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E-Mail: info@braininjurylondon.on.ca Editors: Editorial Committee Layout & Design: Advance Imaging
As we approach the end of yet another year, the Association has continued to grow and prosper. September was an extremely busy month with our involvement in Camp Dawn, the 6th Annual London Brain Injury Golf Classic and preparations to move into our new office. Our Board of Directors is carefully considering a Shared Activity Agreement with OBIA that would offer our members an opportunity to belong to both organizations. Following a break over the summer, all of our committees have resumed their important work of planning exciting events for 2008.

Tickets to our 8th Annual Dinner & Dance are now available for sale. ‘Let’s Get It On..Movin & Groovin to Motown’ promises to be a fun filled evening!

On behalf of the Association, I would like to congratulate Gary Phelps on receiving PricewaterhouseCoopers Volunteer of the Year for this region in recognition of his volunteer efforts within our organization. In addition to Gary’s stellar volunteer contributions over the past few years, the Association also received a donation of $1,000 from PricewaterhouseCoopers in honor of this award.

A joint planning and orientation meeting was held last month with the Support Services Committee and the Support Group Leaders. We now have Support Groups in all 5 counties & are excited to offer two new groups that address the unique needs of specific age groups. Look for more information on these groups in the Support & Volunteer Coordinators report

Earlier this summer, we submitted a grant application to Anderson Corporate Foundation on the recommendation of one of its employees. Just as I sat down to write this article, I received an exciting phone call informing me that we have been awarded a $10,000 US grant to help fund our Respite Care Program! Thanks to Allan Sydorko for sharing the grant information with us, we are now able to provide a much deserved break for caregivers. If you provide ongoing care to a brain injured family member, or know of some one who does, please contact me at the Association to find out more about this program.

The Peer Support Mentoring Program continues to offer a way for survivors and family members to connect with others in similar circumstances. In addition to several matches locally, we also have trained mentors who are matched with partners in Sault St. Marie, Chatham and Windsor. Our office recently hosted training for several new Peer Support Coordinators from across SW Ontario, including our very own Jamie Fairles. Jamie and I had the pleasure of co-presenting with Michele Meehan on the Peer Support Program at the provincial ABI conference in Kitchener. We are hoping to offer mentor training early in the New Year, so if you know of some one who would make a great mentor, have them call the office for more details.

Plans are well underway for Brain Injury Awareness month next June. The Conference Committee is currently securing presenters for our 11th Annual Conference in mid June. The conference brochures will be available on-line as well as in the March issue of The Monarch. The Community Awareness Committee is also busy with plans for our 3rd Annual Brain Injury Awareness Day scheduled for the first day of summer vacation next June.

As you can see, 2008 promises to be just as exciting here at the Association! I encourage you to regularly check out our website at www.braininjurylondon.on.ca to keep up to date on all of our events and programs.

Have a safe, happy and healthy holiday season!

Donna Thomson
Over the last year we have endeavored to establish support groups for persons living with the effects of an acquired brain injury. We have been successful in establishing groups in all five of the counties we serve with 2 groups in Woodstock, and groups in London, St Thomas, Clinton and Stratford. These groups are open to any one who wishes to attend and pre-registration is not necessary.

With the successful establishment of our monthly groups we have begun focusing on exploring the need for groups for identified age groups. After exploration we discovered that gaps in services exist for children and young adults with an ABI. With this information we began to investigate options in which to better serve these groups of persons and we are excited to announce two new monthly support groups.

The first of the two groups is the Social Group, and it is an activity based group for persons 18-30. This group will meet monthly for pre-determined social activities. This group will consist of persons with an acquired brain injury and a group of their age group peers. This group will meet the last Monday of each month beginning in November. There will not however be an activity in December. The activities will vary based on the interest of the group and each month’s activity will be posted on the Brain Injury Association website. There is a cost associated with this group and participants will be required to cover the cost of their activity. The goal is to keep cost to a minimum and will be in the $10-$15 range. Pre-registration is recommended by calling the Brain Injury Association. For information or to register for this group you can contact Joe Zablocki at support@braininjurylondon.on.ca or call (519) 642-4539

The second new group is designed to meet the unique support needs of Children with ABI and their Families. For this group we have partnered with the Paediatric Brain Injury Community Outreach Program (PABICOP). Three separate groups will meet simultaneously at the Thames Valley Children’s Centre 779 Baseline Rd, London from 6:30-8:00PM on the last Wednesday of each month beginning in January 2008.

Kids: “I HAVE A BRAIN INJURY—THINGS ARE DIFFERENT NOW”

For children between the ages of 7 and 12 years of age who have sustained an acquired brain injury and would like to meet other children in a group setting who may have similar challenges or needs for support.

Parents: “MY CHILD HAS A BRAIN INJURY—WHERE DO WE GO FROM HERE?”

This group will provide an opportunity for parents of children with an acquired brain injury to meet other parents and discuss their experiences. The monthly agenda for this group will be directed by the needs of those attending.

Siblings: “WHAT HAPPENED TO MY BROTHER/SISTER?”

Siblings sometimes have difficulty understanding what has happened to their brother and/or sister following an acquired brain injury. This group will provide them an opportunity to share their feelings and experiences with other brothers and sisters.

To pre-register for this group please contact Sara Somers at (519) 685-8500 ext 53483

As with any group we are always in need of leaders, administrative assistance and persons willing to share as a guest speaker. If you would like to assist us with any of our support groups we encourage you to contact us.
Camp Dawn has left us again, but it was a great year. We had it at the same camp as last year. There were cabin challenges, Yoga, meditation, bingo, crafts, high ropes and canoeing. Also, there was great big campfire for everyone and anyone to come and enjoy, plus singing around the campfire.

We also had a surprise visit from Walter Gretzky. He signed autographs for those who wanted one. He also took photographs with fellow campers. His speech was on his stroke, and how he has learned how to deal with it. One thing he emphasized was: “I could not grasp the fact that shoes went on your feet.” He also said he was so glad that there is a camp for people with brain injuries. The fact that he came, made this year at Camp Dawn all that more special.

I personally did something amazing. I’m scared of heights, but I was able to go up and do more of the high rope course than I did last year. Next year I’ll be able to do more.

This year Camp Dawn was amazing and I can’t wait until the next Camp Dawn. Also, I can’t wait ‘til I see you there next year.

Thanks to our sponsors
Camp Dawn 2007 was a tremendous success!

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The Brain Injury Association of London & Region is one of 22 brain injury associations in Ontario that are affiliated with OBIA. Five times a year, representatives from these associations meet as the OBIA Advisory Council (OAC) to share information and ideas about issues that affect people living with ABI. Together, we share the strategies we use in each of our communities to provide support, information, advocacy and education. We also generate new ideas for programs, services, resources and funding that will help people living with ABI.

The OAC met on September 22. We used this meeting time to revisit the purpose of our meetings and the roles and responsibilities of the representatives from participating associations. Each association appoints 2 representatives who are responsible for:

- Bringing information about their associations’ activities, successes, and challenges
- Bringing information about the issues that are faced by survivors, family members and stakeholders in their local area
- Participate in shared efforts through work on committees
- Report back to the local board and community about the efforts of the OAC

The OAC believes that it is crucial to have the involvement of survivors at all levels of planning and delivery, therefore, at least one of the two local representatives must be a survivor.

At our September 22 meeting, we talked about the role of representatives in helping move information to and from local members to local boards, staff and volunteers at OBIA, and the OBIA Board. These representatives have a crucial role in ensuring that the efforts of local association and of OBIA reflect the needs and interests of their members, and that members are kept informed of the efforts and progress, or the barriers we face as we try to move forward.

In the past two years, members of the OAC have worked together to create the Peer Support Mentoring program, the provincial conference, a dual membership program and an online directory of ABI services (coming soon).

A report on the activities of the OAC will be a regular feature in The Monarch. Please watch for updates in upcoming editions.

In our area, your OAC representatives are Kevin MacGregor and Donna Thomson. If you would like to find out more about the OAC, or make your views known, please contact your representatives at 519 642-4539 or by email at info@braininjurylondon.on.ca.

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Peer Support Program For People Living with ABI
Do you or someone you know have a brain injury?

Would you like to volunteer and help someone else who is coping with the effects of ABI?

The Brain Injury Association of London & Region offers a Peer Support program and needs volunteers!

To become a Mentor, you will first talk with the Peer Support Coordinator to find out if volunteering as a mentor is right for you. After a screening interview, you may be invited to a day of training to help you learn basic skills that all Mentors need.

- Offer a listening ear as the partner sorts through the effects of ABI of his or her life
- Share personal experiences in coping with injury
- Share strategies and resources that worked for you
- Support the partner to figure out the strategies that will help him or her.

After training, you may be matched with a Partner who is facing similar problems and challenges that you have.

The Peer Support program is open to all adults (16 years and older) who have sustained a brain injury, or who have a family member, partner or friend who is a survivor.

All contact with your Partner is through phone or e-mail and you can expect to talk to your Partner about once a week. You can decide with your Partner how long you want to talk, and what time suits you best.

The Peer Support program can be a great way to contribute to your local Brain Injury Association and your community, and to gain valuable skills and experience.

For more information, contact:
Brain Injury Association of London & Region
519 642-4539 info@braininjurylondon.on.ca

TERRY EVANSHEN is the spokesman for the PEER SUPPORT PROGRAM
Having support is paramount in any difficult situation. When I sustained my first brain injury nine years ago due to a brain tumour, I had the support of my family and friends. I do not even want to imagine what state I’d be in today if that support system was not there for me. Because of all the support I received, I was able to return to school, get a scholarship to university and graduate four years later after my rehabilitation. However, one year from my graduation, I was physically assaulted and sent back to square one. It seemed as if all the progress I had made had been for naught because this traumatic brain injury has affected me more physically than the first one had. I still have the support of my remarkable family, but as it happens when people age, the support of my friends has been less apparent than the first injury because they have moved on in their own lives. The point is support is a key factor in any successful recovery.

When I heard about the Peer Mentor Support Program, I thought that I could really be of use. After living through two brain injuries, I like to think that I’ve gained some knowledge and can help others that are now facing similar situations that I went through. Both my mother and I were among the first ten individuals to be trained as peer support mentors in Ontario. She mentors a woman whose daughter is a brain injury survivor and I mentor a young man with a brain injury.

I feel that one of the best things about being a peer support mentor is that not only do I help fellow survivors, but I also get a sense of healing dealing with the issues that once plagued me. Issues of losing relationships with friends, going back to school, finding work, and volunteering are all things my partner and I talk about. Peer mentoring is a two-way street. Both of us are helped by discussing certain issues.

For instance, my partner recently returned to school and I told him how beneficial it was for me taking advantage of the students with disabilities service when I returned to university. It’s things like this that I found helpful in my recovery that I can share with my partner and that’s a key feature in any peer mentoring: hearing what worked for somebody in a similar situation. Conversely, the most challenging thing about being a mentor is also one of the most rewarding. Sometimes when we talk, an issue arises that I realize that I haven’t quite come to terms with myself, so in talking through possible avenues to confront the issue, I confront it myself.

Above all though, the most rewarding thing of being a mentor is that it has made me decide this is my place in life. I find extreme pleasure in helping people in less than fortunate circumstances and I have decided to return to school once again to get my Bachelor’s of Social Work so that one day I might become a social worker in a hospital setting. The Peer Mentor Support Program for individuals living with an acquired brain injury is a valuable tool in one’s recovery, whether it is the mentor or the partner.
As Jamie's mom I have been on an incredible journey for the past 9 years. There have been many ups and downs. My participation in the Peer Mentoring program is definitely one of the “ups”. I am always amazed by the resiliency my son demonstrates every day. As a peer mentor I learn about others who also have also demonstrated courage and resolve to move forward as a survivor of ABI. In those 9 years I have learned a great deal and peer mentoring allows me to share my up and downs with another mom whose daughter is a survivor of ABI. Peer mentoring has given me a friend. Neither of us knows what the other looks like but we have a bond and that bond is ABI.

Being a peer mentor has afforded me an outlet to share my experiences with another Mom. Although our children have suffered very different brain injuries there are a myriad of similarities in the emotional roller coaster that is ABI. Supporting my partner in her journey has been a part of my journey of healing as well. I can see just how far both Jamie and I have come from that diagnosis of his brain tumour 9 years ago.

The biggest challenge for me personally has been to not give advice, tell someone else what they need to do or what they should do. Peer mentoring is about sharing and supporting and instilling hope for the future. Like ABI each family has differing struggles and as a peer mentor I am able to provide a safe place to vent anger, to talk about their successes and sometimes just to chat. For me this is the essence of what peer mentoring means. My partner and I have been together for a year and although we try to speak weekly brain injury is not always our first topic of conversation. Life does go on after a brain injury and our weekly chats are proof of this. Although sometimes just remembering to make that call can be a challenge. I often need my son to remind me that it’s time to call......and as he often has said “Just who is the brain injured one in this family?”

Overall, Peer mentoring has been a rewarding and fulfilling experience. I have a new friend that I am sure I will meet face to face some day. Recently she advised me that the past year has allowed her to move on in her healing and given her a new perspective on the future. This is reward enough for me as something very good has come out of something very tragic.

Dr. Alvin Harvey Shapiro
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A person who sustains a brain injury as a result of an automobile accident may spend a long period of time in hospital or in a long-term care facility. Sometimes the brain injury is severe requiring permanent residency in a long-term care facility.

As every family member of the survivor well understands, staff at a hospital or long-term care facility can not and do not provide one-on-one, 24 hour care to their patients. It therefore falls to others to provide the extra care needed. There is some expectation in our society that this will happen, and family members and friends willingly step up and provide the necessary care. They are often present around the clock. Family and friends do much more than visit; they assist the survivor with meals, grooming, dressing, and hygiene. They may also help their loved one with his or her physiotherapy exercises or speech language therapy. They are often there to ensure the survivor has the full-time supervision he or she requires, and are available to call for help immediately if necessary.

Although family and friends may provide these services out of love or out of duty or even out of necessity, the fact is that the survivor is entitled to receive attendant care benefits for the services being provided by family in addition to the care being provided by the hospital or long-term care facility.

This is true even if the insurer is paying for the services of the long-term care facility. It is not open to the accident benefits insurer to pay only for the long-term care facility and insist that all of the survivor’s attendant care needs are taken care of by staff at the facility.

How does one go about obtaining attendant care benefits to compensate family who provide care in hospital? First, the survivor’s attendant care needs must be assessed and submitted to the accident benefits insurer using the Assessment of Attendant Care Needs form. Importantly, the person assessing the survivor’s needs, usually an occupational therapist, should look closely at what services are needed overall, what services are being provided by the long-term care facility, and particularly what services are required to be provided by the family.

It is important to recognize the contribution required and being made by family members to the insured’s attendant care needs while in a care facility. It is very useful to have the attendant care assessor include in the report information or observations of attendant care that is actually being provided by family members in addition to what is being provided by the care facility.

The assessor may wish to identify the amount of attendant care benefit attributable to the family members. In addition, it is helpful in establishing entitlement to the benefits, for family members to record what services are being provided by them and when they are being provided.

It is easy for an insurer to assume that all of the survivor’s needs are being taken care of by staff at the care facility. Family members know the reality. Though they may be happy to do it, family members can and should be compensated for the care they provide to their loved ones in hospital.

Joni Dobson
legate & Associates Professional Corporation
in partnership with the 
Paediatric Acquired Brain Injury Community Outreach Program (PABICOP) 
is pleased to offer three new support groups

Paediatric/Parent/Sibling 
Acquired Brain Injury Support Groups

Kids with ABI
"I HAVE A BRAIN INJURY-THINGS ARE DIFFERENT NOW"
Children between the ages of 7 and 12 years of age who have sustained an ABI and would like to 
meet other children in a group setting who may have similar challenges or needs for support.

Parent Group
"MY CHILD HAS A BRAIN INJURY- WHERE DO WE GO FROM HERE?"
Parents of children who have sustained an ABI and would like to meet other parents in a supportive 
group setting. The group members will decide agenda items for discussion.

Sibling Group
"WHAT HAPPENED TO MY BROTHER/SISTER?"
Brothers and sisters of kids with an ABI and would like to share their feelings and experiences 
with other brothers and sisters.

These groups will be held the last Wednesday of every month beginning:

January 30, 2008
Thames Valley Children’s Centre
779 Baseline Road
6:30-8:00 p.m.

All groups are offered at the same time to allow participation of all family members 
Light refreshments will be provided.

To register please contact
Sara Somers at 519-685-8500 EXT 53483
Email: Sara_Somers@tvcc.on.ca
by January 18, 2007

Space is limited so please register as soon as possible!
OBIA Conference

Mary Carter and Donna Thomson attend the provincial brain injury conference, Coming Together: Quilting the pieces after a brain injury.

Brian Tumour Foundation
Information Day

President Mary Carter and Executive Director Donna Thomson offering support at Brain Tumour Foundation Information Day.

Camp Dawn
2007

Camp Dawn recognizes all of the staff as leaders to he
With every dawn
a new path is found.

www.campdawn.ca

Campers enjoying canoe ride on Rainbow Lake

Campers on a nature hike at Camp Dawn

Special guest Walter Gretzky becomes an honourary camper at Camp Dawn

organizations that send their help run the camp
The Brain Injury Association of London and Region is launching a new Social Group in November 2007. This group will offer monthly planned activities at various venues within London. The group is open to persons 18-30 years old who have sustained a brain injury and are looking for a way to connect with others in their peer group, make new friends and enjoy an evening out participating in a fun activity. The group will be held on the last Monday of each month (there will not be a group in December) from 7:00-9:00 p.m.

The first Social Group will be a

**Bowling Night**

**Monday November 26, 2007**
Palasad Billiards (777 Adelaide Street by Oxford Street)
7:00-9:00 p.m.
The cost of this event will be $15.00 each person for two games of bowling.

The location of the activity will change monthly depending on the planned event. Info can be found on www.braininjurylondon.on.ca or by calling (519) 642-4539

For Further Information
Contact Joe Zablocki, Support & Volunteer Co-ordinator
support@braininjurylondon.on.ca, Tel: (519) 642-4539

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**Brown Beattie O’Donovan LLP**
BARRISTERS & SOLICITORS

**WE CAN HELP**

If you or a family member are suffering the effects of a brain injury or other serious injury, contact Andrew King for advice as you may be entitled to benefits and compensation.

Andrew G. King, Q.C.

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Website: www.bbo.on.ca
1600-380 Wellington Street
London, ON N6A 5B5
Often someone with a brain injury has no outward physical signs of injury, and may have trouble convincing others that they do have a disability.

Brain injury is often called the invisible disability because a person may outwardly appear to be unaffected, particularly if the cause was a brain tumour, near drowning, mild stroke or drugs. Even when the injury is caused by trauma such as a motor vehicle accident, the scars may heal so well that the person appears to be fully recovered.

Unfortunately even a so-called ‘mild’ brain injury can leave a person facing cognitive deficits in memory, concentration, motivation, fatigue, stress, depression and reduced self-awareness. People who acquire a brain injury often find that family, employers and friends have trouble accepting that there can still be problems when there is no physical evidence.

Family members often have the most trouble understanding the invisible nature of acquired brain injury. With effort, the effects of a mild to moderate brain injury can often be hidden or compensated for so that most people will not detect any problems. But families get to see beyond the ‘public face’ due to the amount of time they spend together.

After the brain injury the family is frequently confronted with a ‘new’ personality - a family member who may be negative, unmotivated, unable to carry tasks through to completion, constantly forgetting things, unable take others’ needs into account and prone to depression or angry outbursts.

Before the brain injury, the person usually had some degree of control over these areas and how they chose to act and speak. Now they have lost these abilities and may only regain some control through compensatory strategies, if at all.

HOW TO CONVINCE OTHERS

How do you convince skeptical family or friends that you do have a brain injury? Trying to discuss the issue is often difficult.

Family members are often resentful if they have been coping with some of the more unpleasant sides of a brain injury, such as anger or self centredness.

Discussions can break down into recriminations and the brain injury can be seen as a weak excuse for inappropriate behaviour. Families often come to an understanding of acquired brain injury through simply reading about it.

Previously their ideas may have been based on what they had seen in movies - a person is knocked briefly unconscious, forgets who they are, their memory is restored by another bump to the head, then they are fine again.

There is a wealth of medical research and information showing that even in cases where people were not unconscious, they may face lifelong difficulties with short-term memory, emotional instability and a wide range of other effects - a far cry from the instant recovery portrayed by Hollywood.

continued on page 22
ONGOING PHYSICAL ISSUES

Unfortunately, individuals with a brain injury are often left with much more than life-long cognitive effects such as susceptibility to stress, inability to work, memory problems, migraines, auditory and visual disabilities or neuroendocrine disorders. Insurance companies and generic rehabilitation services are often unaware of the frequently ongoing nature of deficits from traumatic brain injury and that a ‘return to normal health’ does not occur in the majority of cases. In some cases individuals need to take legal action to obtain the rehabilitation and support that their insurance guarantees.

There is a public perception that legal compensation payouts are often very large; but such multi-million dollar awards take into account that the person will need cognitive and physical therapy or support for the rest of their lives.

WHAT ABOUT THE ULTIMATE SKEPTICS?

Some people may refuse to believe a brain injury exists unless there is firm medical proof. Usually a moderate to severe brain injury leaves scarring that will clearly show on MRI or CAT scans. The brain does have a limited ability to heal itself; and in milder cases, a scan conducted years or even months after the injury may no longer show evidence, although the cognitive deficits remain. There is also Diffuse Brain Injury, where the damage occurs at a microscopic level throughout the brain, and will not show on scans despite the huge impact it can have.

In these latter cases a neuropsychological assessment is used to identify a brain injury, its effects and the strategies needed for rehabilitation. Testing includes a variety of different methods for evaluating areas such as attention span, memory, language, new learning, spatial perception, problem solving, social judgment, motor abilities and sensory awareness.

These tests can be quite expensive. Universities offering programs in neuropsychology often provide evaluations at low cost or on a sliding scale as part of their student training.

It is no wonder that brain injury survivors get discouraged when others won’t accept that they have this disability, and the survivors have to face criticism instead of support.

A Brain Injury is a Hidden Hurt.

by Janne Brown

The majority of the population does not know or understand what it is and how it affects individuals living with this “hidden hurt”.

Brain injuries are caused by a blow to the head. This can result from a car accident, playing rough sports, such as hockey, being hit in the head with a heavy object or a brain tumor.

When people are suffering from a brain injury, they may also experience other ailments that are visible to a human eye: Balance, speech and physical ailments. Tiredness, concentrating and conversing with others are some of the hidden hurts a brain injury survivor will experience. Just because an individual has a brain injury does not mean they are stupid, retarded or incapable of doing things on their own. It is truly important to educate everyone in what a brain injury is because, in a split second, it could happen to them.

I suffered a brain injury four and a half years ago: but you would not notice it as you are reading this article.

We Can do More Than you Think.

by Natalie Molinaro

Brain Injury is a hidden disability. Most people see a brain injury and give it the wrong name. For example, disabled, retarded, paralyzed or worse.

Just because some of us have speech impediments doesn’t mean we are stupid. Come and talk to us, in some areas we might even be smarter than you.

Some people think that because you use a wheelchair you are either retarded or are paralyzed. This is not true because some people with a brain injury also use a wheelchair. Some of those people have lost all ability to walk and have to find housing that is either totally wheelchair accessible or housing that easily can be made accessible. There are some people with more of a balance problem and/or cannot walk and/or stand for any great length of time.

Some people also think that those with even the smallest speech impediment are retarded. It is common for a person with a brain injury to have a speech impediment. Those with a brain injury may have problems remembering words all the way to a slur with anything from a couple of words or a couple of letters.

Brain Injury is the invisible disability because you don’t notice until we speak, walk, even just show ourselves. It is the invisible disability because you don’t notice until we do something or you mistake us for having something else. I bet you did not know that the author of this article has a brain injury. We can do more than you think.

Keeping a Positive Attitude after a Brain Injury

By Jamie Fairles

There are several new challenges a brain injury survivor faces on a daily basis that many take for granted. Simple tasks such as getting ready in the morning, planning the day’s meals and activities, grocery shopping and maintaining a job are just a few of life’s daily activities that some ABI survivors struggle with every day. Some survivors are plagued with feelings of loss and futility, and they yearn for the life that they once lived. The fact of the matter is that the past is the past and nothing can be done to change what has happened.

Once one has truly accepted this fact and the new life that has been unfortunately forced upon them, can one truly heal. It’s never easy being a brain injury survivor. Nobody asked to receive a brain injury, so take this “new life” and make the best out of it. My personal motto is negativity is like a soup spoon with holes in it: useless and pointless! Why spend so much energy on being negative when having a negative demeanour only makes things worse. It has been shown that the more positive people are, the healthier and happier they are. Depression and moodiness are not uncommon in brain injury survivors.

Whenever I get down in the dumps, I think about the way my life is now compared to how it could have been. I take solace in the fact that I am here to tell my story. It could have just as easily gone another route and I would not be writing this. The point is to be grateful that what one might have done easily before takes effort now, because even though it can be frustrating, be appreciative that you are alive and able to feel that frustration because the alternative is not to feel anything. Because I can feel frustration I am reminded that I am alive and feel very fortunate to be so, which puts a smile on my face.
Suffering from the effects of a severe brain injury myself, I am well aware of my differences. As a result of the injury sometimes the choices and/or decisions I make are misinterpreted. People have a hard time deciphering between actions that are a result of my brain injury, or whether it was just a poor choice on my behalf.

A great number of my behaviors are in fact a result of poor choices that I have made, such as I use profanities in my everyday grammar excessively. As a result of my injury happening at the premature age of 17, I feel as if I am stuck in the mentality in and around that age. Is my inappropriate swearing a result of the brain injury or a bad habit? Is it just a bad choice of where or when to use this language? Personally I feel that this lack of control that I have experienced over my language, relates directly to the brain injury. I simply have lost a bit of the discipline that I would use to control myself, and my language. So I would have more ability to curfew my cursing, and/or inappropriate speech if I hadn’t suffered an ABI.

Another area in which I am nagged at consistently, is around eating. Constantly I am hearing “eat Mike, eat!” “Mike, have you eaten?” As a result of the part of the brain that was injured, my support team and family feel that I’m not remembering to eat. When in fact I do feel hunger, and it’s just due to the effort involved in preparing food. I make a poor choice and I don’t eat.

Medication is another area of concern. Now I will admit that, having never had to take meds prior to my brain injury, the meds, and constant nagging around something that hasn’t proven to be actually doing anything, is a bit more then annoying. I do however understand that the people prescribing the meds have great knowledge in the field. After all, if its going to help me get any closer to where I want to be at the end of all of this I’m more then willing to give it my all.

As a result of the injury I sustained, I seem to have become terribly irritable. It has been brought to my attention on a number of occasions, and is noticed by myself as well. Unfortunately, due to the brain injury it’s not until after the fact.

When I can look back on the event critically I am able to distinguish between acts of irritability and when I’ve become so unacceptably irritated that I act on that. Unfortunately however, I have lost the memory to control myself. So instead of calming myself, and thinking the situation over realistically I simply act on the feelings, not assessing the actions until after the fact.

The memory deficit that has been noticed by nearly everyone I come into contact with, is well noted as the most significant and severe loss that’s been suffered and is a result of my accident. Life without memory is, too often unbearble from forgetting small insignificant information or happenings, all the way to forgetting what comes naturally to most people that are ABI free, what came naturally to me before my accident. That’s when the injury is most infuriating. It’s the simple things that should be just everyday happenings. Those are often the tasks in question, when I can’t manage to complete the task at hand, and I know that it is only so difficult because I have a brain injury.

Often times it can be found to be to extremely difficult to determine whether actions are caused by the brain injury, or whether it is just a lack of control. Quite often the ABI survivor is the only one with that knowledge. It is the knowledge of, and the ABI itself, that forbids sufferers from being heard.
We will call her Alice. Alice is an active member of Cornerstone Clubhouse. As part of our Transitional Employment Program, Alice stepped up to the plate and announced that she was interested in seeking a job with competitive wages.

She started a job placement at a local variety store. The employer was extremely happy with her work. Alice was originally supposed to work only 20 hours per week.

This had been discussed several times with staff that was supporting her. Because she was so successful at her job, the employer added more hours, now up to 30 hours per week.

Alice was thrilled; she felt she could handle this extra workload. However, tell tale symptoms started arising. She was late for work twice, something that had never happened before.

Her family started reporting that she was exhausted in the evenings, and sometimes fell asleep right after supper. However, Alice felt she was doing well and agreed to go to up to 37 hours per week.

After two months of full time hours, Alice suddenly quit her job! The reason was that she was totally exhausted and was having difficulties with behaviour and fatigue issues with her family.

Unfortunately most employers lack knowledge and understanding of brain injury. Because most people with ABI present so well, things like fatigue are not obvious.

This is an excellent example of the difficulties that face many people living with the effects of an acquired brain injury when they take on too much. As much as Alice felt great about working, she was pushed to the point where she could no longer handle the job. Perhaps if Alice had stayed at part time, she would still be working and not spending so much time alone.
Q. What is a Capacity Assessment?

A. A Capacity Assessment is an assessment of an individual’s (over 18) cognitive ability to manage their property (finances) or personal care (health care, nutrition, clothing, shelter, safety, and hygiene).

Q. What are the reasons for conducting a Capacity Assessment?

A. A Capacity Assessment is conducted in order to reach a decision as to whether a substitute decision maker needs to be appointed, either by the courts or by way of a Certificate of Incapacity allowing the Public Guardian and Trustee (PGT) to become statutory guardian.

In some cases, a Power of Attorney may exist, but the document requires a capacity assessment in order for the individual holding the POA (called the attorney) to activate their authority.

Q. Who may request a Capacity Assessment?

A. A Capacity Assessment can be requested by relatives or friends who believe the individual is not capable of making competent decisions regarding their finances or personal care.

Q. What is the definition of capacity?

A. A person “must be able to understand information relevant to making a decision and appreciate the reasonably foreseeable consequences of making or not making a decision.” (Substitute Decisions Act)

If the person fails either the definition of “understand” or “appreciate”, he/she is deemed incapable.

Q. What is involved in the process of determining a person’s capacity for making decisions regarding their property or personal care?

A. a) A requestor contacts a capacity assessor regarding a capacity assessment for personal care or property.

b) The requestor provides the name of an individual (it can be the requestor) familiar with the person to be assessed. This individual is called an informant and must be able to supply relevant information regarding property and/or personal care. This forms a baseline for the capacity assessor to test the individual to determine his/her capacity.

c) The individual to be assessed must be 18 years or older

d) There are two ways by which a substitute decision maker is determined

i) A lawyer applies to the courts to have an individual appointed as substitute decision maker with a capacity assessment for property and/or personal care in hand.

ii) The person is deemed incapable and the assessor issues a Certificate of Incapacity to the Public Guardian and Trustee, thus making the PGT statutory guardian. The PGT then becomes the substitute decision maker.

e) All individuals have the right to refuse a capacity assessment. They may also have a completed assessment brought before the Consent and Review Board should they disagree with the findings.

In those situations where an individual refuses to be assessed but there is compelling evidence to suggest they are incapable, the courts can order the assessment.

The role of the Public Guardian and Trustee comes into effect when there is no other person willing or available to assume the responsibility of being a substitute decision maker.

Capacity assessments cannot be performed where a legally determined Power of Attorney exists. However, there are certain circumstances whereby a capacity assessment is conducted in light of a Power of Attorney, i.e., in situations when activating the Power of Attorney requires that a person first be deemed incapable.

For further information, you may contact the Capacity Assessment office at 595 Bay Street, Suite 800, Toronto, Ontario M5G 2M6, Tel: 1-800-366-0335, or contact Ike Lindenburger at 519-645-7393
List of Possible Functional Deficits Resulting From a Traumatic Brain Injury

- 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 with pacing activities
- Difficulty with judgment and decisionmaking
- Perseveration, i.e. the mind gets stuck on one issue
- Distractibility, confusion, irritability, impulsivity
- Difficulty dealing with change
- Socially inappropriate behaviour
- Isolating self as feeling different, and therefore treated differently

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

Facts about Brain Injury

Brain injury is a hidden disability. Some survivors show no outward appearance that they are indeed brain injured, but in the past few years, brain injury is coming out of the darkness as more light is shed upon it making more and more people aware of it. Here are some startling facts about this tragic, hidden affliction.

- Every year in Canada, over 11,000 people die as a result of a Traumatic Brain Injury.
- Traumatic brain injury is the top disabler and killer of young Canadians under the age of 40.
- Each year, over 6,000 Canadians become permanently disabled after a traumatic brain injury.
- Each day in Ontario, 44 individuals sustain a brain injury.
- Each day, 100 Canadians sustain a brain injury.
- 80% of children under 15 who had multiple injuries, sustain brain injuries.
- Motor vehicle collisions account for over half of all acquired brain injuries.
- Every year in Canada, over 60 children will die as a result from bicycle-related injuries - the majority from brain injury.
- Over 75% of all cycling deaths involve brain injuries.

- Bicyclists wearing helmets reduce the risk of brain injury by 88%.
- The human skull provides little protection of the brain as it is less than a ¼ inch thick and has a tendency to crack under pressure.
- Long-term consequences of brain injury affect the lives of about 26000 individuals.
- 22% of people with catastrophic brain injuries never leave their homes.
- In Ontario 92% of men and 100% of women who sustain a brain injury never return to full-time employment.
- Damaged brain cells DO NOT repair or replace themselves. Now more than ever, people are surviving from brain injuries because of improvements in medical and trauma care, ongoing safety improvements in motor vehicles, workplace safety, and sporting equipment standards.
- Many who would have previously died from their brain injury, now survive with a diminished capacity for living.
- It is estimated that the direct and indirect costs associated with traumatic brain injury are $3 billion annually in Canada.
Under the Ontario Human Rights Code ("the Code"), individuals have a right to "equal treatment with respect to employment without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, record of offences, marital status, family status or disability." The duty to accommodate is triggered when an employer seeks to apply a standard that is prejudicial to an employee on the basis of one of the prohibited grounds of discrimination set out in the Code. In the employment context, the duty to accommodate involves the removal of barriers that prohibit the individual from integrating into the workplace.

While the scope of the duty to accommodate will vary “according to the characteristics of each enterprise, the specific needs of each employee and the specific circumstances in which the decision is to be made,” there are a number of steps that both employers and employees can take to facilitate this process.

**What are the obligations of employees with respect to the duty to accommodate?**

- To bring to the employer’s attention the fact that he/she requires accommodation.
- To specify the type of accommodation required. This should be done in writing.
- To work with his/her employer to find appropriate accommodations.
- To accept reasonable offers of accommodation.
- In appropriate circumstances, to provide the employer with documentation from health care professionals involved in his/her care.

**What are the obligations of employers with respect to the duty to accommodate?**

- To proactively identify situations where an employee might require accommodation. This could include, for example, designing buildings or creating inclusive programs.
- To respect the dignity, personal autonomy, and confidentiality of the employee requiring accommodation.
- To ensure that there is a procedural framework in place to investigate and resolve requests for accommodation.
- To assume the costs associated with obtaining relevant medical documentation.
- To respond to employee requests for accommodation in a timely fashion.

According to the Code, the employer must accommodate the employee to the point of "undue hardship." There is no precise legal definition for "undue hardship." Courts in Canada have generally taken the view that undue hardship occurs where the employer cannot sustain the economic or efficiency costs of the accommodation. However, it should be emphasized that requests for accommodation by an employee should be considered on a case-by-case basis, with regard for the specific needs of the individual involved.
Workplace Rights of Employees Caring for Family Members with Disabilities

Increasingly, governments recognize the important role played by individuals caring for family members with disabilities. In the last few years, a number of important legislative changes have occurred which assist employees caring for loved ones with disabilities or illnesses. Two of the most important are the Personal Emergency Leave and Family Medical Leave provisions of the Employment Standards Act, 2000 ("ESA").

Personal Emergency Leave: Employees who work for employers who regularly employ 50 or more employees are entitled to personal emergency leave under the ESA. Personal Emergency Leave entitles the employee to ten unpaid calendar days of leave per year. Employees may take a Personal Emergency Leave in cases of personal illness, injury, medical emergency, or urgent matters relating to: a spouse, a parent, step-parent, foster parent, child, step-child, foster child, grandparent, step-grandparent, grandchild or step-grandchild of the employee or the employee’s spouse, the spouse of an employee’s child, a brother or sister of the employee, relative of the employee who is dependent on the employee for care or assistance.

Family Medical Leave: the ESA provides eight weeks of unpaid leave (in a designated 26 week period) to employees if the employee’s spouse (including same-sex spouse), parent, step-parent, foster-parent, child, step-child or foster child is diagnosed with a serious medical condition that involves a "significant risk of death" within 26 weeks. Anyone in Ontario who is covered by the ESA is eligible to take this leave. Family medical leaves are not subject to the "undue hardship" exception.

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We all know that people who have disabilities live with many things: pain, fatigue, restricted mobility, faulty thought processes, uncertain employment prospects, fear and so on. Many of them also live with, or have close contacts with, other people: spouses, significant others, children, in-laws, other family members, friends, neighbours and perhaps colleagues.

These other people, most especially those in the same household as the person with the disability, often find themselves taking on the role of caregiver, helping the person with the many activities of everyday life the person has difficulty doing independently. Some of these people take on the caregiving role willingly, some very reluctantly.

The nature of professional work requires that time be spent with clients or patients. However, when health care professionals are not on the scene providing treatment, the caregivers remain. It can be a 24/7 job, evenings, weekends, time off work to attend appointments and other demands.

As our population ages, the number of people cast in the caregiver role is increasing. Some caregivers find themselves suddenly having to care for family members with disabilities or illnesses and maybe their own dependent children at the same time. In some cases, caregivers have little time to attend to their own needs or to get on with their own lives.

Imagine a teenager having to care for a parent so disabled by a stroke he can scarcely move out of bed. What about the twenty-something daughter trying to help her mother with the activities of daily living every day of the week? Would you like to be a wife with a responsible job and have to leave your husband at home every day lying on a couch with constant pain?

As professionals concentrate efforts on helping clients recover, they also need to keep in mind the lives of caregivers who will remain to help their loved ones or friends long after the professionals are gone. The burdens caregivers face can be enormous and they are often ill-prepared to handle them.

Caregivers can be valuable allies to health care professionals. If they make no attempt to support caregivers, enlist their help, understand their situation and learn about the patient, they do the caregivers and their patients a great disservice.

The challenges caregivers face are legion. These are some of the more important ones:

1. Financial: insurance matters, disability pensions, taxation issues, work-related benefits, banking affairs, household bills, etc.
2. Legal: insurance settlements, wills, property ownership, powers of attorney and living wills.

3. Housing and Long Term Care: ongoing suitability of present home, adaptations needed, substitute accommodation when present caregiving arrangements falter and/or needs can no longer be met, death or illness of a caregiver, reluctance of a caregiver to acknowledge that more care than they can provide is needed.

4. Daily Care: medication, diet, clothes, groceries, medical and other appointments, sleep problems, stimulation, social activities, etc.

5. Personal Adjustment: guilt, frustration, anger, anxiety, stress, despair, loss of personal and social life, isolation, burnout, family role changes, strained relationships, signs of abuse of the client, to name a few.

6. Living with Deterioration: in some cases caregivers have to watch a formerly capable loved one gradually lose abilities and become increasingly dependent (becoming more common with the senior population and aging processes).

The ability of caregivers to continue along their inexorable paths can be enhanced if their skills can be developed, their needs met and their feelings considered, respected and understood.

A few moments of time spent by the health care professional at each meeting with the patient to check out how caregivers are coping can mean much to their self-esteem and ongoing adjustment. It can be helpful to be alert to signs of stress, helplessness or burnout. Pointing caregivers in the right direction to get help for themselves can make a big difference in the quality of their lives, just as the work professionals do is intended to improve the quality of life of the people with whom the caregivers’ lives are so closely entwined.

The author was Executive Director of the Brain Injury Association of London and Region from 1994 to 2005. Since then he has been Manager, Community and Professional Services, at Brainworks.
Monthly Support Groups

London/Middlesex
Great Canadian Superstore
2nd Floor Community Room
Oxford Street East and Gammage Street
London, Ontario
Last Thursday of Each Month

**NEW**
Social Group for Age 18-30
Location Varies
www.braininjurylondon.on.ca
or call 519 642-4539 for more info
Last Monday of each month
Beginning November 26, 2007
There will not be a group in December

**NEW**
Paediatric/ Parent/ Sibling
Support Groups
Thames Valley Children’s Centre
779 Baseline Road East, London
Last Wednesday of each month
Beginning January 30, 2008
6:30 – 8:00 p.m.
TO REGISTER PLEASE CONTACT SARA SOMERS
519-685-8500 EXT 53483 BY JANUARY 18, 2007
These are three separate groups offered at the same time.

Elgin County
St Thomas Senior’s Centre
225 Chestnut Street, St. Thomas ON
Third Monday of Each Month

Oxford County
Woodingford Lodge
300 Juliana Drive Woodstock, ON
Last Tuesday of Each Month

Woodstock Public Library
445 Hunter Street, Woodstock, ON
Third Thursday of Each Month

Perth County
Zehrs Markets
2nd Floor Community Room
865 Ontario Street, Stratford, ON
Last Tuesday of Each Month

Huron County
Huron County Health Unit,
77722B London Road, South
(Located behind Huronview)
Clinton, ON
Last Thursday of Each Month

Unless noted otherwise all groups meet from 7-9 p.m.
All locations are wheelchair accessible
Information available at www.braininjurylondon.on.ca

OR
Contact:
Joe Zablocki support@braininjurylondon.on.ca
(519) 642-4539
The Brain Injury Association of London & Region gratefully acknowledges the following people and businesses that have made a donation since the last publication of the Monarch.

It is this type of generosity that enables the association to maintain our commitment to maximizing the quality of life of individuals living with the effects of brain injury.

Special Thanks to the Following:

PricewaterhouseCoopers
London Claims Association
East Park Golf Gardens
Elexco Ltd
Anonymous Donor of $3,000
Upcoming Conferences and Events

February 7, 2008
Brain Injury Association of Sarnia Lambton presents its 4th Annual Conference
Body Mind Spirit
Contact Susan St. Pierre at 519 337-5657

February 16, 2007
Brain Injury Association of London & Region hosts our 8th Annual Dinner & Dance Gala
‘Let’s Get It On. Groovin to Motown’
London Convention Centre
Tickets now available online at www.braininjurylondon.on.ca
Contact 519 642-4539

April 9-12, 2008
The International Brain Injury Association is pleased to announce details for the Seventh World Congress on Brain Injury at Pestana Palace Hotel in Lisbon, Portugal

June 20, 2008
Brain Injury Association of London & Region presents its 11th Annual Conference
Reserve the date & look in the March issue of Monarch for further details

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