day Joel's bilirubin was up and he had a yellow color. His liver and kidneys were not working properly. His temperature went as high as 106 degrees F. The doctors continued to run tests such as an MRI, x-rays, blood cultures, and an EEG. They also kept him sedated all day with a sedative that causes amnesia. The doctors told us that this would keep Joel from having any memory of all the terrible things he had endured over the past few weeks while in hospital. The following day they did not administer a sedative at all and Joel opened his eyes and followed the nurse with his eyes as the nurse moved around the room. He then gave nurse Fernando the “thumbs up” and opened and closed his eyes on command.

Watch for the second part of this story in the September Issue of 'The Monarch'.



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Providing Information to the Respite Caregiver

by Joe Zablocki

Caregivers face many challenges and one of these is finding and utilizing the services of respite care. Caregivers need time a break from their caregiving responsibilities to relieve stress and prevent burnout and recharge their own physical and emotional batteries. But, many caregivers fail to use respite services fearing that something may go wrong and they will not be there to assist. Although no one can guarantee nothing will go wrong there are steps that a person can take to minimize the risk and allow them to relax while they are away from their family member.

One of the ways to minimize the stress and worry is to prepare a check list of things the respite caregiver will need to know. This list should be personalized to meet the unique needs of each person but could include some of the following:

Contact Information

Although the purpose of respite is to provide the regular caregiver with a break it may be necessary in case of an emergency to contact this person. Contact information for the primary caregiver and alternate decision makers should be provided.

Medical Information

All caregivers will require a list of current medical conditions and any procedures that may need to be performed. Is the person diabetic, do they have seizures, are there any allergies, are there any upcoming medical appointments are all items to consider. The phone number and address of the family physician, the nearest emergency department and the person's health care and medical insurance should be provided to the caregiver and also posted next to the phone.

Medications

If the person receiving care is taking any medications a list of all medications and the medication routine should be written out and placed with the medications. This should include times to be taken, method of administering, i.e. with food, on empty stomach, etc. For longer periods of respite information regarding refills and pharmacy location should be provided.

Emotional Status

Is the person generally happy, do they get angry easily, do they sometimes appear sad, do they like to be alone or do they like to talk? Information about the emotional status of the person and how to respond will help the caregiver respect the individual's preferences and reduce the chances of emotional stress for both the caregiver and the person.

Meals and Snacks

Some people have very set meal routines while others eat only when they feel like it. Others may require prompting and/or encouragement to eat. Some are able to eat independently while some



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require assistance. It is important that the respite caregiver know what the person's preferences and/or requirements are. Providing a list of favourite foods, snacks and foods to avoid is very beneficial for the person who is not the regular caregiver. It is also important to know if there is risk of choking and how food is to be prepared to reduce risk.

Personal Care and Activities of Daily Living

Some people require assistance with personal care and activities of daily living like shaving, dressing, bathing and/or walking etc. If assistance is required in any these areas a checklist of the activities requiring assistance and those that the person can perform independently should be given to the caregiver.

Assistive Devices

Does the person use an assistive device and are there maintenance procedures to be followed? By example if the person uses a powered wheelchair, how often does the battery need to be charged and how far will it travel on one charge? There are many and varied aids for daily living and providing a list of the ones used by the person will reduce the opportunity of accidents.

Entertainment

We all have personal preferences for entertainment. Information about the person's entertainment preferences will be helpful to the caregiver. Do they like to watch television? What type of movies do they like? Do they like to read? Do they like to play card, board and/or video games? Do they attend sporting events...etc? Also a list of activities to avoid should be provided.

Sleep Routines

If the respite care is for an overnight the caregiver should be provided with the regular sleep schedule. Does the person have a regular time to go to bed to rise? Do they have a snack prior to retiring? What is the bathroom routine? Does the person awake during the night? Do they nap during the daytime? Do they have a nightlight and/or special toy they use when they sleep?

This article in no way exhausts the possible items to provide to a caregiver but hopefully it provides a starting point for a caregiver to begin to develop their own personalized checklist. As with any list this list will grow and adapt to it current needs but will be invaluable when handing the responsibilities of care to another person.

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Care for the Caregiver

By Dr. Margaret Weiser

Most parents and adult children have learned to live apart, often for years. But after a brain injury, this prized independence and autonomy can change overnight. Many families find themselves living closer, both emotionally and day-to-day, as rehabilitation moves from the hospital back to the home and community.

Those who were living alone and managing on their own “quite well, thank you” may suddenly find themselves surrounded with well-intended helpers. Family and friends may be frequently in contact by phone, by email, or visiting daily, dropping off food, doing laundry, or offering transportation to appointments. Lives that were separate are now again overlapping.

While the help offered is usually genuinely appreciated, and indeed usually given with sincere heartfelt caring, sometimes other emotions simmer beneath the surface.

Disgruntlement and irritation may appear, along with resentment and even a sense of entitlement. Deep-seated grudges and old sibling rivalry may re-emerge, when other family members’ concerns need to take a back seat. “Why can’t you take me shopping? You have too many medical appointments!” Life feels out of balance. “Why are you spending all your time worrying about me?” the survivor may ask.

While all may try to remain patient, it soon appears that after the initial joy of hospital discharge and return home, “the honeymoon is over”.

What can we do to remain helpful, caring, and compassionate, while not becoming “bossy, overbearing, and nagging”? Many young survivors have spoken of feeling “wrapped in cotton”, with family members trying to protect them from all possible harm. Others - spouses or parents - tell of “walking on eggshells” while trying not to say or do anything that might hurt feelings or start an argument.

How to help while recognizing your limits:

Some “red flags” to watch for (that might tell you “I’m too involved”):

1. being too tired to participate in enjoyable recreation with others - refusing invitations
2. falling asleep in unexpected places and at inconvenient times
3. lying awake in the middle of the night making to-do lists
4. driving “on auto-pilot” and missing a turn-off
5. arguing with family members over chores that no one wants to do
6. making calls for people who should do it themselves

Some self-care routines to consider, to take care of yourself as a caregiver:

1. walk, as often and whenever you can
2. take three deep breaths before answering difficult questions
3. let the phone calls go to the answering machine
4. schedule time for answering email, and don’t keep checking while completing other tasks
5. pat a pet (borrow one if you have to)
6. watch funny TV shows without excuses or embarrassment

Other resources and sites to visit:

1. “Crooked Smile” by Lainie Cohen. A mother struggles to keep her family together after her eldest son suffers a brain injury in a car crash. A moving and inspiring memoir written with emotional honesty, filled with hope and celebration for life’s small successes.

<http://www.crookedsmile.org>

2. Rachel Oliver is a cartoonist with 2 books published about the horse world. On May 6th, 1997, an accident changed her life. She was hit by a car while jogging. Rachel suffered 2 broken arms and legs and a brain injury. <http://www.racheloliver.com>

3. Dr. Claudia Osborn is a survivor of traumatic brain injury. Her website <http://www.claudiaosborn.com> explains “My purpose is to explain what living with a brain injury means, to the survivor, to the family and significant other, to the rehabilitation professional ... and to communicate the knowledge that it is possible to create a fulfilling new life and move beyond grieving about what has been lost.”

4. IMPACT program (Impaired Minds Produce Actions Causing Trauma) <http://www.lhsc.on.ca/trauma/injury/history.htm> is a volunteer project for London clinicians. IMPACT is an integrated education module to London high school students, offering a unique learning experience at London hospitals and a chance to meet people who have survived traumatic injury. Part of our message is the effect of trauma, hospitalization, and rehabilitation on the entire family. Put your positive energy to work volunteering in a community project that matters deeply to you. Consider health, the environment, youth or aging, or even politics! As they say in the movies, “Move with a purpose!”

5. Contact your local Brain Injury Association to discover the many programs they offer. www.braininjurylondon.on.ca.

Did you know the Brain Injury Association of London & Region offers services to both survivors and caregivers? Contact us to find out more about our Respite Care Program, Support Groups, Peer Support Mentoring Program, Advocacy Assistance, and volunteer opportunities. We are here to help!



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It's Okay to Ask for Help: Respite Care Program

By Mallory Seager

Do you feel overwhelmed, isolated, and need time to reconnect with family and friends-and the life you had before a love one suffered a brain injury?

Oftentimes people associate the difficulties and hardships that accompany a brain injury to the brain injured individual exclusively. However, the affects of a brain injury weigh tremendously on the individual's family, friends, significant others, and coworkers-and not just for one day or one week, but for a lifetime.

It can be emotionally and physically draining to care for a loved one who has suffered a brain injury. The needs that develop after a brain injury are often drastic and unexpected and caregivers may need help dealing with the unexpected stress and workload. Remember it is okay to ask for help and everybody is entitled to rest, especially because rest will allow you to rejuvenate your mind, spirit and physical stamina to better care for your loved one.

The Brain Injury Association of London & Region offers a Respite Care Program that allows you to return to the familiar lifestyle that you were accustomed to prior to the accident. The program will allow you to take some much needed time for yourself, to reconnect with family and friends, and to once again take part in activities that need to get done or activities that you simply enjoy doing. Errands like "running to the bank" and "grabbing a quick bite to eat" are not as feasible when you are constantly caring for another, but you will be given the time to complete tasks that may seem so minimal, but are so vital to retain your strength and vitality in such a trying time.

Our program funds Respite Care for up to 4 hours of service a month, and families who do not use the monthly-allotted hours may accumulate up to 48 hours per 12-month period. This can include personal support worker and/or homemaking services from trained experienced Personal Support Workers. As long as you are a member of the Brain Injury Association of London & Region, you can apply for Respite Care at anytime; it could be during the acute stages that immediately follow the injury or later on in the survivor's life when care is

still needed. Also, this program is completely free for those families that qualify.

Quote

Remember, as much as you feel the need to constantly care for your loved one, you must take time to de-stress and reincorporate the neglected activities and people back into your life. This program provides the perfect opportunity for some much needed you time.

For more information or to apply to the Respite Care Program please contact:

The Brain Injury Association of London & Region

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E-mail: info@braininjurylondon.ca

Website: www.braininjurylondon.on.ca

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Summer Support Groups

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to see if the group in your
area is meeting.



Traveling with a Brain Injury or other Disability

By Jamie Fairles

Now that it's June summer is here and what better time than summer to take a family vacation? If you do decide to travel this summer, and if you or somebody traveling with you has a brain injury or other disability, there are some important things to keep in mind to ensure that you have a safe, happy, restful, and stress-free vacation. Before choosing a destination and method of travel you have to take into account the disabled traveler's special needs and then search for travel providers and agents who know and can accommodate those needs.

If the person requires a wheelchair make certain that wherever you're going is fully wheelchair accessible and where the handicapped parking is. This information is readily available at airports, train stations, ship docks and travel agents. Don't assume that staff members will know and understand the traveler's needs, make sure they know by informing them in advance.

You will want to pack accordingly. This includes packing enough proper clothing, medications, and other necessities. You don't want to be miles away from home then realize that you forgot a day's worth of medication, or underwear for that matter.

Check what sort of ground transportation is available. Arrange ahead of time for a wheelchair to transport the traveler through busy, congested areas and if you're traveling with your own wheelchair it's advisable to check that the holiday insurance policy covers any aids or equipment that you might take with you. Also you might want to reserve the bulk head seats and an aisle seat so that the traveler is afforded more leg room and can easily get in and out of their seat, and is thus more

comfortable while traveling.

Although most travel lines allow special needs passengers to board first, allow enough time for boarding because some travel lines may not follow the same procedures as others do. Keep in mind that most airlines, trains and ships do not generally provide services to help with eating, drinking, taking medication, or help inside the washroom.

An attendant may be needed to travel with the disabled traveler to see to these matters. A medical attendant may receive a reduced fare, but medical documents are needed as proof when booking your travel transportation. If the traveler has vision issues and needs a seeing-eye dog, keep in mind that for some international travel, seeing-eye dogs require a health certificate and proof of vaccination whereas some countries (including Britain) don't allow service dogs, so it's a good idea to

research the rules and regulations on disability travel of whichever travel line you choose to go with.

You are not required to pay extra for any disability services, being a traveler with a disability; you are entitled by law to receive these services.

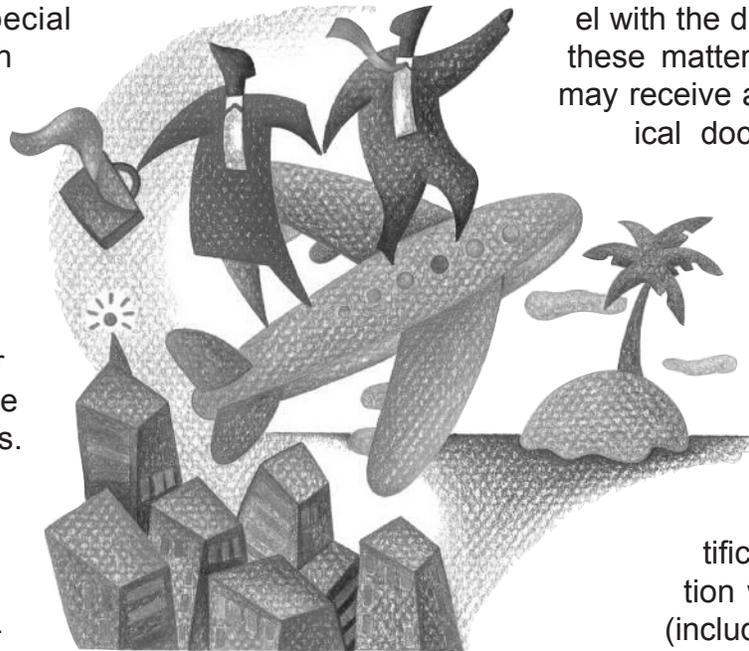
If you have any further questions or concerns about traveling with a disability, contact a travel agent, or visit one of these websites:

http://www.fredericktravelwaterloo.com/accessible_travel.html

<http://www.transitionsabroad.com/listings/travel/disability/keywebsites.shtml>

http://access-able.com/graphical_index.html

<http://www.handitravelservices.com/index.htm>



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Greenhills Golf Club, London Ontario
Registration 9:00 a.m - 10:15 a.m.
10:30 Tee Time

Presented by:

H.A.B.I.T. (Helping Acquired Brain Injury Treatment) and
The Brain Injury Association of London & Region

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\$ 50.00 for dinner only
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Total Owing- _____

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Please make cheques payable to H.A.B.I.T. Brain Injury Golf Classic.



Family Life and Brain Injury

By Jamie Campbell MBA, M.Ed., RRP, CCRC, CCC, CCLCP

Please visit www.braininjurylondon.on.ca for a listing of references for this article as well as information about the author

Brain injury continues to be one of the leading causes of death and disability in North America. It can happen to anyone, young or old, during a variety of activities. Brain injury can have life altering changes on the person injured, and is now recognized to cause significant distress and change for the family and friends of the person injured.

In Ontario brain injury occurs at a rate of approximately 18,000 per year. In Canada, it has been reported that approximately 50,000 people per year are hospitalized with brain injury. In the United States, the annual incidence of brain injury is estimated at a rate of 250-300 per 100,000 population or 1.5 million per year. At this rate, the city of London, Ontario alone may have more 750 brain injuries per year.

Approximately half of brain injuries are reported to be caused by motor vehicle accidents, and 80% are reported alcohol related. Twice as many males as females experience brain injury. More than 50% of people that experience brain injury are men between 15 and 30 years of age. More than 50% of the people that experience brain injury are under the age of 20 years.

However, it is not just young males with risky behaviours that experience brain injury. Each year over 5000 children in Canada experience brain injury from bicycle accidents. Brain injury can happen to an elderly person while falling down the stairs. Brain injury can happen to both genders, young or old, in a variety of settings. Brain injury in Canada is a significant issue, for people with injury, families, friends and others trying to provide their care.

Although brain injury is typically classified by level of severity, injury to the brain can affect control and monitoring of physical, cognitive, behavioural, and emotional functioning. The brain controls heart rate, breathing, blood pressure and swallowing, and injury to the brain can be life threatening.

One of the functions of the brain is to help assess what is going on outside of the body, so that the person can act and interact in their environment. The brain helps to assess what

is happening, to process this information, to compare this information to similar experiences encountered, to decide which action to initiate, to carry out the intended action, to monitor and assess the action, and to store the results into memory for future use. Injury to the brain can affect these functions and affect how people behave, including how they behave and interact with family, friends and other caregivers.

Practitioners in the hospital and community rehabilitation environment are familiar with the course of events after a motor vehicle accident brain injury. People with brain injury, and their families, typically experience the process for the first time. After injury the person injured is usually transported by ambulance to an acute care hospital. They may undergo surgery but are soon transferred to a rehabilitation hospital for more in patient care and therapy. After multi disciplinary in patient treatment, people with

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brain injury are discharged home. Once home, community rehabilitation providers start to treat and interact with both the person with injury and their family. Family members may or may not be ready at this stage, but are often required, to provide care to people that have been injured.

When brain injury happens to a loved one, family members can find themselves struggling to cope with the impact the injury has on their own lives. For example, brain injury to a pre accident academically gifted child who now has difficulty doing basic arithmetic, can have significant impact on the emotional or psychological well being of a parent.

Brain injury to the sole breadwinner of a family, can cause family members stress and worry over how the family will financially support itself. In a single income family, a pre injury stay at home mother may be required to re-enter the work force and become the breadwinner for the family. Pre injury plans may need to be modified and family members may need to learn new ways to survive. Family

members often need both the capacity to provide care to the person injured, and ability to adjust their own lives.

The family member without injury may not have the skills needed to return to the work force. They can now be faced with the task of preparing for work while trying to deal with their own emotional, providing care to the injured person, all in the midst of family dysfunction. The situation is often not easy for families to deal with.

Researchers have documented that there is long term psychological distress for families after brain injury. Families can experience denial, guilt and anger after brain injury to a family member. The family may question why the accident or injury happened to their family? The feelings and emotional turmoil that families experience, can go on for years after injury. It is clear that the injury affects not only the person that has experienced injury, but often affects many if not all members within the family. Researchers have reported that individuals with

brain injury, their mothers, spouses, siblings and the family unit, all have more family distress after brain injury as compared to norms.

Following brain injury, there may be persistent behavioural changes to the family member with injury. The person may not respond to treatment as fast as or as well as hoped and families can question their own adequacy as caregivers. Family members can blame themselves for lack of progress or outcomes. Care for the person with brain injury is often provided by parents, spouses or other family members, who may not be well prepared to provide care.

There may be anger directed at the family member with brain injury. There may be anger at other family members, a spouse, a child or a sibling, who may not be coping well with losses and changes in the family system. Family members may not function well individually, or the family as a

Dr. Alvin Harvey Shapiro Psychologist

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whole may not function well. Brain injury can affect the entire family system.

Denial is often present after injury. As an emotion, denial can be helpful and harmful to families. Some families that deny potential for negative outcomes may put forth extra effort to access resources for the injured family member. The extra effort may help the family member reach maximal recovery. However, for families that deny permanent impairments or significant post injury changes, denial can cause families to have unrealistic expectations for the future. The emotional distress can promote prolonged family dysfunction.

Role changes often occur within the family system. Pre injury, parents typically expect children will become more independent as they mature through teenage years. However, after brain injury parents may be required to provide much longer term care to their children than they had planned before the injury. Some parents may need to alter their retirement plans, in order to provide care and support to their children. Expectations and roles for siblings may change after injury.

Care giving needs can restrict families from pursuing their own activities. Family members may need to alter their pre-injury lifestyle. Supports that existed pre-injury may disappear. Families may become socially isolated after a family member experiences brain injury.

In Ontario, families providing care to a family member as a result of an automobile accident may receive insurance funding to do so. Some families may even be able to recover financial cost of providing care through the tort system. This “benefit” can provide some financial relief to families caring for injured family members. However, even with attendant care benefits and tort recovery, after brain injury many families can face emotional distress, financial hardship and family dysfunction.

After having provided case management and counselling in the Southwestern Ontario rehabilitation community for several years, I can offer that in recent years, access to information and availability of services to help families after brain injury has improved.

However, for some families, for example those that fall through the cracks in the system or those in rural communities, they can still experience lack of



access to information and support services. Some families continue in distress with little help.

After brain injury, some families learn to cope well. They make adjustments and they learn to function. Other families are not as resilient or lucky. Some families do not remain intact and some struggle with ongoing family discord. One partner may decide to leave. Some parents may not be able to cope with the intensive care giving needs. Relationships between partners and children can be forever changed. Relationships between parents and non injured children, and relationships between siblings can change. Families are often faced with altered relationships and ongoing stress.

Counselling for families and individual family members can be helpful after brain injury. I have observed in my own case management and counselling practice, that counselling has helped many families after brain injury. Published clinical guidelines suggest that families may require counselling help with anxiety and guilt, and to recognize their self worth and competence. Families may need to learn to use their individual strengths and to draw on each other for support. When needed after brain injury, counselling has the potential to help some families cope and rebuild their lives.

However, some families may not be ready to deal with the potential emotional pain that can come with counselling. They may prefer to try to continue to meet their own needs and to function independently, in spite of the distress that they may be experiencing.

The issue of whether to involve the family member with brain injury in family counselling needs to be addressed by the family and counsellor. If the





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*The Helmets on Kids Community Partnership will again
distribute bicycle helmets to children in London schools.*

family member with injury is able to participate in counselling, can explore, gain insight and understanding from the counselling, then involving the family member can be helpful. Some family members may need individual counselling, to express and explore issues too difficult or uncomfortable to divulge in family groups. Group processes can be helpful, but individual counselling to family members and the person with injury, may also be required.

Families may require help to develop appropriate support networks in the community. The Brain Injury Association of London & Region (2008) has received 2 years of funding to offer monthly support groups to survivors and families in a number of locations in Southwestern Ontario. This community support can be tremendously helpful to families with brain injury. Many health providers in the many community rehabilitation agencies, psychologists, psychotherapists, counselors and social workers, are often prepared to help families deal with changes after brain injury.

Counselors can help families develop peer and natural supports. Without taking anything away from

the professionals providing rehabilitation care, some families can benefit more from families that have dealt with similar experiences and challenges who are willing to share their knowledge. The families that have struggled, and those that have survived and grown, may have the potential to help families in need.

After brain injury, once survivors and families have had a chance to grieve and adjust to their loss, families learn to create and tell new stories about themselves. In spite of their ongoing distress, they develop new scripts and schemas, learn new ways to cope and function. Families learn to care and interact with the person injured, with other family members, and within their communities. They continue to live and love. Families create new histories as they provide care and go about their lives. The experiences they encounter create new understanding. For people with brain injury that have survived, and for their families, life is dynamic, not static and will continue to change.



Promoting your Family's Well-Being

Adapted with permission of the Brain Injury Association of Queensland

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 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 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 is always best to know where your teenagers are and who they are with). Don't sweep conflicts 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 counselors 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 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

taking time to be with them- something that is not often 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 counselors. This can be a good thing, but if these people have little knowledge of 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 TV. 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 reassurances or advice. Give them time to talk, to express their feelings. It is important to remember children's behavior 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 usually better able to support and understand the difficulties facing their brother or sister with 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.

*****Did you know that the Brain Injury Association of London & Region in partnership with PABICOP offers a Sibling Support Group? Brothers and sisters of children who have sustained an acquired brain injury are invited to attend this group where they can share their feelings and experiences with other siblings. Check out www.braininjurylondon.on.ca for more information*****



Upcoming Conferences and Events

June is Brain Injury Awareness Month across Ontario and many events are being held by various Brain Injury Associations to acknowledge this.

Children's Safety Village Birthday Party-Helmet Exchange

June 1, 2008,
Fanshawe Park

3rd Annual Brain Injury Insert

June 4, 2008
Pick up your free copy of 'The Londoner' to see our featured insert.

7th Annual Helmets on Kids Campaign Kick Off

June 18, 2008
St. Pius X School, 255 Vancouver Street, London

Open Minds:

Exploring Neuroplasticity and Non-traditional Therapies

Brain Injury Association of London & Region's
11th Annual Conference
June 20, 2008
Four Points Sheraton London, Ontario

Annual General Meeting

Brain Injury Association of London & Region
June 20, 2008 4:30 p.m.
Four Points Sheraton London

3rd Annual Brain Injury Awareness Day

June 26, 2008 12:00 - 7:00 p.m.
Eastpark Golf Gardens, London
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September 25, 2008 Greenhills Golf Club



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