



**BRAIN INJURY
ASSOCIATION
OF LONDON
AND REGION**

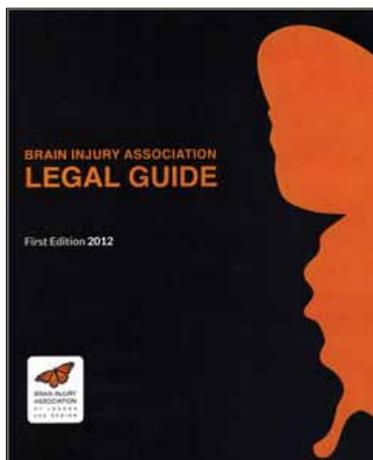
Summer Issue June 2014

THE MONARCH

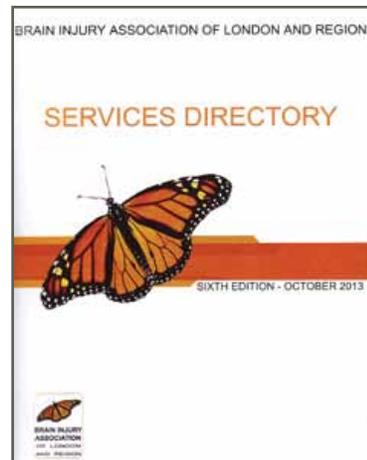
Changing Family Dynamics After ABI



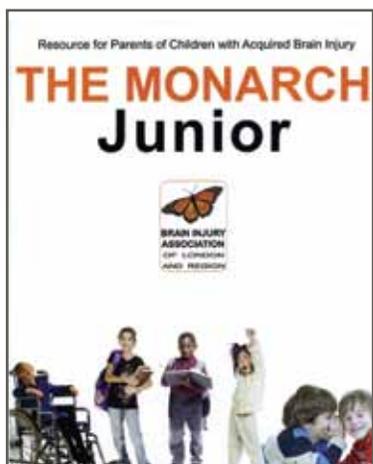
Check Out These Great Resources!



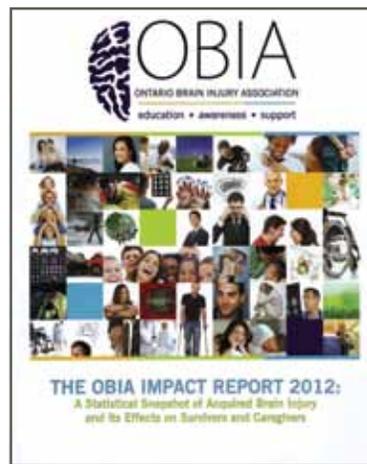
This legal guide is published by BIALR, in collaboration with Harrison Pensa, and is in its first edition. It is designed to provide straightforward accessible explanation of key legal issues and fundamental legal rights of those who have suffered brain injuries and their support teams. Print copies are available from the BIALR office and electronically on the website.



This directory is published by BIA London and Region and is in its 6th edition. It is designed to help individuals suffering from the effects of a brain injury identify and locate the services in London and Region. (Print copies are available from the BIALR office and electronically on the website.)



This resource is published by BIALR and is in its first edition. This compilation of articles is designed as an informational resource for parents of children who are suffering from the effects of an acquired brain injury. Print copies are available from the BIALR office.



The OBIA Impact Report 2012 is published by the Ontario Brain Injury Association (OBIA), with support and funding provided by the Ontario Neurotrauma Foundation. It is designed as an easy to read statistical snapshot of acquired brain injury and its effects on survivors and their caregivers. Electronic copies are available on the OBIA website.

Online Resources:

Brain Injury Association of London and Region - braininjurylondon.on.ca

Ontario Brain Injury Association - obia.ca

Brainline.org, preventing, treating, and living with traumatic brain injury - brainline.org

Brain Injury Association of Queensland - synapse.org.au

National Resource Center for Traumatic Brain Injury (Virginia Commonwealth University) - www.tbinrc.com

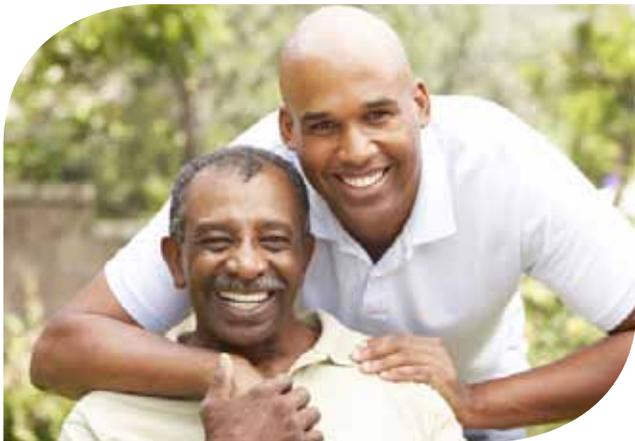
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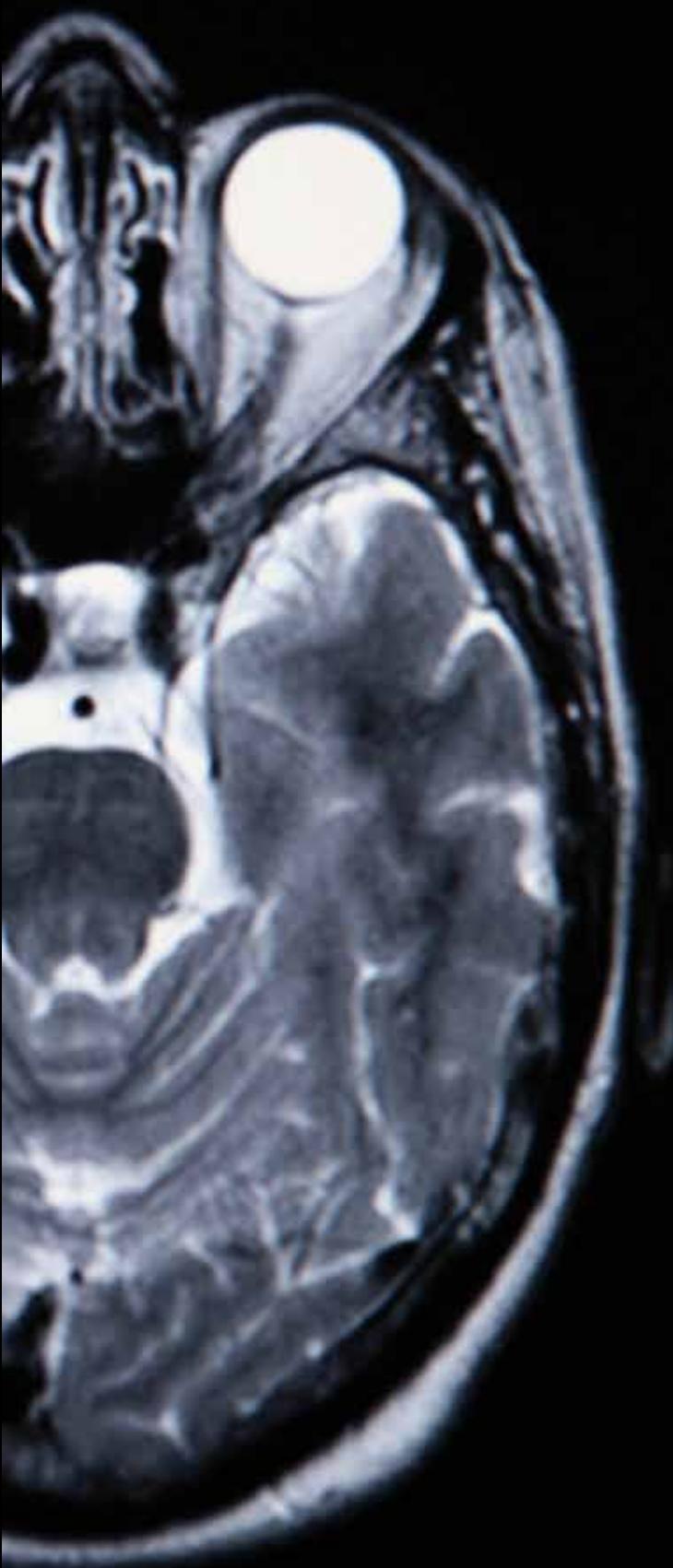


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Letter from The Executive Director

Brain injury happens to the whole family. This issue of the Monarch is dedicated to those dealing with family hurdles of all kinds. At the Brain Injury Association we understand the impact and consequences of a “brain injury” on any individual, family or relationship can have an effect that reaches far beyond the injured survivor. As how a brain injury affects who a person once was; it also affects how a primary caregiver and family once were. Relationships, family roles and responsibilities can experience change. Inside you will find articles written from the various roles that make up a family, as well as therapeutic worksheets that can be used to develop healthy communication.

Kudos to our Fundraising Committee who did a fantastic job planning our 14th Annual Gala. Many of the guests raved that this was the best gala yet! Of course, we could not have made this night happen without our incredible sponsors, donors and guests!

A great big thank you also goes out to our Conference Committee for the organization of our 17th Annual Brain Injury Conference on April 9, 2014. Delegate responses indicated another successful day, with interesting speakers, topics and exhibits.

We are busy gearing up for the Helmets On Kids Kick Off campaign June 19th at the Holy Family Catholic School. We recently trained 12 new helmet fitting volunteers to assist us at various events throughout the summer. We are still seeking donations to cover the cost of the helmets that will be distributed through the Helmets on Kids Campaign. Please consider helping us put helmets on the heads of kids who may not have the financial resources to buy their own. You can donate at www.helmetsonkids.ca or send in a cheque to the Association. All proceeds go directly towards the purchasing of helmets.

We have recently partnered in a joint grant application with the Brain Tumour Foundation of Canada & Dale Brain Injury Services and are eagerly awaiting a response from the Ministry of Training Colleges and Universities. We are planning for a Year of the Brain project that will create a network of neurological health organizations in the London area, develop educational materials and community events.

Practise your swing this summer, and don't forget to register for the 12th Annual London Brain Injury Golf Classic at Greenhills Golf Club on September 18, 2014. Please consider helping H.A.B.I.T. (Helping Acquired Brain Injury Treatment) and our Association raise funds by donating an auction item, become a sponsor, or sponsor a hole.

On May 27, 2014 Mike Hamilton set out from our office on his 3rd Annual Awareness and Fundraising Walk. This year, Mike chose to walk to Port Stanley, ending at Mackie's on the beach. We want to congratulate Mike Hamilton for another successful walk!

The Association receives much assistance from the work of student intern placements, who contribute to the success of our organization. We would like to thank Matt Tymoczko, our most recent Fanshawe Social Service Worker Intern who has been a great help these last few months. Matt has contributed an article in this issue about the importance of a positive mindset.

Donna Thomson

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Highlighting Our..... Volunteers



Doug Bryce

Tell us a little about yourself?

My name is Doug Bryce. I am a lawyer with Siskinds LLP in London. For over 20 years I have represented accident victims in pursuit of fair compensation for their injuries. I am married to Dawn-Marie and we have two wonderful children, Kevin and Rachel.

How long have you been volunteering with the Brain Injury Association?

My volunteer experience with the Brain Injury Association of London and Region began about 10 years ago when I joined its Board of Directors. For the past five years I have been privileged to Chair the Helmets on Kids Campaign.

Why did you choose to volunteer with the BIA?

I first became aware of the Brain Injury Association when some of my seriously brain injured clients sought out its services. Their reports were so positive I wanted to learn more. Once I did so there was no going back.

What makes you come back to BIA year after year?

There are few organizations that make such a positive difference in peoples' day to day lives. Unfortunately, the financial realities of our current medical system means that those suffering the debilitating effects of brain injury often find themselves without adequate resources. The Brain Injury Association helps to fill that gap

Do you have a favourite moment from your time here that you can and would like to share?

While on the Board I had the honour of working with Jamie Fairles. His passion, commitment and dedication to those served by the Association always inspired me. I vividly recall his speeches at conferences and fundraising events and the impact his words had on all in attendance, but in particular on those suffering from brain injury themselves.

What would you say to someone that is considering volunteering with BIA?

If you want to know with certainty that what you are doing with a volunteer organization is making a difference in peoples' lives then the Brain Injury Association of London & Region is for you. You will never regret the experience. I certainly have not.

Just A Note To Say Thank You!



Mike Hamilton

Tell us a little about yourself?

My name is Mike Hamilton I am 54 years old. I was born in White Horse, Yukon Territory. I was adopted at the age of 5 months by George & Margaret Hamilton. My dad was an Anglican Minister. We ended up moving to Pelee Island when I was 7 years old. At the age of 12 I was hit by a car while riding my bike. I received a serious head injury.

How long have you been volunteering with the Brain Injury Association?

I have been volunteering for about 3 years.

Why did you choose to volunteer with the BIA?

I wanted to make more people aware of brain injury and how easy they can be acquired.

What makes you come back to BIA year after year?

I enjoy being part of the organization and doing a yearly walk on May 27th to help raise needed funds.

Do you have a favourite moment from your time here that you can and would like to share?

After doing my first walk 2 years ago to Leamington I was honoured to be asked to do more walks to cover the 5 districts covered by the London office.

What would you say to someone that is considering volunteering with BIA?

We never can have enough help in spreading the need to make more people aware of brain injuries.

Special Congratulations Goes To Mike Hamilton For His 3rd Successful Walk To Raise Money For Brain Injury Awareness. Way To Go Mike!



DUAL MEMBERSHIP PROGRAM

Brain Injury Association of London and Region & The Ontario Brain Injury Association

Invite you to belong to both organizations for one low fee!

Further information and the application form can be found at

www.braininjurylondon.on.ca under "How to help"




Cornerstone Clubhouse



A Dale Brain Injury Services day and evening program for adults living with the effects of an acquired brain injury.

- A place to come and belong
- The opportunity for meaningful work
- The opportunity for meaningful relationships

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Opinions expressed in the articles are those of the authors and do not necessarily reflect the opinion of the Board of Directors.

All articles remain in their submitted un-edited form to preserve the original views and intent of the author.

The publication of an advertisement does not imply support of the advertiser by the Association. If you have any questions, comments, or concerns please contact us at:

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Peer Support Coordinator's Report

This past April OBIA hosted the first PSC (Peer Support Coordinator's meeting of 2014 in Toronto. Of the 12 participating associations; we welcomed 2 new faces to the table. The PSCs from the Brain Injury Associations of Sarnia and Lambton County as well as the BIA of Peterborough Region were introduced and welcomed. We also learned that the Peer Support Program has been granted to be funded for another 3 years from OBIA's LHIN (Local Health Integration Network), which is great news as this is only one of the terrific programs OBIA and some of the community associations offer to those whose lives have been affected by brain injury. The theme of this month's issue is Family Strain & ABI and there is nowhere I can think of as a better place to get advice and support from more than people who have experienced it themselves. Next month on May 7, London will host its ninth mentor training to welcome 5 new mentors and 2 previously trained mentors who wish to have a training refresher because the program keeps on evolving. In fact at the PSC meeting in April we learned that mentors are expected to have a refresher training every 12-16 months to keep up with the changes and procedures. If you're a trained mentor and you think you'd like to attend a training session for a refresher, call the office and let me know. Likewise, call the office if you wish to have a mentor or be a mentor. We typically hold mentor training sessions twice a year: once in the spring and again in the fall.



Jamie Fairles

Peer Support Coordinator
519-642-4539

editorial@braininjurylondon.on.ca

Looking To Get Involved?

We are looking for individuals to become mentors in our Peer Mentor Program. Mentors provide support and share information and resources with partners who are coping with a similar ABI-related situation. We are in particular need of mentors who are family members and caregivers. Visit our website or contact our Peer Support Coordinator for more information.

www.braininjurylondon.on.ca

Brain Injury Support Groups

Please Be Advised:

All support groups will be closed for the summer months, July and August 2014 and will open again in September 2014.

For more information please visit www.braininjurylondon.on.ca or call 519-642-4539

 <p>Huron County Support Group Meets the last Monday of each month At the Huronview Home for the Aged 77722A London Road Clinton, On. N0M 1L0 7:00 - 9:00pm</p>	<p>London Social Leisure Group Meets the first Thursday of each month Cornerstone Clubhouse 781 Richmond Street London, On 6:00 - 8:00pm</p> <div data-bbox="829 617 1053 722" style="border: 1px solid black; padding: 5px; text-align: center;"> Your logo could be here </div>
<div data-bbox="90 953 318 1058" style="border: 1px solid black; padding: 5px; text-align: center;"> Your logo could be here </div> <p>Perth County Support Group Meets the last Tuesday of each month Zehrs Markets 2nd Floor Community Room 865 Ontario Street Stratford, On 7:00 - 9:00pm</p>	 <p>Oxford County Support Group Meets the last Tuesday of each month Dundas United Church 285 Dundas Street Woodstock, On 6:30 - 8:30pm</p>
 <p>Perth County Social Leisure Group Meets every Wednesday of each month Central United Church 194 Avondale Avenue Stratford, On 1:00 - 4:00pm</p>	 <p>Elgin County Support Group Meets the second Wednesday every month At the Real Canadian Superstore 2nd Floor Community Room 1063 Talbot Street St.Thomas, On 6:30 - 8:30pm</p>
 <p>London/Middlesex Support Group Meets the last Thursday of each month First Baptist Church London 568 Richmond Street (parking in rear) London, On 7:00 - 9:00pm</p>	<p>Elgin County Social Leisure Group Cancelled We apologize for any inconvenience</p>

Party Pooper

Submitted By: Stephanie Hutton



The weather has warmed up and the flowers are in full bloom bringing with them family get together, bar-b-ques and party invitations of all sizes. For someone dealing with a brain injury even a small family gathering can quickly become overwhelming and problematic. This doesn't mean you have to lock yourself in a dark room alone missing out on all the fun. Armed with a healthy sense of humour and these five tips you can enjoy the festivities while saving yourself a literal pain in the head!

1. Know the venue

If the event is somewhere you have never been, call ahead or have someone make a visit to the space to give you a lay of the land. No matter if it's a house, park or banquet every place has at least a bathroom where you can take planned breaks from the action. A coatroom or spare bedroom can also be a great spot to take a time out from all of the conversation and hectic activity. Look on the bright side, planned breaks can save you from have to pitch in on helping with dishes!

2. Know your script

"How are you feeling?"

"When are you going to be better?"

The people who care about you are bound to ask about your brain injury journey but if you are uncomfortable talking about it prepare a script to turn the conversation back to them. Something like "Recovering from a brain injury is harder than I ever imagined, so I'm taking it day by day and doing fabulous at that. How is the new house?" Remember people love talking about themselves; any question about their lives will take the focus away from you.

3. Bring a buddy

Ask a partner, sibling, parent or friend who may also be attending the event to be your parachute. Give your buddy a code word or sign ahead of time that will signal to them that you are in need of rescue. Whether it's making a quick excuse to get you out of a conversation or sneaking you out of the party unnoticed your buddy can make a sticky situation better in no time.

4. It's your right to remain silent

No matter how insightful people will never remember what you say, they will only remember how they make you feel. If making conversation is difficult for you, know that it's okay to just nod and smile. They may give smiles away free at McDonalds, but they can be worth a million dollars from someone special. YOU are that someone special.

5. Plan your escape

Even the best laid plan can go off the track so be prepared in case you get anxious to remove yourself from the event at anytime. Don't try to say good-bye or stick it out, you know when you've had enough and no one will notice if you quietly walk away. If your friend drove be sure to hold on to the keys so that you can head straight to the car where they will know to meet you should you disappear. You can always send a polite card, email or text message to the host later in the day thanking them for the invitation, that will leave a much bigger impression than saying good-bye in a frantic state.

6. RELAX!

It's just a party! Whoever invited you to the event loves you and wants you to be a part of the event no matter how long you can stay or how much you can participate in. There will always be another holiday, birthday or gathering that you can attend, so what if you can't do the three legged race this time around. Enjoy what you can and forget about the rest.

RESEARCH QUESTIONNAIRE



OBIA continues to conduct research on ABI in Ontario and in 2012 released **The OBIA Impact Report 2012: A Statistical Snapshot of Acquired Brain Injury and its Effects on Survivors and Caregivers.**

Through your participation in our Research Study, you provide us with the information needed to report on brain injury statistics across the province, allowing us to better inform policy makers, government officials, service providers and the general public.

For information about our Research Study or to request an OBIA Research Questionnaire, please contact: **Katie Muirhead** at 1.800.263.5404 ext. 229 or kmuirhead@obia.on.ca

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Our Toronto office remains available as our central administration and referral office for services across Canada.



Our “Happy” Home:

How we cope with ‘Off’ days to avoid strain in our marriage

Submitted By: Jamie Fairles

Marriage is hard work for anybody let alone 2 brain injury survivors. Throw in a 17 month old daughter and life gets exponentially tougher. Both my wife, Crystal and I have brain injuries which can be both beneficial and detrimental to our marriage. It’s beneficial because we understand each other and we know when one another is having an off day. Which is the term we give to the days when we just don’t feel like ourselves and nothing seems to work in our favour. When either of us are having an off day, we give each other space to figure out a solution to put an end to feeling off. Everybody has days like this, but to a brain injury survivor they are more severe and frequent. One of us could just wake up that way, for no rhyme or reason, or something triggers a bad mood and puts that person into a funk. Whenever either of us has one of these days, the other person tries their best to accommodate by staying clear of any situation that may exacerbate that person’s mood and remain open and honest with each other. We live by the rule never go to bed angry and before

we go to sleep, we talk about our day and express our feelings. This way, nothing is ever kept from the other and we live in a communicative, open environment. Since I only volunteer as London’s Peer Support Coordinator on Mondays and Wednesdays, and Crystal is looking to go back to work as soon as our daughter, Reese is accepted into nursery school We are with each other constantly. It’s hard being constantly around anyone for long periods, but we feel that it is because of how we deal with our respective ‘off’ days and knowing when to leave well enough alone is the key to a successful and happy marriage with minimal strain. In fact, we have been praised by a number of people for how little we argue. Most people without brain injuries could not handle the stress of getting married, buying their first home and having a baby all within 6 months – with minimal strain and are often told that we should be very proud that we have successfully managed to do so!



DOMESTIC VIOLENCE

And Brain Injury

<http://synapse.org.au>

Challenging behaviours after a brain injury can easily lead to domestic violence within a family.

It is possible that people with a brain injury may develop behaviours that lead to domestic violence. Many of us were raised to believe that we should stand by our family members no matter what. This stance is put to the test when threatened or actual violence occurs. Choosing to ignore the behaviour can mean your family member does not get constructive feedback on the negative behaviour, which can lead to a cycle of violence.

One of the most aggravating things that a family can experience is that the person with acquired brain injury can be the picture of politeness when speaking to the rehabilitation nurse or a visitor. Once you see that they can act appropriately, it is more difficult to accept abusive behaviour at home on a regular basis. There are different explanations for this, which may not make challenging behaviour or aggression easier to tolerate, but they do provide a framework for understanding.

Reasons for Violent Behaviour

We all tend to let our hair down with family, as opposed to strangers or acquaintances. Of course, after a brain injury a person's interpretation of letting hair down may be well beyond what most would consider acceptable, particularly if their self-awareness has been affected. They may justify their violence by saying that others provoked them, not realising that the brain injury has increased their sensitivity to stress and decreased their ability to handle it.

The frontal lobe is often damaged in brain injury. This area of the brain is involved in reasoning, problem solving and controlling our more basic instincts such as anger. An individual who has sustained a brain injury has often lost these skills and therefore may have trouble controlling anger and violent outbursts. In many cases brain injured individuals often lose some of their social judgement capabilities and are not effectively able to reason out the appropriateness of either their own behaviour or the behaviour they expect from others.

Overall, a family's patience can be quite worn after months of care of this individual. What makes matters worse is that the brain injured person may have little insight into their impact on the family.

The following are some examples of abuse a family may encounter:

- An adolescent spits in his mother's face when he is not allowed to drive the car
- Grandfather screams constantly at his niece he adored prior to his accident
 - A wife constantly accuses her husband of having an affair
- A husband hits his wife the moment she doesn't agree with him on an issue.

Management Techniques

Do not allow a pattern of family abuse to become established in your home. You will need to make some allowances for changes brought on by a brain injury but continued abuse and violence is not acceptable.

When the person still retains self-awareness, they will need to relearn communications skills, anger management, relaxation techniques to manage their anger and tendency to violence. Your Brain Injury Association should be able to provide or refer you to suitable support in this area.

Unfortunately there will be cases where a lack of self-awareness means that an individual cannot relearn these skills. In these cases, it is necessary to develop a behaviour management program to minimise or prevent violent outbursts.

When your loved one lacks self-awareness, don't continually bring up reminders of the violent behaviour. This will only serve to upset them and will not be conducive to change.

There should be 'family rules' of which the person is aware prior to coming home. If anger or violence could be issues it is much better to discuss and work these out with the person before they return home. Do not take the abuse personally - this will only interfere with your ability to implement effective behaviour management. However it pays to look at what the triggers were in each case and see if these can be minimised.

Treat each occurrence as an isolated incident. A person with a brain injury may not remember their abusive outburst yesterday. Try to find out what the triggers were and minimise these in future where possible.

Keep in contact with your support systems - you need to have people with whom you can discuss problems of family abuse.

Have a family meeting whereby all members are trained to treat family abuse in a consistent manner to keep the person from learning to use family abuse as a method of manipulating the family.

Join a support group in your area so that you can find out how others have handled this problem. Do not allow yourself to live in a reign of terror. If problems persist, you may need to consider professional support with a programme geared at behavioural management. Your local Brain Injury Association should be able to refer you to specialists in this area.



The Last Resort

Finally, a brain injury can never be an excuse for domestic violence. If all fails after professional support, then you may need to begin looking at other options. In some cases the person with a brain injury will continue to regularly assault their partner despite professional support and a behaviour management program. Often the only option left is eventually to leave and take out restraining orders to prevent further violence after leaving.

Your State Brain Injury Association should be able to link you with agencies who can advise you on legalities, emergency accommodation and restraining orders, and also help to provide supports for the individual with the brain injury.



The “Healthy Marriage” Quiz

Couples often report big changes in their marriage after injury. Professionals who work with them often find that people face common challenges in rebuilding their lives and relationships as they try to find a new normal. By understanding common post-injury challenges and learning to use effective coping strategies, you can improve your marriage and build a healthy, satisfying relationship.

To help you understand more about your marriage, read the statements in each section below and circle True or False.

Communication Challenges:

1. My spouse has no idea how I am feeling.
True / False
2. Talking about our problems only makes things worse.
True / False
3. We are always arguing about something.
True / False
4. He/she doesn't hear anything I say.
True / False

Changing Responsibilities:

8. I have to do everything myself.
True / False
9. We don't know who should do what in our house anymore.
True / False
10. My spouse acts more like a child than our children.
True / False
11. I can't trust my spouse to do things right.
True / False

Changing Priorities:

5. We're so busy going to doctor's appointments, who has time to work on a marriage?
True / False
6. We don't have an intimate relationship anymore.
True / False
7. He/she used to care about our family, now I'm not so sure.
True / False

Emotional & Personality Changes:

12. My spouse gets upset at anything I say or do.
True / False
13. I'm married to a stranger.
True / False
14. I'm worried all the time about what he/she will do next?
True / False

Tips To Heal Your Marriage



Read, think about, and try the suggestions below to improve your marriage

Remaining married and happy is a challenge for many couples with or without brain injury. Whatever your situation, you can have a positive and healthy relationship by understanding the challenges in your marriage and making a commitment to treat your partner well. If your problems seem more difficult than you can handle, seek help from a local marriage counselor who knows about brain injury.

Communication:

- Patiently listen to your partner and show a positive attitude. Are there parts of what he/she is saying that you can agree with?
- When your partner makes a statement be cautious about disagreeing. Edit your thoughts to avoid saying only negative things that come to mind.
- Be willing to compromise.

Changing Responsibilities:

- To avoid misunderstandings, have an honest discussion and make a list of who is in charge of what.
- Once the list is agreed upon, expect that your partner will attend to his/her jobs perhaps in a different way or in a different time frame than you would like. Even when you think something could be done differently, avoid being critical.
- Always express real appreciation for the things that your spouse does, even small things. People who feel appreciated are more likely to contribute their time and energy to help each other.

A Change in Priorities:

- Make a commitment to having a good relationship, something you did well when you first met one another. Plan times when you and your partner can enjoy something fun — a movie on television, a board game, a walk — and make this an activity that can't be pushed aside for something else.
- Focus on the positives in your new life. Couples that are happiest make five positive statements about their relationship or their partner for every one negative statement. So, even if you are having a bad day, make sure to point out one or two good things about your spouse or your relationship and say them — out loud.



Emotional & Personality Changes:

- Look for opportunities to laugh with your spouse. Sometimes at first laughter can feel forced. The more you try to have a good time with your partner, the more natural having fun together will feel. Couples who laugh together are lots happier.
- When your spouse does something you don't expect, see if there is a different way to look at it. Rather than feeling embarrassed, hurt, or angry, see if you can find a reason to smile.
- It is o.k. to expect and demand that your partner treats you with respect. Please do not tolerate hurtful behavior, even if it seems to make things easier for a short time. If your spouse says something or does something hurtful, calmly state "I will not allow you to treat me this way" and then leave the situation.
- Remember, brain injury or not, many couples do not agree on everything.



My Child's Brain Injury: Family Matters

Brain Injury Parents: Navigating the School System
brainline.org

A child's brain injury is felt by the whole family. It changes the way a family works and challenges even the strongest relationships. Below are some common problems - and solutions - that some families use to help them feel supported and strong.

Siblings

Brothers and sisters are affected when a sibling has a brain injury. Younger siblings may suddenly be asked to take on more responsibility, including providing care for their injured sibling. As siblings deal with their sense of loss, their emotions may be compounded by feelings of jealousy, anger, and rivalry for your attention.

When so much of your attention is focused on your child with a brain injury, it's understandable that your other children may feel left out or ignored. How children express their feelings varies widely. Some become fearful and overly cautious. Others become angry and rebellious. All of these feelings are normal reactions to the uncertainty and disruption of brain injury and the changes in a family. Depending on their age, children may be more likely to act out their feelings than to talk about them.

Frequently, your child with the brain injury will need more attention and time than your other children - that's just a fact of your family's situation. By checking in with your other children and letting them know you're there will help them feel connected and important.

Suggestions:

- Focus on your children's accomplishments and needs. Ask how they did on a quiz that day, or encourage them to talk about their favourite pastime or friends.
- Arrange individual time for them when you can. Even an ordinary thing like grocery shopping can be fun and give special attention to a child.
- Understand their feelings of frustration or jealousy. Let them know that brain injury affects everyone in the family.
- Help them with their guilt about their feelings. It's normal to feel angry at the sibling with a brain injury or at you, for example.
- Work out ways to spend time together as a whole family.

Spouse

Having a child with a brain injury causes overwhelming stress for parents. Financial difficulties. Changes in roles or jobs. Disrupted family time and social activity. Parents frequently report that having so many responsibilities creates little or no time for each other. All this can lead to a loss of closeness and intimacy. You may feel like your role as husband or wife is on the back burner.

The good news is, statistics show that parents of a child with a brain injury are no more likely than other couples to break up. In fact, many couples use creative ways to manage the stress and find ways to connect.

Suggestions:

- Do things together as a whole family. Find respite care for occasional (or more frequent) dates or nights out.
- Share an interest. Talk about something besides caregiving and stress. For example, plan a garden or follow a sport or television show.
- Arrange time to listen and talk after the kids are in bed.
- When possible, work together on caregiving tasks.
- Seek social support together, such as going to a club or support group.
- Remember that time together is precious for all parents, and even a little alone time, like going for a walk in the neighbourhood is important and meaningful to your relationship.

Extended family

Many people turn to their siblings, parents, and other extended family members for support and caring when times are difficult. However, many parents report that all types of social support gradually slip away as the effects of their child's brain injury continue through the months and years. It can be particularly difficult if you feel unsupported by or disconnected from your extended family members.

This lack of support has many causes. Family members may be far away, have hectic schedules, or have difficulty understanding the effects of the brain injury and how your life has changed. You may find yourself frustrated by the need to justify your stress and explain the impact of the brain injury over and over again. You may find it hard to ask for help. When family members say, "I'm just so busy" or "I have problems too," it can be very difficult to ask them for support.

It is often the case that family members simply don't know how they can support you in ways that are manageable for them, or that don't intrude on you. How many times do people say to themselves, "I would have called but I didn't want to bother them" or "I'm not sure what they need?" Understanding their lives and asking for specific help can keep you connected to a broad base of family support.

Suggestions:

- Family members who are far away can help you with emotional support through emails or phone calls. You can tell them how much you value being able to talk about what's happening, or get a bit of relief by listening to what's happening with them.
- Capitalize on individual talents. For example, if your mother is great at networking and getting information, put her to work. For example, have her investigate community sports opportunities for kids with disabilities.
- Ask for specific help. If it would make a huge difference to you to have dinner cooked for you once a week, ask someone to make an extra casserole for you.
- See if family members would be willing to help with the other kids (e.g., helping with homework, or taking them out when you can't).
- Encourage family members to participate in school activities or even IEP meetings if that would help them better understand the effects of the brain injury.
- Admit when you're feeling low or stressed. Your family may not realize how much the situation is affecting you.



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Family Change Questionnaire

Excerpt from www.braniline.org

Nancy Hsu, Jeffrey Kreutzer, and Jennifer Menzel, The National Resource Center for Traumatic Brain Injury, Virginia Commonwealth Model Systems of Care

Recognizing how your life and the lives of other family members have been changed by injury is an important first step in recovering emotionally. We have developed the Family Change Questionnaire (FCQ), a tool to help people recognize and think about the changes. The FCQ has 17 questions relating to topics such as feelings at the time of injury, fears about long-term injury effects, and the emotional reactions of other family members. The FCQ also asks people to think about changes in their responsibilities, roles, transportation needs, finances, and plans for the future.

In our experience, the FCQ has been a useful tool, helping people understand how the lives of more than one family member has been affected. Discussing your answers to the questions will help improve understanding and communication. Regular family discussions about feelings and ideas can undoubtedly strengthen the family support system and help people successfully overcome challenges on the road to recovery.

1. How did you feel when you first learned that your injured family member was injured?
2. How did you feel when you realized that your injured family member was going to live?
3. How did you feel when you began to recognize that the brain injury might have long-term effects?
4. How have other family members reacted to your injured family member's injury?
5. Have you made yourself available to provide more emotional support to your injured family member and other family members? If yes, how so?
6. Before the brain injury, what were the most important plans you had for your future and your family's future?
7. How has the brain injury affected your plans for the future?
8. What responsibilities do you now have to care for your injured family member?
9. In what ways do you help your injured family member get back and forth to appointments?
10. Do you attend therapy and doctors' visits with your injured family member? Please explain.
11. Do you help your injured family member with filling out insurance, registration, medical, and disability forms? Please explain.
12. Do you help your injured family member get authorizations for medical and rehabilitative care? Please explain.
13. Have you taken over responsibilities from your injured family member or uninjured family members?
If yes, what new responsibilities do you have related to caring for the house, maintaining the car(s), working, paying bills, and caring for children?
14. Have you changed your work responsibilities or hours since the injury, so that you could help your injured family member or the family? Please explain.
15. How has your family's income been affected by the injury?
16. What new expenses are you facing because of the injury?
17. How have your sports, social, and recreational activities changed because of the injury?

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Ask A Lawyer

What does it mean to have capacity to instruct counsel?



Brent T. Hodge
Legate And Associates

Capacity to instruct counsel is a legal determination. When a client has a brain injury or other disability that affects his or her ability to make decisions, the impairment may be minor or it may amount to legal incapacity. The determination of capacity may be made by a lawyer or the client may be referred to the Capacity and Consent Board for a formal hearing.

There is a presumption that an adult client has capacity to make decisions about his or her legal affairs and to give instructions to counsel. When a client's capacity is called into question, a lawyer's first obligation is to provide accommodation. The idea behind accommodation is that a person who is unable to perform a function due to a disability may be able to perform the function adequately if they are provided with the proper assistance (e.g. frequent repetition or extra time).

If capacity is still a concern despite accommodation, the client must be assessed to determine if he or she has capacity to instruct counsel. The determination of capacity involves two elements:

- 1. Does the individual understand the information that is relevant to making a decision?**
- 2. Does the individual appreciate the reasonably foreseeable consequences of a decision or lack of a decision?**

Both elements must be satisfied for a finding of capacity.

The determination of capacity becomes more challenging when a client's competence gradually declines or the client loses the ability to make decisions in some situations but not others. In addition, a client's capacity may be episodic. As a result, lawyers must continually assess a client's capacity to provide instructions.

If a client lacks capacity to instruct counsel, a lawyer must refuse to act until other arrangements have been put in place, such as the appointment of a litigation guardian with authority to make decisions in the client's interests.

While capacity is often a sensitive subject, it is important that lawyers and clients have open and honest discussion about this issue. The rules regarding capacity are in place for the protection of the client, and it is the lawyer's role to enforce these rules while also respecting the autonomy and dignity of the client.

Please e-mail any questions, comments, or suggestions for future articles to the writer, Brent T. Hodge, at b.hodge@legate.ca.

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Intern Insight

Submitted By: Matt Tymoczko
Fanshawe Social Services Fast Track Program

My experience during my internship at the Brain Injury Association of London and Region has been an eye opener. I have met some incredible individuals that inspired me further for my thirst for knowledge within the Brain Injury community. Going into my internship I wanted to be able to contribute by providing support, education, advocacy, and public awareness so that I could be a useful addition to the association. With this in mind, I have been given the opportunity to apply my perspective in various scenarios and in doing so would like to introduce the 'hurdle strategy', which has a focus on a strength based approach and is something I have learned during my time in the social services' field.

The Power Of Authentic Happiness



Focusing on our strengths and applying a positive mindset to our daily lives is something that we can all do as individuals. In this, I want you to think of something positive you are already good at and then a barrier or obstacle you had to overcome to become good at it. For example, as a student I can be overwhelmed with the numerous assignments, presentations, and exams that have to be completed throughout the school year. This can trigger anxiety, self doubt, and overall negative thinking. However, if I apply this idea of coming up with something that I am already good at, such as reflecting on all the successful assignments, presentations and exams I have already completed, then I can realize that I am capable of overcoming the barriers of anxiety, and negative self-doubt to once again successfully complete my school work. The key to this idea is to combine this thought process with listing or identifying how exactly you overcame this barrier. So in my example as a student, staying on task and completing rough drafts or practicing presentations beforehand, can be used as a list of how to overcome my barriers. What we can get from this approach is

that as individuals, uncovering and realizing our personal strengths is an important and essential aspect in our daily lives so that we can reach our full potential and utilize our strengths to overcome any barrier within our lives. In combination, when we are faced with a 'down and out' moment it is vital for us to reignite positive thinking in the necessary steps we each require, and know that we can do it and that we all really are capable of so much. If you are interested in expanding on this idea further try taking a character strengths survey via the authentic happiness website at:

<https://www.authentic happiness.sas.upenn.edu/>

This survey will allow you to answer some key questions and will then identify your top character strengths based on the answers you provide. Along with the character strengths survey, there is an abundance of information regarding positive thinking through questionnaires, books and various articles made accessible in the authentic happiness website.

The Not-So-Secret Confessions Of The Caregiver

A Blog By Abby Maslin About Loving And Learning After TBI
www.brainline.org



One thing I readily accept after more than five years as a part-time caregiver for my father and 15 months as a full-time caregiver for my husband is that, try as we might, none of us are mind readers. This is especially true after a brain injury.

In an instant, the one person who used to know me better than I knew myself — my husband, TC — lost his ability to anticipate my needs and feelings. Tasked with getting himself healthy again, he no longer possessed the mental or physical energy to understand me in the way he used to. Losing this connection with the person I trusted most has been one of the most painful, isolating experiences of my life. As a caregiver, I know I'm not alone. Although many of us rarely get a moment to ourselves, we often feel as though we're living a life sentence of solitary confinement. We wish people could see beyond the brave exterior. We wish we could better articulate our own needs. We wish everyone in our support system were capable of understanding the tough choices we've been forced to make. But at the end of day, we're simply too tired to explain ourselves.

If I could hand a brochure to the people in my life explaining what it's like to care for someone with TBI, it would probably read something like this:

1. I didn't sign up for this gig.

Now, don't get me wrong. That doesn't mean I'm not willing to do the hard work. It doesn't mean I won't stick around or refuse to enjoy the happy moments ahead. It simply means I don't have to love every moment of this experience. I'm entitled, now and then, to feel scared out of my mind or overwhelmingly sorry for myself. I promise that in time I'll rise above these feelings, but please forgive me. I'm a caregiver, but I'm also human.

2. Brain injury is contagious.

It should be clearly stated that my brain also stopped working the day my husband's was attacked with a baseball bat. Shock and stress do crazy things to one's brain, including obliterating one's memory. I may make plans and forget them or promise to do something and then fail to do it. It's not that I'm irresponsible or that I don't care. I'm just juggling a plate of such epic proportions that it's a wonder I remember to get dressed in the morning. So, if you notice my acting flaky, it's probably a sign I could use some extra help.

3. I don't always know how to ask for help.

One of the problems in learning how to live day-by-day or even hour-by-hour is that you can't always anticipate your own needs ahead of time. In the weeks after TC's injury, I was overwhelmed with offers of support. Unfortunately, I didn't know what I needed until five minutes before I needed it. I felt guilty calling people last minute, so I often just took care of things myself. For me, the most valuable offers of help have been the ones that free up time, my most valuable resource. I call these "no strings attached" offers. They don't require me to do extra coordinating or to go out of my way or even to send a thank you note. These offers are wonderfully selfless, which, in themselves, are a gift to the guilt-ridden caregiver.

4. Taking care of myself is a group effort.

I don't know how many times I've been reminded over the past year to take care of myself. It's excellent advice, really, but it took a good long time for me to give myself permission to do so. Ironically, when I did start returning to exercise, getting more sleep, and sneaking in a few minutes of relaxation here and there, it didn't go over so well with a few of the folks who had been pushing this advice. For me, taking care of myself means giving myself permission not to return people's phone calls or e-mails right away. It means learning to say "no" to some invitations and giving myself quiet space away from the world. To truly support a caregiver in his or her self-care, it's critical to ease up on your expectations of this person. Doing so will lift the caregiver's load enormously.

5. I'm not perfect and I sure wish there was a manual for this.

There are a few small things I wish I'd done differently over the past year, but for the most part, I'm proud of all I've been able to hold together. Beyond helping TC in his recovery, my biggest goal has been to stay present as a mom. Every one of the million decisions I've made over the past year may not have been the right ones, but when I witness how well-adjusted and happy our son, Jack, continues to be, I can sleep easier at night. If there was a manual for how to handle TBI, my copy clearly got lost in the mail. All a caregiver can do is to try his or her best and ease up on the self-judgment.

6. Brain injury doesn't go away.

Trust me, I get it. Some people may be tired of hearing about our brain injury woes. Believe me when I say I wish those days were behind us. But even with a remarkable recovery like TC's, there are lingering health concerns, psychological issues, and fears. Our life will never go back to the way it was, and neither will we. Over time friends and family will have to adjust to a new way of interacting with us. We hope you'll like us for the new people we are, but we understand if you miss the old us. We miss us, too.

It's easy for caregivers to bottle up their frustrations. With such a demanding role to fill, we are apt to put our own needs last. And as much as we sometimes wish others could read our minds or occasionally walk in our shoes and feel these demands themselves, our only real option is to stay honest with the people in our lives.



7. Making lemonade from lemons is an art form.

Over the course of the past year I've fielded a few off-hand comments about our lives being "ruined." I have to admit that word "ruined" stings a bit. Our lives are different now, but I refuse to accept the idea that brain injury is a life ruiner. If anything, brain injury has provided us with the challenge of living better than we were before. Living better is a goal TC and I practice daily and it requires some serious mental stretching.

We may not be able to put this attitude into action 24 hours a day, but it's certainly what we're working toward.



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Strategies To Achieve Healthy, Balanced Daily Living

Submitted By: Lisa Hutchinson



Finding balance with our daily activities can be challenging! This can be more difficult following an acquired brain injury, when other factors such as changes in physical, emotional and cognitive functioning can occur. In looking at a healthy lifestyle, there are many aspects that need to be considered, including nutrition, sleep, exercise, social outlets, and emotional well-being. Considering all of these factors can be overwhelming, to say the least.

Here are some simple tips you can try that may help.

1. Establish daily routines. Routines can help us get out of our box and give us a sense of being productive. Try setting a time to wake up in the morning and to map out activities for the day. If your day lacks structure, you can achieve this by adding in activities to create it such as getting your mail, going out for a coffee, or walking the dog. Identifying what activities you want to plan, and how often in a week, may be a good start to establishing a daily routine.
2. Prioritise, plan and pace out your activities. Set up a time each day to check in with yourself. This can be over coffee with your planner, phone, or whatever tool works for you. Prioritise what activities you need and want to complete and plan out the activity by breaking it down into steps. Establish realistic goals based on how you are feeling and your abilities. Balance activity with rest.
3. Conserve energy and simplify. Ensure that you have enough energy to complete desired activities. Taking breaks and using correct body mechanics can help. Simplify tasks when possible. For example, if choosing clothing in the morning is difficult, lay out what to wear the night before. Delegate when you can. The importance of proper nutrition, exercise and sleep can't be stressed enough! Planning out meals in advance, making a shopping list and using visual cues and alarms if you have trouble remembering to eat can help. Establishing a regular sleep pattern and fitting in exercise into your day is essential!

It is important to remember to be kind to yourself, and not to expect perfection. We are all human, and we all have days that may not go as planned. Be sure to celebrate your achievements. By implementing some of the strategies above, you will be much closer to achieving your desired goal of maintaining a more healthy and balanced lifestyle.

Lisa Hutchinson is an occupational therapist who has practised in the area of brain injury rehabilitation for over 15 years. She is employed at DMARehability.

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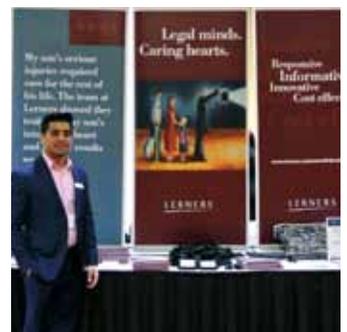
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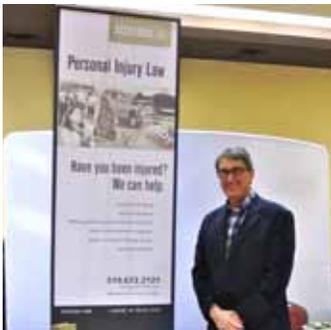
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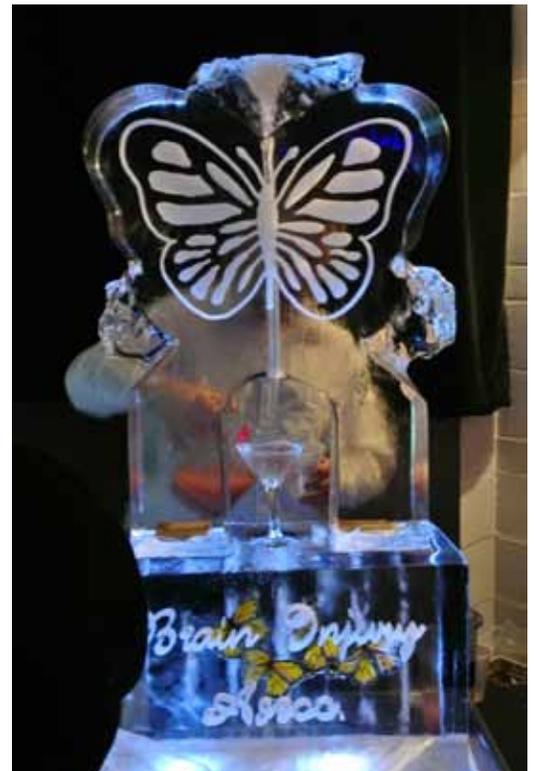
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