Caregiving:
Support, Hope
and Resiliency
Meet Adam. This type A personality gets up before dawn every morning to run and competes in marathons and road races at every opportunity. Whether running outdoors or running to a courtroom, Adam is in a constant competition. A runner’s focus and a well-defined plan ensure that even the smallest aspects of a complex personal injury case are done exactly right.

Before he joined Oatley Vigmond, Adam practiced with a prominent Toronto litigation firm, defending physicians in malpractice claims. With this valuable experience and insight into the way Canadian doctors are defended, Adam now uses that understanding on behalf of clients injured at the hands of the health care profession.

Successfully settling a case and seeing the smiles on his clients’ faces while he helps them to move on with their lives is gratifying for Adam. To him, it’s the same feeling as crossing the finish line in a race, knowing he has given it his all.

To learn more about Adam visit www.oatleyvigmond.com/adam
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Caregivers are a cornerstone to the recovery and support of people living with brain injury and we acknowledge the tremendous amount of time and dedication needed to be a caregiver.

RUTH’S DESK

A Time of Reflection

During this holiday season, we can take the opportunity to reflect on the past year. For some, the reflections will be of gains that have been made; for some it may be losses and for many it may be a combination of both.

When I think of those who have sustained brain injuries and their families, the first thing that comes to mind is the remarkable resiliency of both the survivors of brain injury and their loved ones. With brain injury, lives are literally changed in an instant leaving no time to prepare for the many challenges that lie ahead. Family roles are often disrupted, leaving both survivors of brain injury and their loved ones struggling to find a new way of being.

It is not easy, it is not simple, and struggles occur on a daily basis, yet remarkably many people are able to find their way, carve out a new path—a different path, but one that can still have meaning. What we do know is that when community supports are available and utilized, both the person who has sustained the brain injury and their families are better positioned for a positive outcome.

This is where the Ontario Brain Injury Association and our 21 affiliated community associations across the province make a huge difference. With associations from Ottawa to Windsor, North Bay to Sault Ste. Marie, Thunder Bay and everywhere in between, people are finding community—a place of hope and solace.

This season always provides OBIA the opportunity to reflect on the supports and services that we provide. Some of you may be very familiar with what we offer; for others this is an opportunity to learn more about what we do.

I want to highlight some of our services. Our helpline (1-800-263-5404) has been operating since the day OBIA opened its doors and we have had close to 100,000 calls. What we have noted in recent years is that now approximately 50 percent of our calls are concussion-related. In response to this and through the generous grant by the Ontario Trillium Foundation we now provide an Online Concussion Support Group, which is facilitated by a social worker. In just a little more than a year, 240 people have attended our groups.

Caregivers are a cornerstone to the
recovery and support of people living with brain injury and we acknowledge the tremendous amount of time and dedication needed to be a caregiver. Therefore, we have just created a special program to support caregivers called Support, Hope & Resiliency.

Peer support has been demonstrated to provide a unique opportunity for survivors of brain injury and their caregivers to render and receive encouragement from one another. Our Provincial Peer Support Program has been running for longer than 10 years.

Education is so important for those who work with people in the community, families and loved ones. With our Certificate Brock University Training Programs and our Brain Basics, both in class and online, we have had more than 14,000 attend our training.

Brain Injury Speaks is a new initiative by which we are building a stakeholder engagement network. The network collects the brain injury communities’ responses to important provincial issues and presents them as one voice to government planners and decision-makers.

We are also thrilled to announce that a foundation that has funded our North Eastern Advocacy Program has made an additional investment to fund this program in Sault Ste. Marie.

When I reflect on the work of OBIA and the countless number of people that we speak with and meet, it is indeed a privilege to be able to provide hope and support to both survivors of brain injury and their families.

For more information on all of our services, please check out our website at www.obia.ca.

On behalf of the board of directors and staff of OBIA we wish you all the best during this holiday season and a happy and healthy New Year.
Caregiver Education Workshops

Support, Hope & Resiliency: An Education and Training Program for Caregivers of Acquired Brain Injury Survivors

WHAT
A free interactive half-day workshop for unpaid caregivers of ABI survivors designed to increase their ability to meet the varied needs of their loved ones and reduce caregiver strain.

WHERE
To be implemented at various locations throughout the province of Ontario and organized in collaboration with Brain Injury Associations and other ABI service providers.

WHEN
Workshop sessions begin April 30, 2019 and extend through to Spring of 2020

CONTACT
Nancy LaJoie, Caregiver Education Specialist, OBIA
Email: nlajoie@obia.on.ca  Ph: 1-855-642-8877 ext. 248

The Caregiver Workshops are completely FREE but require registration online.
Register at: www.obia.ca/caregiver-education-program/

Funding provided by: Ontario
A husband describes the “stepping up” of the children following his wife’s brain injury. The mother of an adult son talks about her yearly “essential” trip as a way of recharging and a caregiver offers to have coffee with a fellow caregiver who has no one to talk to that “get’s it”, following her husband’s traumatic brain injury.

These are just three of the more than 200 informal family caregivers who have attended a session of “Support, Hope & Resiliency: An Education and Training Program for Caregivers of ABI Survivors”. This free three-hour Caregiver Education Workshop is currently being delivered by the Ontario Brain Injury Association (OBIA) and hosted by our affiliate Brain Injury Associations, local service providers and the provincial ABI System Navigators. Funding for these workshops comes from a two-year grant provided by the Ministry of Health and our goal is to facilitate this workshop at 42 different locations. Additionally, Gluckstein Lawyers has provided exclusive sponsorship for the facilitation of five pediatric sessions for parents of children who have sustained an acquired brain injury.

**Year One of Support, Hope & Resiliency**

**What do family caregivers want and need?**

To be sure that we would not be offering something already available to ABI caregivers, we completed a province-wide environmental scan in Fall 2018. Specifically, we wanted to know about the free supports local brain injury service providers were offering only for ABI caregivers. What we discovered was that there were three locations that planned social group activities for caregivers and eight locations providing training and education sessions specific to caregivers of brain injury survivors. When considering this was a province-wide review, we can draw the conclusion that supports for ABI caregivers are scarce. Not only did this environmental scan highlight the lack of supports but also identified the lack of consistency across the province. From this environmental scan, we knew that our Caregiver Education Workshop would be unique and we wanted to plan a workshop that would assist caregivers in meeting the complex needs of their loved one. To design such a workshop, we needed to hear directly from ABI caregivers.

In order to gather information from caregivers across Ontario, we met with individuals and small groups of caregivers. In addition, the Caregiver Educational Program Needs Questionnaire was developed and completed by 364 caregivers. This questionnaire identified the top priority of most caregivers is to understand the effect of brain injury on their loved one’s cognition, behaviour and emotions. Caregivers also wanted strategies and skills to assist with these changes, as well as, ways to manage their own emotional well-being. Following the review and analysis of our caregiver consultations, an advisory group of caregivers was created to assist in the co-creation of the caregiver workshop. In addition, Caron Gan of Holland Bloorview Kids Rehabilitation Centre and Wendy Spenst of the The Ottawa Hospital agreed to provide their professional expertise and guidance.

**Designing the Workshop**

Knowing that all brain injuries are unique and all caregiving situations are unique, it was important to design a workshop that would be applicable to all caregivers who attend. In
order to do this, we needed to provide caregivers with information about brain injury and offer opportunities for caregivers to apply the information to their unique experiences.

Through monthly collaboration with our advisory group and professional contacts, the following workshop outline was developed:

- Part A: Understanding and Managing Change in My Loved One
- Part B: Understanding and Managing Change in Relationships and Family
- Part C: Understanding and Managing Change in Myself after Brain Injury
- Part D: Resources & Advocacy
- Part E: Support, Hope & Resiliency

To assist in providing information that caregivers could access following attendance at a Support, Hope & Resiliency Workshop, a Participant Handbook was developed. This handbook includes Fact Sheets about the Physical, Cognitive and Emotional/Behavioural Changes following Brain Injury, Caregiver Tip Sheets and Caregiver Tools.

In May/June 2019 we facilitated our completed workshop at two pilot locations, Peterborough and North Bay, and gathered feedback from the 35 participating caregivers. At both pilot workshops, we observed the automatic connection between caregivers and the desire to share their personal experiences with someone else who totally understands. Using the feedback provided, our Advisory Group guided us in revisions to the workshop which included increased opportunities for caregivers to interact and share with each other.

Year Two of Support, Hope & Resiliency

Meeting and Supporting ABI Caregivers

At the time of this article, the Support, Hope & Resiliency Caregiver Education Workshop has been facilitated at 22 different locations across the province. Attending caregivers are introduced to local service providers and provided with phone numbers and contact information of their ABI Systems Navigator.

Feedback provided by caregivers informally and formally have identified common experiences and benefits of workshop attendance. Many caregivers have shared that there is comfort in knowing that they are not alone and that other caregivers have similar feelings and experiences. Caregivers also agreed that they have benefitted from attendance at the workshop and have improved their ability to manage the daily challenges of being a caregiver.

The following are direct quotes from attending caregivers who describe why they would recommend this workshop to another caregiver:

“Lots of great info also a whole workbook to take home.”

“I learned of all the available resources and have met so many in similar situations.”

“Helpful and good to hear others share and not feel alone.”

“Felt good to be around others with similar situations.”

“Informative and created a safe space to connect with people”.

The following are direct quotes when caregivers were asked to identify their biggest take away(s) from the workshop:

“My feelings are valid and there are tools to help me understand brain injury and how to cope.”

“Positivity, remember “Think Brain First” and use resources.”

“Take better care of myself.”

“The biggest take away is that I learned how normal/common my husband’s symptoms are. I want to educate my family, friends and colleagues. I am going to have a family meeting.”

A consistent recommendation of caregivers has been to increase the amount of time for the workshop to a full day or provide additional/follow-up sessions. Although this two-year grant limits us from providing additional sessions beyond March 2020 at this time, it is our hope that ABI caregivers have been launched into a new world of support, allowing them to travel on their caregiver road with hope and to further strengthen their personal resilience.

If you are interested in registering for an upcoming session of “Support, Hope & Resiliency: An Education and Training Program for Caregivers of ABI Survivors”, please visit http://obia.ca/caregiver-education-program/. For more information please contact Nancy LaJoie at nlajoie@obia.on.ca.

Call our toll free number: 1-800-263-5404

Visit us online at www.obia.ca

“Care for self, reach out for support, use tool kit to manage emotional outbursts.”
I was scrolling through Facebook one day and came across a saying: “One day you will tell your story of how you’ve overcome what you’re going through now, and it will become part of someone else’s survival guide.” I am not sure who wrote it but when I read the words, I was overcome by what it actually meant. I, together with seven other moms who, in another world may have never crossed paths, have been connected by what our incredible children have survived. We were brought together with Caron Gan from Holland Bloorview Kids Rehabilitation Hospital and Nancy LaJoie from the Ontario Brain Injury Association to join forces and use our lived experiences in the hopes of being a tool box for caregivers of children and youth living with Acquired Brain Injury (ABI). We all have different family journeys, ups and downs, but what connects us is that we have been there. We have all walked through the hospital emergency waiting room praying that our child was going to fight for their lives. We have all sat by their bedside in critical care bargaining with all we have to just let them pull through, to bring them back to us. Watched, white knuckled, holding back tears as they start different therapies to help regain some of what they lost, holding onto the hope that they will achieve each milestone ahead of them, celebrating when they reach one and mourning for the ones they don’t. Feeling unimaginable sadness and guilt that we can’t switch places with them and allow them to be the carefree kids we dreamed they would be the minute they were born. Regardless of the stage of recovery our child is at, 12 years post ABI or one year post ABI, we all know, we all remember each and every moment as if it were yesterday.

We have all felt the weight of having to be strong for the sake of our kids and our families, and what is even more draining is feeling like we are carrying this burden alone. Making connections with others who have had similar family trauma helps lift some of the load. Whether it’s a phone conversation, social media connection or support group, these connections bring a sense of comfort knowing that we are not the only one facing these unexpected challenges and changes.

Being a part of a dedicated group of moms, working together to co-create a workshop for caregivers of children and youth living with an ABI, has been a rewarding and cathartic experience. Not only did all our lives change in a moment, but our coping systems and inner strengths were tested as well. Being able to use these changes and tests from our own lives to help other families struggling with the new path they are on has been the driving force for us to ensure that these caregivers feel validated and that they have renewed sense of hope for the future.

Being able to bring our hopes to life for what these workshops will provide to other caregivers who need to know that they are not alone navigating the new unexpected path their families, themselves and the world around them has taken has become our collective passion. We have come together and used our families’ journeys to start conversations, to allow other caregivers to talk about their role and what that actually means to them to wear that hat. These workshops allow each caregiver to have a voice to express what their trials and successes are
and we, as a community who understands the emotional stress, are there to listen and help one another through their journey.

Our goal is to provide a safe space where no one feels alone; where everyone’s fears and concerns are real and validated. We all have thoughts and feelings and each one is normal and OK. Learning to balance the negative with the positive is a process, and being in a room filled with a group of caregivers who share similar experiences, we hope, makes every caregiver feel like they have become part of a community that they feel truly understands and does not judge.

These workshops are designed to start conversations and make connections...what can we as a community do to help one another through this journey? Each of us has our own story which, in one sense, is so different but, in another, so similar and relatable to everyone in the room. Having the comfort knowing that there is a room full of people who have lived through and will continue to live through some of the same challenges and changes can help to empower each and every one of us to pick up the pieces and move forward for the good of our families and ourselves.

We all have our reasons, whether it’s therapeutic, giving us a release of what we internalize daily or simply choose to deal with another day, or “paying it forward” to other parents by sharing experiences, discovering new strategies and letting them know that they aren’t alone in their journey. Whatever our reasons, it has brought us together to create a powerful tool for other caregivers to reference whenever they need.

Our children’s acquired brain injuries do not in any way define who they are and definitely do not put any restrictions on what they are capable of achieving in their lives. Each of them is a strong survivor and has become an inspiration for each of us, as caregivers, to share our family stories to empower others to move forward with a revived sense of strength knowing that they never again have to feel like they are alone.
Everything in life can change in a single moment or in the blink of an eye. It was a Friday night when the police knocked on our front door. The officer told us we should get to the hospital right away. We had no idea what had happened but we would soon find out. Filled with fear, we headed for the hospital. Our 26-year-old son Cory had been in a bad car accident and had been taken to the hospital by air ambulance. By the time we arrived, Cory had already been admitted into the Intensive Care Unit at the Hamilton General Hospital. That is where we first saw Cory, not a mark on his face or body, but he was connected to a breathing machine, a feeding tube and a lot of wired sensors. Cory was sedated and motionless. We were left wondering, would he survive the night?

Okay now what are his injuries? The doctor explained that he has broken ribs, a damaged lung, neck injuries from the whiplash, bumps, bruises and a brain injury. I could understand the physical injuries, but asked further questions about the brain injury. Is the damage repairable? How long will his recovery be? Will he walk, talk and what will the long-term effects be? That is when we entered the uncertainty of the brain injury world. I just wanted all of this fixed but I felt helpless—a horrible feeling.

Cory underwent several CT scans and MRIs in the first couple of days. The good news was that the bleeding in his brain had stopped; however, at the time of injury there had been several areas of bleeding in his brain and some of the damage was near the brain stem. This type of injury is very bad. The doctors said there was nothing to do but wait and see. They could not be sure what effects the brain bleeds would have and it was too risky to do anything around the brain stem. I tried to get a time estimate for recovery but nobody could provide that information. The doctors and nurses said that Cory was young and physically fit, which would help in his recovery. I found it very frustrating not to be able to get answers regarding the brain injury.

Hours turned into days and days turned into weeks as our family surrounded Cory in the intensive care unit. I am not really a people person, but I have to say that I met some outstanding doctors, nurses and therapists in this journey. The doctors and nurses would take the time to explain everything. I appreciated everything the medical team did for us but I still felt so helpless as there was nothing I could do to make this all better. It also became obvious that a brain injury affects each individual differently and the doctors really did not know what the outcome would be.

Dr. Shanahan pulled us aside and talked to us about taking care of ourselves, so that we could help Cory when the opportunity presented itself. The doctor was so right. The mental and physical fatigue from worrying and constantly standing by was already taking a toll. We had to make sure we were eating, sleeping and other things to maintain our mental and physical health.

After a couple of days, Cory finally opened his eyes. He looked scared. It was not long before his eyes closed again. One of the nurses had already suggested talking to Cory because he may be able to hear us and our voices may be comforting to him. We would talk to him regularly about the weather, pets, sports and whatever else came to mind. After a while Cory would keep his eyes open longer and we eventually got him
There is hope for a better tomorrow.

Thomson Rogers is dedicated to getting accident victims the compensation and support they deserve.
to blink his eyes for “yes” or “no” questions. Finally, we were able to make simple communication. Something this simple was such a huge thing for us—he recognized us and seemed to understand. I felt there was hope but recognized how much time and work was ahead. I was starting to realize that not much else really mattered to me except the recovery of my son. I would be there as long as I could help him.

Over the next couple of weeks, Cory started moving his right side. Mostly his right leg, but he was also able to do thumbs up and a slight wave. It wasn’t long before he was able to flip the bird to his sister. I would massage Cory and exercise all of his joints to stop muscle atrophy and stimulate sensations. It made me feel as though I was doing something useful and hopefully it would help him.

Cory was recovering from his physical injuries, but being immobile in a bed had its side effects. Cory had lung infections and reactions to the different medications. The breathing tube was removed but the left lung would plug and the breathing tube had to be re-inserted. Cory wound up having a tracheotomy and a feeding tube put directly into his stomach. There were definitely setbacks along the way but we tried to keep things positive and recognize the achievements. This process was very hard to deal with but I had to be there for Cory.

A month or so in intensive care got Cory healthy enough to move to a step-down unit in the neuroscience ward (7 West). Cory was starting to be able to talk in syllables. It was minimal, but at least he was talking. He was healthy enough to be spending more time in a wheelchair and start more physio-type activity. Cory continued to work hard toward his recovery. This whole experience was new to us and we did not know what was next. The 7 West group worked with Cory for several weeks to get him strong enough and healthy enough to qualify for a rehabilitation unit. I am thankful for their effort and commitment.

On May 22, Cory moved into the Regional Rehabilitation Centre attached to the Hamilton General Hospital. I lived in Hamilton all my life but had no idea that this facility existed. Cory was put in a semi-private room and Elyse was assigned as Cory’s rehab worker. Elyse would help Cory with his daily activities and help to co-ordinate his therapy sessions. Cory got physiotherapy, occupational therapy, a speech-language pathologist and hydrotherapy. Cory's ribs had healed, his neck injuries were getting better and his trach tube was gone, but the brain injury was still healing. The brain injury was affecting his movement, balance, eyesight and eating/swallowing. Cory had already defied the odds in his recovery but had a long way to go. I spent a little more than four months with Cory in the rehabilitation facility. I was so thankful for Elyse and her co-workers. Cory was walking with a walker, feeding himself, drinking water and doing so many other things on his own. Cory was working so hard on his recovery and I hoped he was ready to come home.

October 4 was the day Cory left the rehab centre. Saying goodbye to Elyse and the rest of the staff was hard but it was time for the transition to home life. I would be his primary caregiver but all the therapies would continue. I was afraid that I would not be able to maintain a positive environment and keep Cory motivated to work on his recovery. There were times that I wanted Cory to do more but I had to remember that Cory had a brain injury and many regular tasks were exhausting for him. Everything seemed to take so long, but Cory was doing it on his own, which was great.

Cory’s strength and motivation are helping to get me through this ordeal and I continue to learn more about myself. I am glad that I had family and friends providing support to help us all have a successful recovery. Although there were frustrating times, I frequently used “remember when” scenarios for both Cory and myself to remember where he was and recognize the accomplishments he has made. Looking back, I am glad that I committed the time and effort for Cory’s recovery. I think the daily routine of flexing Cory’s muscles and joints, and stimulating his sensations played a positive role in his recovery. We were able to maintain a healthy positive environment to keep Cory on the right path. The uncertainty of brain injury continues and we are working toward maximum recovery.

Cory has been at home for almost two weeks. His daily routines are coming into place. We have daily walks and other activities to keep Cory moving. Cory is reluctant to be seen in public but this is something we are working with. Recovery is very complicated and personal. Cory continues to improve but the path will be very long. ☹️
Authentic Partnerships:
Building on lived experience to co-design caregiver supports

By: Caron Gan, RN, MScN, RP, RMFT, AAMFT Clinical Fellow
Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital

Studies on family needs after childhood Acquired Brain Injury (ABI) have documented needs for education about ABI, stress management, peer support, advocacy, and sibling/family support. Additional needs identified include: health information, school support, and emotional support across the care trajectory from the time of the injury to the child’s return home and well into the future over the course of the child’s development. In spite of this well recognized need for caregiver/family support, publicly funded resources are lacking across Ontario, especially for families of children with ABI. When Ruth Wilcock, the executive director of the Ontario Brain Injury Association (OBIA) invited me to collaborate in the development of workshops for caregivers of children with ABI, this partnership was an exciting opportunity to enhance publicly funded family supports for this underserved population.

As a family therapist working in the brain injury rehabilitation team at Holland Bloorview Kids Rehabilitation Hospital (HBKR), I was committed to embracing HBKR’s core values of client and family-centred care (CFCC) with the caregiver project. With the help of HBKR’s Family Leadership Program, eight dedicated family leaders (FLs) were engaged to partner with Nancy Lajoie (Caregiver Education Specialist at OBIA) and myself to co-design the pilot workshop. This partnership approach enabled us to merge multiple perspectives: the lived experience of the caregivers, the educational background of Nancy, my clinical perspectives as a family therapist and researcher with an interest in family needs and family interventions after pediatric ABI.

Consistent with CFCC core principles of shared decision-making and collaborative partnerships, the FLs were engaged as co-experts around the needs of caregivers of children with ABI. The caregiver team met every one to two months for about a year. Meetings lasted two to three hours and were held onsite at HBKR, with the option of joining via teleconference. The majority of the FLs joined in-person as their schedules allowed. Although the group was comprised of mothers of children with ABI, they adopted a family system perspective and included the views of other family members (e.g., siblings and fathers). The unique cultural perspectives of one member was also welcomed, valued, and embraced. The diversity of her input was invaluable as the group found creative ways to facilitate inclusion of her ideas and voice, while respecting her wish for anonymity.

The FLs assumed multiple roles throughout the project:

**Advisor** – FLs were introduced to core content that had been developed for the workshops for adult caregivers of people with ABI. Although much of the content was applicable to caregivers of children, the unique aspects of pediatric ABI needed special consideration, such as the developmental aspects of ABI and the changing family needs over the course of the child’s development. The FLs identified content areas that were missing, such as school advocacy or dealing with younger siblings and peers/relationships. They also advised on areas in need of enhancement, such as dealing with the trauma and loss that can come about as a result of the child’s
sudden and unexpected ABI, and the episodic loss reactions over the course of family life. They guided our team around the right mix of didactic informational material versus sharing and peer support amongst the caregivers.

Co-presenter – The pilot workshop was divided into key areas: 1) Understanding and Managing Change in my Loved One – Unique Considerations of Pediatric ABI, 2) Understanding and Managing Change in Family and Relationships, 3) Understanding and Managing Change in Myself, 4) Advocacy, and 5) Support, Hope, & Resiliency. Involving FLs as co-presenters provided authentic voices to augment the workshop content. An FL introduced the day and set the stage for the importance of supporting caregivers. A different FL introduced each of the sections of the workshop, which contained a mix of didactic and caregiver discussion. Their introductions were videotaped to facilitate inclusion of their voices in other pediatric workshops throughout Ontario.

Mentor – We had one or two FLs sitting at each table with the workshop participants. They had special nametags that made them easily identifiable so they could act as mentors and be available for support and guidance throughout the workshop. As our group had anticipated, there was sharing of grief, trauma, laughter, and tears. The FLs natural ability to reach out and embrace each of the caregivers’ needs for support was truly powerful and remarkable to witness. This highlighted the power of caregivers supporting caregivers and mutually empowering one another in their caregiver journey.

Although the FLs showed great compassion, strength, and resilience in their newly acquired roles as advisor, co-presenter, and mentor, we recognized that their own emotions and trauma memories were also triggered. They naturally became their own support group for one another, reaching out and offering unconditional support. Their outpouring of support for one another and for others warmed my heart as they illustrated how communities of support can be developed through family caregiver engagement in the healthcare system.

Key learnings from the pilot:

- Engage caregivers in both the design and delivery of the workshops to provide authentic and meaningful partnerships. Fully engaging FLs in this process has been a critical factor in the success of the pilot.

- FLs should be farther along their healing journey (at least one year) to ensure they have the coping resources from their lived experience to participate with ease in the planning discussions. Our group was comprised of parents who were one to 13 years post-injury.

- Ensure a large representation of different FLs at the table. Our working group had a 4:1 ratio (eight FLs, one OBIA representative, one clinician). Incorporating zoom video technology can be a way of facilitating greater FL involvement.

- Find ways of recruiting more representation of fathers and other caregiver roles (e.g., grandparents, siblings).

- Employ creative strategies to facilitate greater inclusion of families from a diversity of backgrounds.

- As FLs are typically volunteering their time, find ways to compensate them for their time and expenses. The FLs in our project were given free registration for OBIA’s Brain Basics e-learning course ($250 value). Lunch and parking expenses were also provided.

- Although involvement of FLs is important, recognize that their losses and traumas can also be reactivated in the process. Ensure a safety net is available for these caregivers, either through peer support, de-briefing, or taking timeout from the planning process as needed.

- Engage a variety of stakeholders who share a vision around the importance of caregiver supports (e.g., family caregivers, brain injury associations, hospitals, community organizations, private sponsors).

- Identify a champion from the hospital or community organization who can not only bring their expertise, but also help with stakeholder engagement, marketing, sharing of resources, and consideration of the unique aspects of each community.

In closing, the success of this pediatric caregiver workshop pilot would not have been possible without the dedication and commitment of the amazing FLs who gave their heart and soul to the project. I experienced firsthand the value of cultivating authentic and meaningful partnerships with caregivers and learning from their lived expertise. It has been a privilege and honour to learn from this amazing group of caregivers - this was truly the highlight of my 28-year career in the ABI field.


EPS Settlements Group of Canada has launched!

Brad Cantwell, President of EPS Settlements Group, and Bob Nigol are pleased to announce a partnership through the launch of EPS Settlements Group of Canada.

EPS Settlements Group is the flagship company of the oldest and largest structured settlements organization in North America.

Bob Nigol is a former owner and President and CEO of Henderson Structured Settlements and now the Managing Partner of EPS Settlements Group of Canada.

Together Brad and Bob wish to invite past and prospective clientele to engage in what assuredly will be the very highest standard of service achievable in the structured settlements market in Canada.
Caregiver and Father:
It’s what I do

By Adrian Reid-Cowell, RMT

I found my mind wandering today; then I found it wondering... about rehabilitation, my nine-year old son’s rehabilitation from an acquired brain injury (ABI), and specifically my role in his recovery. I was looking around the cafeteria at the rehabilitation centre, seeing kids with varying challenges at various stages of recovery and parents with them, supporting their children and their children’s rehabilitation plans.

Some of the children at the rehabilitation centre were born with great challenges, others acquired theirs along the way. My son has both. I share care with his mother, and our arrangement is biweekly; I’m here for a week, his mom is here for a week, and we are not together as a couple. Together, we have another, older teenage son, and I have a partner, who has a younger teenager—so we have a blended family with a child with an ABI as well. This means we do a fair bit of parenting from another city...a unique situation that we weren’t familiar with prior to our youngest son’s ABI. This presents a myriad of its own challenges and hardships, but here I want to focus on some of the challenges associated with caring for a child with an ABI. Specifically, some challenges that are initiated within a system that is not intentionally set up to be limited, quite the contrary.

In October I was fortunate enough to participate in a workshop developed by OBIA. This workshop was fantastic and helpful, presented great information, insights—and, yet, was unintentionally exclusionary. The language and content was derived from multiple sources, multiple experiences, life events both similar and dissimilar to my own, but there was a commonality. Caregivers were gendered as female. It has been my experience that moms are the majority of the visible advocates and caregivers, but we (all caregivers) all need the support. In this day and age of more complex family structures and family or parenting dynamics, it is important to recognize that the caregiver landscape is also changing. Caregivers are dads, moms, aunts/uncles, grandparents, close family friends, really, anybody who provides support and/or care for the affected child, but is not a healthcare professional, directly involved with their care. And caregiving is a tough road to travel. It can be extremely rewarding, defeating, exhausting, exhilarating—the outcomes, energies, and emotions run the entire spectrum, and they can change within minutes and at any stage of recovery or rehabilitation. As an example, you can watch your loved one walk, unassisted for the first time, three months removed from being too weak to sit on a plinth (bench) for longer than a couple of minutes. Then a few minutes later, watch as they soil themselves, unaware, because they didn’t recognize the need to void. It can be an emotional rollercoaster.

Biweekly, as the caregiver dad, I give my son everything I’ve got. All the positive energy I can muster. All the positivity that comes from home and the immense support we are truly fortunate to share. Encouragement, understanding, love, music, smiles, laughs, tears, grumpy faces, razor sharp wit, everything, I give him all that I have to help fuel his success, his progression. When my week ends I’m usually exhausted from the output...and I wouldn’t have it any other way.
I can’t help but wonder, though, over the course of my weeks with him: why am I doing this, and for whom? This question crosses the mind of many caregivers, whether they acknowledge it or not. Obviously, I want him to recover as best as he can, whatever that looks like...and I think it is in that window, the “what it looks like” window, where that question, and possibly the answer, lie. Specifically, for whom am I pushing his progress?

Parents/caregivers generally want the best for their children. We don’t always know what that is, or recognize “it” when we first see “it,” but we know we want “it.” It should be noted that as I sat down to write this, looking out the window from his hospital room at the near leafless fall plants and the darkened and overcast morning sky, I didn’t have an answer. But as I wrote, an answer began to creep into my mind and the blueness of the sky began to break through the clouds and the sun shone with a brightness that required sunglasses. It is helpful to appreciate the beauty as an answer to a different question, “Am I on the right track, am I progressing positively through all this caregiving?”

As it turns out, there is some truth to my notion that, selfishly, my energies are singularly directed toward “helping” him, not just for him but for me. I want him to be able to do more; I want as few barriers in front of him as possible. I haven’t asked him enough times what he wants regarding rehabilitation goals. I made assumptions and acted accordingly, because, of course, he wants all the things that his mother, other caregivers and I want for him. Who wouldn’t?

And I did all this because, as it turns out, I’m human. I’m a loving parent, and I’m uniquely gifted at helping people, not just loved ones, through therapy, rehabilitation, and recovery (it’s also my paid profession). Wanting for people better than they can imagine for themselves, I’m told, is a lovely, laudable notion, even vocation. And I fortunately thrive at it.

He and I are going to have a chat. He likely can’t articulate everything he wants, but we’ll lay down some groundwork and see what he is aware of regarding goals as we move to our final month at the rehabilitation centre. We can add goals and/or milestones as they arise, just as we can cross some off as they are achieved. He’ll get a “voice” in this, his process and he’ll use his voice to relay it. And I’ll continue to support him with everything I’ve got. I’ll shower him with love and affection, and I’ll give him every piece of positive energy I possess. Because I’m his dad...and that is what I do.

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For more than 35 years, I have been involved in the representation of very badly injured plaintiffs. Most suffered severe brain injuries because of car accidents, while others suffered terrible injuries from skiing, falls, intoxication, bullet wounds, medical mistakes, and accidental poisonings. I would like to say most, if not all these plaintiffs, have become friends.

Accidents happen to a family. We all talk about it, but there can be nothing worse than a police officer knocking on your door to tell you a son or daughter has been injured. If you are reading this article, either you have experienced this, or you know a family that this has happened to.

When we enter the world of injury, moms become the main caregivers. They provide the services, the love, and the compassion to ensure the family survives. This is especially true in cases involving children. Not to take anything away from fathers, but in my experience, moms are the glue. In a heartbeat, they somehow provide 24-hour care and supervision to a loved one while continuing to manage all of their other responsibilities.

This caregiving can take many different forms – everything from overseeing treatment, therapy, medications, medical meetings, hygiene issues etc. We can try to capture the injured person’s needs in a Life Care Plan, but it is impossible to quantify a mom’s devotion.

Moms though, cannot do everything. Without the proper help - in particular with attendant care, they are prime candidates for “burnout.” The second problem, which is rarely discussed, is the constant worry: “who is going to take care of my son or daughter, when I pass away?” My advice has always been this.

I have found the better the attendant care, the better quality of life my friends have. Moms cannot do everything, and they should not. Quality of life is predicated on getting help. If you or a loved one has been seriously injured in a work-related accident, apply to the Workers’ Safety Insurance Board for caregiving. Injured parties should also consider the Local Health Integrated Networks/Ontario Community Case Access Centres, and in some instances, the March of Dimes. Since most people are badly injured from a car accident, check your rights and remedies. A car insurance policy provides contractual Statutory Accident Benefits (SAB) for various health care needs and, if you were not responsible for the accident, you can sue the at-fault driver (Tort claim) for the injuries suffered.

Remember there are a plethora of excellent advisors who can point you in the correct direction when dealing with government and private services. The Ontario Brain Injury Association (OBIA) can provide suggestions for exceptionally knowledgeable companies when it comes to figuring out government and private caregiving services.

Caregiving is very expensive. You therefore need to look for ways to pay for it:

1. Ontario and Canadian disability tax credits should be claimed;
2. Short-term and/or Long-term disability benefits may be available from an employer;
3. Employer major medical policies;
4. Unemployment insurance benefits;
5. Loss of income benefits from your car insurer;
6. Caregiver benefits from your car insurer;
7. Ontario Disability Support Payments (ODSP);
8. Canada Disability Pension (CPP); and
9. If travelling, some credit cards have hidden benefits.

You need to be aware that some of these benefits are taxable. If you receive a T4 or T5 slip, you will need to include it as income in your tax returns.

1. Attendant care services - past, present and future have a special place in personal injury accident claims. In tort, the value of the services provided can be claimed by the injured party or by the family claimant who has provided the services via the Family Law Act (FLA).

2. Monies received in the context of a personal injury lawsuit such as the Plaintiff's financial compensation for attendant care is not subject to taxation. The income derived from receiving a lump sum settlement is.

There is a difference in contractual claims and tort claims.

In general, contractual SAB insurers pay benefits submitted by the insured person directly to them. Alternatively, the insurer, when certain conditions are met, will pay the money to a company providing med, rehab, attendant care services. The insured person does not pay taxes on these payments.

If SAB attendant care benefits are paid to the insured person and then given to a family member for the services rendered or even paid directly to the family member; the monies can be considered a taxable income in the hands of that person. The family member might have to claim this income on their tax return, regardless of the fact a T4 or T5 is not received.

Make sure you discuss this with your tax advisor or lawyer.

If SAB attendant care benefit is being paid to a family member because of a tort claim (including FLA), the payment should be properly documented as part of the lawsuit. The total amount paid should be included in all of the SAB and tort releases to make sure the payments are not considered taxable. Again, discuss this with your lawyer.

Understand the importance of long-term tax-free income.

Structured settlements date back to the 1950s. They first appeared in the USA in the form of a structured judgement and have been used extensively since then. The more prominent early examples being the Thalidomide drug cases, and those against Ford Motor Company for the exploding Pinto vehicle cases.

Every serious personal injury claim should be a structured settlement. The preservation of capital is the most important consideration especially if equipment and services will be needed over a lifetime. It helps alleviate a family's concerns about protecting a loved one. It allows the injured person the protection of tax-free income. It is the only financial vehicle that both the IRS in the USA and the CRA in Canada, allow exemption from taxation. It is non-attachable and non-transferrable.

Lastly, structured settlements help mothers (and lawyers) sleep at night.

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The Power of Community

By Kim Belfry

When our eldest son Rob experienced his motor vehicle accident, I never thought my role was that of a caregiver. I felt my role was a mom, dealing with the cards that were dealt, knowing he was dealt the worst hand.

Caregivers encompass the entire family, extended family, friends, neighbours, and community. Looking back over the past 20 years, I can say that what got me to this point in time was my husband, who, even in the most dire of situations, can always make me laugh. Our daughter, Eliza, and youngest son, Luke, who grew up quicker than most, grew into compassionate, caring individuals, never complaining of the time we spent with their brother—always knowing we would have done the same for them.

Early on, there is a period of numbness; of hearing words but not always registering. Being told “he will never be the same” numerous times a day.

I’ll always remember a nurse who commented that I was exaggerating when I told her my son had beat me at a card game of “31.” She said “If he can’t talk, he can’t read the cards.” She was the same one who cried that night with me when he spoke for the first time.

After the acute phase in the trauma centre, reality starts to settle in. This is the time to get serious and put any thoughts of feeling sorry for yourself or “why us?” out of your mind and focus on recovery. It’s a long and winding road. Professional therapists and case managers are welcomed. Not all are able to have these key services and supports available. Seek out local brain injury associations and really listen to the help you receive; they are a wealth of information.

Realizing it would be “one step forward, two steps back” early on, I started to look at recovery in six-month increments. Looking back every six-months and seeing improvement of any amount was viewed as an accomplishment based on a successful group effort!

Some days are definitely darker than others, but good friends, neighbours, and family always seem to intuitively know when to call, visit, or lend a helping hand. A good support system is a wonderful asset, so seek out others to help.

Glasgow Coma Scale, Rancho Los Amigos Cognitive Scale are terms you have likely learned. Perseveration, confabulation, and psychosis are terms you may have heard of but never lived until now. With each stage of recovery, a new situation will arise. It’s like teaching a toddler to walk, then worrying about them falling.

While I focused on my son’s writing, reading, and academics, my husband focused on regaining his balance, and teaching him to whistle—the necessities of life. Being a sister, my daughter Eliza told him when he was doing something wrong. He always listened to her; her effort paid off. His younger brother Luke wanted his buddy back to play sports with. Everyone plays their part. Embrace everyone who lends a helping hand!

Rob has returned to driving and holds a part-time job. He has a wonderful disposition that allows him to be happy with the life he leads, the majority of the time. Fatigue does lead to havoc, but he has learned to be mindful of resting. We also live in a wonderful community. People always amaze me. Our resiliency and desire to overcome as humans is truly admirable.
“The most beautiful people we have known are those who have known defeat, known suffering, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitvity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen”

Elizabeth Kübler-Ross

This is my favourite quote. After 41 years of employment as an optician working with high-end sales, I am now employed with the Brain Injury Association of Peterborough Region. My employment came after I was asked to volunteer instructing yoga to a peer-led Women’s Group. This changed my direction. Kübler-Ross’ quote resonates with these women. The support and respect they extend to each other is commendable. Love Your Brain (LYB) Yoga uses this quote during their Fundamental Series. Both LYB Yoga and the Women’s Group know first hand the power of community. Welcome others into your circle, lean on them when needed, lift them up when you can—the results will be profound.

When others ask me how things are going 20 years post-TBI, I respond with, “We used to have mountains to climb, now we overcome speed bumps,” achieved by hard work, determination and the power of community.

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The three siblings at Rob’s 40th birthday party. Left-Right, Luke Belfry, Rob Belfry and Eliza Nicholson

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I’m Better... Really

In September 2017 the Ontario Brain injury Association printed an article I wrote titled ‘Concussion on Vacation.’ The following is a continuation of that story.

By Dave Breznik.

I think I’m over it, said I to my spouse. It was Tuesday morning past that I uttered those words. I had a few good sleeps I explained, without the aid of sleeping pills.... Yeah!

After almost five years, I’m better! Feeling good was I.

Six hours later

360 minutes later

I felt the folly of my earlier exuberance

As I mentally crashed... crashed to being nowhere man

Living life through a fog-covered drizzle

Where I watch but don’t see

Where I listen but don’t hear

Where I walk into things Struggle with balance

Battle with daily functions Slur my words

Brutalize sentence structure And just stare

And pretend It’s all OK

How? How did this happen? From feeling so good....

to not feeling

What did I get involved in? What did I do?

How did I push myself beyond my new limits?

I didn’t

- bump or hit my head again
- wander in a store with loud music
- drive
- or participate in a myriad of other daily activities

What I did do...

with my spouse...

was visiting some good friends.

We sat around their table had a bit of lunch

and chatted

We don’t normally spend longer than two

maybe three hours when visiting

But we hadn’t seen them for a time
We were catching up

The visit was about five hours

After four hours I noticed my participation dropping off

At least I was able to notice. In times past I would not have noticed that...

I was not doing much talking Just kind of listening Answering questions when asked

It was like I was outside my body just looking down at the table top

There, but not there

In that foggy state Like the woken up
from a deep deep sleep
Aware of my surroundings ....kind of aware
But not feeling being in my surroundings

I tried to stay with it
My spouse our friends
were enjoying the conversation
I don’t want to spoil things
I hung on for an hour
Then knew I had to get out.

I was polite Very polite
I wanted to run
To push my way to the door
To run through it
To get away
To go
Just go
I was polite I think I was polite
I don’t know for sure
Not easy Not easy at all
Almost shaking inside me
Because I felt I would explode
I didn’t want to insult anyone
But I had to leave...
I had to

Concussed for five years
So I have learned a bit of coping a little of control
But I was reaching the end

The elevator The darned elevator Where was it?
Why was it taking so long?
Take the stairs?
Many fights down.
Could I balance?
Could I make it?
I knew I’d fall Where is that elevator?

Finally Finally that elevator opened its doors quickly I stumbled in fumbled for the floor button
A sense of relief

As it started
But still anxious
Finally home
Just sit
Just walk around the house
Familiar
Breathe
Don’t think
Based on the past few years
There are no doubts
That tonight I will not sleep
Unless I take a pill
I take that pill
I love the pill But I hate the pill’s control
Reluctantly I take it and head to bed.
It puts me out. I sleep.
I sleep through the night
I wake
Have breakfast Things still aren’t clear
I lay down
I sleep
I wake
I feel better
But not at all feeling like I did yesterday morning
I’m still nowhere, man
Two mornings later And even the pill is not working
Sleep toys with me teases me through the night

How could I even think I was cured?

Over the past years This has happened many times I’m better
I’m not
It is hard to accept I want to be better

I fool myself into thinking I’m better
But I know I know deep down
That it will never be better
I will grow better
I will grow worse
I will gain I will lose all I have gained.

I know eventually I will have a new normal
Eventually, I might have it

But After five years my benchmark is elusive
For now my new normal is Up and down Better and Worse

Present amongst others Present in body only Being quiet wanting quiet not participating not giving It will be like this For the rest of my life

It’s hard Made harder Because only those who know me Can see it

To everyone else man I look normal

But it’s not All doom and gloom

Actually I may even be Feeling better

Yeah! Maybe I can ……
(to be continued)
Caregivers: Ensuring travel is made easy

By: Nancy Watters

Caregivers take on many responsibilities and I know first hand how much work is involved when it comes to taking a truly wheelchair-accessible holiday. Whether it be an overnighter or an extended family vacation, there is definitely more involved than for an able-bodied holiday.

For example, on weekend getaways I used to be able to manage without bringing help but the older I get the less physically able I am to handle Shawn’s care entirely myself. The last time we went away alone for the night, we took the train into Toronto. All I can say is that trying to toilet an adult in an “accessible” train bathroom while it is moving is not something that I ever want to do again. Being able to get away for a weekend has limited us a bit because it is not always feasible to find someone to go away with us for a night or two to help with care.

Fortunately, we have been able to take several vacations but it does not come without an extensive amount of time doing research to find the best vacation that will work for our family. In the past, I have tried to go away without bringing additional help but then it turns into complete exhaustion for me and not a vacation at all. Part of looking after yourself as a caregiver is knowing when it is time to take a break for yourself too, at least from the physical part.

Accessible travel has come a long way from the days of 11 years ago when I was trying to figure out where and how to get away with Shawn and the kids. I had no idea what to expect from plane travel to hotels to transportation. I remember being at the airport with my children and they were flying out to see their grandparents. I had asked the airline check-in counter personnel out of curiosity how does someone who can’t walk get on a plane. The procedure seems easy enough when it is explained but still to this day it is always an ordeal. Not only am I helping get Shawn on the plane, I am weighed down with his carry-on bag, joystick and seat cushion. Never send those items with the wheelchair down to cargo because there is no guarantee they will be returned undamaged.

It has really been a hit and miss with planning at first but I have learned that Plan A can easily fall through so best to have back-up plans. No matter how hard you try to confirm a million times with the hotels, air carriers, cruise lines etc., the risk of something not meeting the needs can really make or break your vacation. I soon came to realize as well that hotels don’t seem to think that wheelchair users have a family. It is an anomaly to find an accessible hotel room with two queen beds. We have checked into hotels that I was guaranteed a roll-in shower and it was a tub with grab bars. We had an accessible van booked for a week-long trip to Hawaii and got a call at the airport that the van was broken. No alternative was provided from the company. I have shed many a tear over my hard work falling apart so that is why I always have Plan B and sometimes C. I make sure I know if accessible taxis, subways, buses etc. are available in case of a situation like that.

When we first started travelling, we stuck with the obvious choices like Disney World and cruises because we knew they were pretty much sure things for accessibility. However, over the years we have started to get more experimental with our choices. Whether it be finding our own accessible shore excursion on cruises or most recently touring Italy via train, which I am proud to say that all my research paid off because it went off incredibly well. Well, almost since we did have a wheel fall off Shawn’s wheelchair but that is one of those
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things we handled well because we knew what we needed to do. I can’t stress enough how you should always be aware of local medical equipment locations (if any) wherever you are visiting in case of emergencies like this.

Another consideration that many people don’t have to think about is medical equipment and medical supplies. We used to have to source out companies to find shower commode rentals. We now travel with our own commode that we easily can take apart and set up at our destination. I started a blog to not only share our experiences and help others with accessible travel but share some of the accessible travel hacks I have learned on the way. Travelling when you have special needs can be so overwhelming but it doesn’t have to be. Yes, it takes a lot more planning but there are so many accessible travel blogs and websites now that it is opening the world up for wheelchair users. I would like to say that the role of a caregiver gets to go on holidays, with or without additional support workers, but they don’t. You don’t get to take off the caregiver hat because you are always thinking one step ahead, will our shuttle show up, will it have a wheelchair lift, will the hotel have a roll-in shower like I booked, will I run out of supplies, and the list goes on and on. I have learned to accept that this is how it works and that is why I travel with an information binder full of information because we can’t just jump in another cab or take another room. Many destinations in the world will always be out of the question but with lots of research many are not. Sure, many countries are more of a challenge but not a deterrent. The more we travel the more confident we become!

Accessible Travel Blog  [www.accessiblegetaways.com](http://www.accessiblegetaways.com) Check out on Facebook “Accessible Getaways”

Life as A Caregiver Blog [https://life-as-a-caregiver.com](http://https://life-as-a-caregiver.com) Check out on Instagram this_is_us_lifeasacaregiver

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OBIA Advisory Council (OAC) Report

The last meeting of the OAC was held on Saturday, September 21, 2019 at the Miles Nadal Jewish Community Centre. Julia Borsato from Aphasia Friendly Canada, a project from the Cognitive Neuroscience Lab at the University of Windsor, presented on the communication barriers that face someone with aphasia as a result of stroke or brain damage. Other presentations at the meeting were made by Ruth Wilcock and the local updates by the community association representatives.

Archived videos of past workshops can be found on OBIA’s Vimeo page: https://vimeo.com/obia.

The following reports are from some of the local community associations:

BIA Sudbury & District

Brain Injury Association of Sudbury and District

the Recipient of the 2019 Award of Excellence in Brain Injury Rehabilitation.

BIASD had its beginning 24 years ago (1995) as a result of one parent’s need for her child. Since then, BIASD has developed into an organization with a board of 14 highly dedicated individuals focused on ensuring the continuance of their member-centered programs and campaigns in Sudbury District and Surrounding areas.

Our mission is to enhance the lives of individuals of Sudbury and District living with the effects of acquired brain injury through education, awareness, and support and we achieve this through support, collaboration, leadership, and inclusion.

Last year the Unmasking Brain Injury program was launched through OBIA and with that, BIASD wanted to elevate the engagement and raise the awareness “throughout the community—with the community—in the community.”

For 24 years, BIASD has been devoted to serving individuals affected by brain injury, their families, and those that care for and about them.

Seizure & Brain Injury Centre (Timmins)

Our once-a-month Women’s Social Evening kicked off with guest chef Merv Russell teaching the class the fine art of making homemade pizza. The women were able to try a variety of pizza including a potato and a green apple pizza! Everyone enjoyed a dinner of Caesar salad and trying the various pizzas they created. They even had samples to take home to share.

We are now offering two new programs: a Men’s under 45 cooking class and a youth cooking class for those 18 to 25 years old. It seems food has been a great draw for our clients.

BIA Windsor-Essex

The Brain Injury Association of Windsor and Essex County is excited to share two new programs. The first is a program for students from grades 7 to 12. We instruct students about basic brain biology, brain injury prevention, the effects of a mild concussion and, most importantly, the need to tell an adult if and when they have hit their head. The program was approved by the two public school boards and is currently presented by two fourth-year University of Windsor nursing students.

Here’s what one of the teachers said about the program: “I specifically
attempt to implement safe, thoughtful practices that reduce the risk of concussions on a daily basis during PE class, intramural and intermural sports. These presentations assist with that. They also foster community partnerships with local professionals, thereby raising the level of concussion awareness for both staff and students. Thanks in part to the information delivered during these assemblies, our students now understand that timely identification and reporting are the first steps to a successful concussion recovery. Building mindfulness around concussions allows each student the competence to self-assess their own symptoms, and instills the confidence to report them openly to a trusted adult."

The principal of one school said, “It was extremely worthwhile as the team presented the information at the student’s level of understanding and created opportunities for student participation.” Another principal said, “The presentations are informative and were well received by staff and students alike. The presentations are not only relevant to my specific students; overall they are a great support to the new Physical Education and Health Curriculum.”

Our other program is a home improvement project, paid by funds raised by the staff at Lowe’s Home Improvement (eastside) as part of their Heroes program. BIAWE is coordinating home repairs and purchases of much-needed appliances to those in the ABI community who require it. Members of the Lowe’s team and BIAWE’s volunteers will deliver goods and engage in some of the home improvements. This is a community partnership that allows us to reach out and assist more of our members, and is in keeping with our overall mission of enhancing the lives of those affected by an acquired brain injury.

**Hamilton BIA**

It’s been a busy and exciting summer and fall at HBIA!

We ended the summer with our fourth Annual Drive for ABI Charity Golf Tournament. Thank you to our committee, sponsors, golfers and donors for making this the most successful year yet! We hope to see you next year on Monday, August 17, 2020 for our fifth Annual Drive for ABI! Visit “Fundraisers” at www.hbia.ca for details.

HBIA kicked off the fall with our first ever Bikes, Blades and Boards fundraiser. We launched a six-game volleyball league that brought many community
HBIA has introduced a number of new programs to our Clubhouse including Chair Yoga and a monthly Women’s Support Group. We are always welcoming new members!

In October, we gathered at the Clubhouse for our third Family and Friends Event of the year. Our Halloween Social was a great way to bring our members and their families together for a fun-filled Halloween event. Thank you to Melanie Crawford for hosting “scary-oke” to close out the evening!

Are you caring for a loved one with an acquired brain injury? Join our free Online Caregiver Conversations Group from the comfort of your home.

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November 6-8, 2019 saw more than 700 people attend the 2019 Provincial ABI Conference in Niagara Falls, Ontario. On behalf of the participating community associations, OBIA would like to thank the knowledgeable keynote speakers, winners of the Pioneer Caregiver Awards (pictured below), the many concurrent speakers who shared their time and experience with the delegates, the sponsors, exhibitors, emcees Dee Sperry and Steve Noyes, entertainers, our staff and many volunteers for making this conference a huge success.

Since the late 1980’s, many of the pioneers in developing community supports for persons living with brain injury were caregivers. These family caregivers not only took care of their loved ones, but developed supports through the establishment of local community associations.

In celebration of the launch of “Support, Hope & Resiliency” An Education and Training Program for Caregivers of ABI Survivors we would like to honour these pioneers who have dedicated their lives to supporting people living with the effects of brain injury.

Dawn Newmann, PhD, FACRM
*Know Thy Emotions: A New Treatment Approach for Emotion Regulation After Brain Injury*

Meg Soper
*Bring It On... Strategies for Balance and Resilience*

Robert van Reekum, MD, FRCPC and Emma van Reekum
*Understanding and Coping with the Dual Challenge of TBI and Psychosis*

Tom Dow
*I Survived a Brain Injury: So Now What?*

Carole Vincent - Brain Injury Association of Quinte District
*Pioneer Caregiver Award Winner*

Wendy Charbonneau - Brain Injury Association of Ottawa Valley
*Pioneer Caregiver Award Winner*

Shirley Athoe & Jackie Denham - Brain Injury Association of Fort Erie
*Pioneer Caregiver Award Winner*

Toby Meehan - Hamilton Brain Injury Association
*Pioneer Caregiver Award Winner*
When the Juggling Act Isn’t Working:
Five Key Strategies to Reduce Compassion Fatigue and Burnout

By Françoise Mathieu, MEd, RP (originally published in The Family Caregiver, September 2016)

For many of us, becoming a family caregiver was not necessarily part of the plan. Instead, sudden life circumstances have thrust us into this role: a friend or relative has an accident and has sustained a traumatic brain injury, a child is born with a profound disability or develops a life threatening illness, a spouse, friend or relative has an accident or is affected by a debilitating condition, our parents get sick or need increasing support as they age, and so, we become, often by default, sometimes by choice and also through a sense of love and/or duty, family caregivers.

A recent report by Statistics Canada called “Portraits of Caregivers 2012” revealed that nearly half of all Canadian adults will provide care to a friend or relative “at some point in their lives” and that, at any given time, “over eight million Canadians provide care to a chronically ill or disabled friend or loved one.”

Most family caregivers never received any training in how to care for a disabled or very ill patient: We learn on the fly, as our loved one’s health and caregiving needs dictate.

The Sandwich Generation

Being a caregiver is more complicated than it has ever been before:

More women work full-time outside the home, and our family demographics have changed - many of us are now part of the sandwich generation,” which means that we are juggling caring for aging parents while also attending to the needs of our children. In fact, recent data shows that 28% of family caregivers in our country are currently part of the sandwich generation. According to Statistics Canada, three-quarters of caregivers do not live with the person they are caring for (often their parents), which means they have to travel to their loved one’s home to provide care.

As a result, family caregivers are performing a complex juggling act, trying to work, run a household, parent, be a caregiver, stay on top of their relative’s medical and care needs, sleep, and maybe, just maybe, have some leisure time in the mix. The risk of burnout and compassion fatigue is never far away.

“Grieving by inches…”

For many caregivers, there is also a significant element of grief and sadness surrounding the illness of their loved one. Caring for a child with cancer, a seizure disorder or a profound developmental disability can be extremely difficult emotionally. Having a spouse or parent with a degenerative illness such as Alzheimer’s or ALS can mean that we are “grieving by inches” (in Sherri Showalter’s words) as we witness the progression of the disease in our loved one, losing them a little bit more each day. We may also find ourselves isolated from friends who cannot relate to our situation and do not know how to help.
Family dynamics are rarely simple

As a therapist who has worked in the mental health field for the past 20 years, I have seen every permutation of what constitutes a family: healthy ones that seem to lead uncomplicated lives and get along with one another (they are the exception in a therapy office, for obvious reasons), blended families with many layers of divorce, remarriages and step-children trying to get along with step-parents, too many families with “cutoffs,” which means that someone in the family is estranged and not speaking to someone else, and finally, families with histories of addiction and abuse.

We sometimes forget that just because a father is 85 years old and frail does not mean that all family members had a healthy loving relationship with him throughout their lives. Just because our child is born with a profound disability doesn’t mean that our marriage will be strong enough to withstand the challenges of sleeplessness, exhaustion and financial strain associated with his care.

Family relationships are complicated at the best of times, and the cracks in the foundation are never as salient as when a relative develops a chronic illness and is in need of care: Will there be one primary caregiver or will this duty be shared? Is there agreement on the level of care that should be provided? Should the loved one receive services in the home or in a long-term care facility? Who will pay for the mounting costs of medical services?

Often, one family member chooses (or is selected by default) to be in the caregiver role. Some of these caring individuals are glad to be able to help their loved one, but over time, they can start burning out, which can lead to resentment towards other family members.

Finally, with families often living far apart geographically, some caregivers are truly alone in providing care. This isolation can become very problematic over time and also contribute to burnout and compassion fatigue.

“Intensity of caregiving”

Statistics Canada’s Portraits of Caregivers 2012 refers to an important metric called “The intensity of caregiving” which is directly correlated with stress and exhaustion in the care provider. The report seems to identify 20 hours or more a week as the magical number: “Overall, the vast majority of caregivers (95%) indicated that they were effectively coping with their caregiving responsibilities, with only 5% reporting that they were not coping well. However, the feeling of being unable to cope grew with a greater number of hours of care. By the time caregivers were spending 20 or more hours per week on caregiving tasks, one in ten (10%) were not coping well.” Basically, the more hours spent caregiving, the higher the risk of burnout and poor work-life balance.

Burnout and Compassion Fatigue

The concept of burnout was first coined in the 1970s by psychologists studying the effects of professional depletion. Since that time, the term has been widely used to describe the physical and emotional exhaustion that individuals can experience when they have low job satisfaction and feel powerless and overwhelmed at work. This could happen to any of us, in any occupation, including in our caregiver role.

In the 1990s, researchers began to explore a more complex picture of burnout among helping professionals and caregivers: It was clear that in addition to burnout, depleted caregivers and helping professionals were also experiencing a shift in their ability to experience empathy and compassion towards their loved ones, or their patients.

If you are a family caregiver, it is very possible that you have had moments you are not proud of: have you ever felt impatient, short-tempered with the person you are caring for? Wishing they would move faster, finish their meal more quickly, stop complaining? Or perhaps you have been shocked at the coldness of a nurse or a physician caring for your child or parent.

The term “compassion fatigue” refers to the profound emotional erosion of our ability to experience empathy and compassion towards others. It is characterized by increasing irritability, cynicism, emotional and physical exhaustion, depressed mood and for some, feelings of hopelessness. Of course, experiencing these emotions as a family caregiver can lead to feelings of intense guilt and a loss of compassion towards ourselves.

Compassion fatigue is considered to be a normal consequence of doing a good job. As Naomi Remen (a physician who has worked in the field of cancer care for many years) said, “We burn out not because we don’t care but because we don’t grieve. We burn out because we’ve allowed our hearts to become so filled with loss that we have no room left to care.” (Remen, Kitchen Table Wisdom, p.52) The solution lies in early intervention: recognising the warning signs of compassion fatigue and seeking help before you burn out.

What can I do? Five Key Strategies for Family Caregivers

How can you sustain yourself and stay healthy while juggling the demands of caregiving? Here are five key strategies that can help:

1) Pay attention to your warning signs

Many family caregivers put their own needs last, and tend to run on fast food, insufficient sleep, and not enough exercise. Caregivers also often ignore their own physical symptoms of stress: palpitations, migraines, irritable bowel syndrome, heartburn, rashes, insomnia, back pain. All of these are your...
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body’s way of letting you know that something isn’t going well - it is your built-in warning system, and are often a result of chronic stress. Unfortunately, most of us either ignore these warning signs or medicate them so they will stop interfering with our lives. Over time, we can develop serious chronic illnesses that could have been prevented had we addressed the root cause earlier.

**Try this:** When you are stressed and overwhelmed, what is the first physical symptom that you notice? Do you tend to suffer from chronic insomnia, or are you more a migraine type? Back trouble, or heartburn? Irritable bowel? Racing heart? Hives? Take a minute to think about which physical warning sign is your most frequent visitor. Then, reflect on what you normally do when this symptom shows up in your life: take pills? Ignore? or reduce stress?

In his thoughtful and eloquent book *When the Body Says No: The Cost of Hidden Stress*, physician Gabor Maté explores the connection between chronic stress and depressed immune responses. There is now solid evidence that demonstrates that many caregivers have lowered immune responses as a direct result of the chronic stress they experience.

### 2) Beware of self-medication

“Self-medication” is a term used in counselling to refer to ways we numb ourselves out when we are overwhelmed by stressful feelings and distressing situations. The most common forms of self-medication are of course drugs and alcohol. There are, however, other ways to numb out which can also become problematic over time: compulsive overeating, watching excessive amounts of television or movies, gambling, “retail therapy” even when we cannot afford it, and workaholism are all ways of avoiding difficult feelings and situations. Sometimes, a pleasurable treat (a nice glass of wine after a long day, watching our favourite TV show) can become our crutch that we start relying on excessively. Thanks to new technology, it is now very easy to watch an entire season of a TV show in one evening, but is it a good idea on a regular basis?

**Try this:** Is there something that you would currently identify as your “guilty pleasure”? The idea is not to eliminate it completely, unless you have a serious addiction. However, the goal is to start objectively monitoring how much space it takes in your life. The first way to check is to ask people around you if they think that this is something you are doing too often or relying on too much. Then think about how and when you use this strategy: is it when you are hungry, tired, angry or upset? How would you feel about stopping this habit for a week? If you worry that you may be suffering from a serious addiction, please seek some help - there are many excellent resources available online and in most communities.

### 3) Let others know how you are feeling

Here is another lesson I learned from my many years as a therapist: people cannot read your mind! If you do not tell others how you are feeling, you cannot expect them to help or to understand. This is true for your spouse, your family and your friends. Let them know when you are starting to feel overwhelmed, or when you notice the first warning signs of burnout or compassion fatigue.

**Try this:**

If you feel unhappy about the division of labour around your caregiving responsibilities, consider having a family meeting. Say what’s on your mind, but try to use non-blaming language. Before the meeting, decide what one or two key messages you want to communicate. Don’t try and resolve decades of family conflict in one sitting! If you are overwhelmed with your ailing mother’s appointments, ask for concrete help: “Could you drive mom to chemo every Tuesday, or if that doesn’t work, could you take responsibility for contacting hospice and finding out if they have a program with volunteer drivers” rather than “It would be nice if someone else helped out around here.”

### Establish a support system

In their online article on caregiver stress and burnout, Melina Smith and Gina Kemp recommend joining a support group: “A caregiver support group is a great way to share your troubles and find people who are going through the same experiences that you are living each day. If you can’t leave the house, many internet groups are also available.”

### 4) Establish what you have control over

Some caregiving situations are extremely complex and unpredictable from week to week, depending on your loved one’s health and the progression of their illness. It may be that you have very little control over the situation, and find that resources are extremely limited. In spite of this, most of us do retain control over certain aspects of our lives: the few minutes of peace and quiet when your loved one is sleeping, taking time to have a cup of tea or read the paper when you are waiting at a medical appointment. Although these may seem like small things, they are a place to start, to try and replenish ourselves.

**Try this:**

Take a look at a typical day in your life as a family caregiver. Ask yourself...What do I have control over? What do I not have control over? Are there some chores that you could let go of? For example, taking a nap during your down time might be a better idea than doing the dishes. It may be that you have to lower your standards about your clean house while you are caregiving intensively.

### 5) Ask for help/Accept offers of help

I was recently speaking to someone who coordinates care for developmental services and she said that one of her biggest challenges was convincing older caregivers to seek help when they need it: “I don’t know if it’s a generational thing, but they tend to be extremely proud and very uncomfortable asking for
“Is it true for you? Sometimes, the healthcare needs of our loved one are so complex that we can’t imagine delegating any of them, or accepting respite care.

**Try this:**

A neighbour of mine, who is the mother of two young children, recently fractured her pelvis in a serious car accident. She was bedridden for 12 weeks, and was left unable to care for her little ones. A dear friend of hers sent an email appeal out to her entire network, and within days there was a huge response from friends and neighbours. We had all been horrified by the accident, and were wanting to help, but without this email, many of us may have not felt comfortable reaching out.

Start small – draw up a list of very specific tasks that you need help with, even if you cannot at the moment imagine anyone else doing them: shoveling your mother’s front walk, going to the drugstore to get your child’s medications, covering a night shift, driving to and from appointments, groceries etc. Then, swallow your pride and ask your network for help with very concrete tasks. You will likely find that most people in your circle of friends are more than willing to help but don’t know what to do. If you post a list of tasks, they can then choose something that they are comfortable with and that fits with their time limits and abilities.

**Conclusion:**

Although being a family caregiver can be a stressful, tiring and often under-appreciated task, it can also provide many rewards. I recently spoke to a colleague whose husband is dying of a degenerative illness and she said “I am so grateful for every day that we get to spend together.” This caregiver is celebrating the many years of happiness they had together, and appreciating the time that is still available to them.

Remember, compassion fatigue is a normal consequence of being asked to provide more care than is sustainable. As Naomi Remen said in *Kitchen Table Wisdom*: “The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.” The key is to identify our early warning signs of compassion fatigue, and reach out to others for support before we get into the danger zone.

If you are feeling overwhelmed and burned out, please reach out for help, and remember to have compassion for yourself too.

**The Author: Françoise Mathieu, ME, RP**

Françoise Mathieu is a Registered Psychotherapist and a compassion fatigue specialist. She is Executive director of TEND, a company that provides education, training and resources to helping professionals. Françoise is the author of “The Compassion Fatigue Workbook” which was published by Routledge in 2012. For more information visit: www.tendacademy.ca

**Additional Resources:**

- Mathieu, F. (2012) *The Compassion Fatigue workbook* (available at Amazon)
- Tedx Talk: The Edge of Compassion: What is the sweet spot between caring too much and not caring at all?

**Websites:**

- www.tendacademy.ca

**Sources:**

- Showalter, Sherri [http://dreses.blogspot.ca/2013/03/grief-is-grief.html](http://dreses.blogspot.ca/2013/03/grief-is-grief.html)
- Melina Smith and Gina Kemp [http://www.helpguide.org/elder/caregiver_stress_burnout.htm](http://www.helpguide.org/elder/caregiver_stress_burnout.htm)
Caregiving from the male perspective

By Jim Clark

I am a male caregiver for my wife who experienced a brain injury as a result of surgery related to a brain tumour in the left temporal lobe. As a male caregiver, I seem to be a minority.

Whether it is at a caregiver support group or a caregiver workshop presented by the Ontario Brain Injury Association, the Brain Tumour Foundation of Canada or the Alzheimer’s Society, female attendees outnumber males by an overwhelming margin. Is this because more males suffer brain injury than females or because males allow ego and machismo to stand in the way? I believe it is the latter. We males don’t like to admit that we need help, or we believe that we can manage on our own.

The truth is: male or female, we all need help as caregivers from time to time but we have to actively seek it out. It is so important for the caregiver to maintain their own physical and mental health. Without that, who would be left to provide the assistance and guidance needed by the brain injured survivor?

Since there are many various causes of brain injury and different parts of the brain may be affected, the symptoms vary widely from person to person. In turn, so do the issues that the patient and the caregiver deal with on a frequent basis.

I feel very fortunate that my wife is a highly functioning brain injury survivor but that doesn’t mean there aren’t challenges.

As caregivers, we all are dealing with many of our own emotions including anger, frustration, grief, sadness and depression, to name a few. We have to try to bury these emotions in the presence of the person with the brain injury. They can’t be expressed verbally OR physically. The wrong body language such as dropping your shoulders, rolling your eyes or a heavy sigh can be as detrimental to the self-esteem of the patient as spoken words! We have to remember that the brain injured person may be experiencing some or all of those same emotions as well, but don’t get the idea that it is easy!

Although we have to do our best to conceal our emotions, it isn’t healthy to bottle them up inside. That’s where external sources of support and education may be helpful. Some remedies/suggestions may be as “simple” as finding time for a hobby, exercise, reading, mindfulness exercises or meditation. There is no magic bullet or cure-all that will work for everyone. If they cannot be left alone, external help may be required to be with the patient while you are having your personal time.

As I stated earlier, my wife is a highly functioning brain injury survivor. In our case, the main deficits that developed from her brain surgery include impaired comprehension, impaired short term memory, moderate aphasia, occasional loss of awareness of appropriate vocabulary for today’s society and loss of patience, particularly with herself. All of these conditions have a sometimes significant negative impact on our ability to communicate. However, we are both thankful that she is still here with us and that she is able to perform many of the tasks that she did prior to her first surgery.

Sure, I have had to assume some of the tasks and responsibilities that my wife used to do; banking and bill payments being the most significant one. But that is a small price to pay for her continued presence with us today.

As emphasized in the OBIA Caregiver Education Workshop, when a situation or an incident arises, caregivers and all other people who come in contact with the brain injury survivor
must always THINK BRAIN FIRST! In our case, in many conversations, I have to refrain from completing my wife’s sentences or thoughts for her. I have to let her work to verbalize what she is thinking as clearly as she can. I have to read her body language and jump in to help her with a word that she is just unable to find, at just the right time; not too early and not too late. It is a delicate dance to say the least!

My wife also relies upon me from time to time to help her to spell a word she wants to use in an email or an ecard. She refers to me as Mr. Webster (as in the dictionary sense).

In all of these situations, I have to remind myself THINK BRAIN FIRST. Although she says that she died and a new person was born after each surgery, deep down, she is still the same caring, loving, nurturing and compassionate person she was before her initial seizure and the first surgery. It’s her brain that has been affected, not the person.

Another thing that comes to mind but maybe not often enough and not as a feeling of pity for her is that I can’t begin to imagine what it must be like to be in her shoes. I get caregiver motivation from that because I know that if the roles were reversed, she would make what I do as a caregiver look like a drop of water in Lake Ontario.

We both truly wish that her brain injury from surgery didn’t happen; but it did, 16 years ago. My wife has been determined to fight on to reclaim as much of her “self” as possible and that has probably made my job as caregiver somewhat easier. When she had her grand mal seizure in 1995, she was told that she probably wouldn’t see our children graduate from high school or get married and that she probably wouldn’t be around to see grandchildren. She’s proven them wrong on all three of those milestone events!

I am fortunate and glad to have done what I could to help us to experience those milestones together and to continue to experience new family milestones together in the years to come.

Remember, as tough as it gets from time to time, THINK BRAIN FIRST! ☛☛☛

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Caregiving 101: Self-Care is Not Selfish

By Deb Crowe

Caregiver. It’s not a title that we think will be in our life unless we are going to have a child and then mother is truly the epitome of the word caregiver.

Caregiver is a family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person.

The caveat to becoming a caregiver is that it unfortunately can come into our life by accident, those life occurrences that happen in seconds and bring us to our knees in emotion and turn our world upside down.

I have been here in my 20s with my father. My 30s with my Nana and brother. My 40s with my father-in-law and my oldest daughter. I am hoping in my 50s for a reprieve; however, I have many close friends and relatives who now also don this title.

Here’s the good news. Like any other element of our lives that cause us stress, we must first and foremost look after ourselves. Enter self-care.

Self-care is not as elusive as it once was. And what’s more, it is not only required but also necessary. Luckily, however, self-care is now beginning to be widely accepted as a staple of healthy living. Taking some time for yourself, be it yoga, meditation, fitness, or even a good, long, relaxing bath, will help you get through the day and keep yourself healthy in the process while you are caregiving.

Nevertheless, there are still a lot of people out there, hard-working moms, workaholics, diligent students, you name it, who are always looking at self-care as something indulgent and over-permissive. If they are not working until near exhaustion (like a caregiver), they don’t feel like they are deserving or that they are somehow slacking off.

Well, the fact of the matter is that it’s not. In fact, giving yourself some time to unwind and relax is healthy, necessary, and it doesn’t even need to be time-consuming.

What Is Self-Care?

Self-care can take on many shapes and sizes, and it can be unique to every one of us. It is anything and everything that makes us happy, confident, and feeling whole. Yoga, light physical exercises, showering, traveling, reading, clothes shopping, listening to music, or meditating are, among many others, examples of self-care. The foundation is having a disciplined mindset daily to incorporate the exact self-care routine and/or task that is best for you.

The beauty here is that the more you take care of yourself, the better and brighter your days will become. Do it regularly, and you will not want to change a thing. And as luck would have it, the only person standing in your way from investing more time in yourself is you. Imagine how well you will feel and what you will bring to your caregiving role?

Eliminate Distractions and Time Wasters

The reason so many people do not take the necessary time for themselves is that they feel they don’t have enough time to begin with. But unbeknownst to us, there are plenty of time wasters and distractions around us that eat up a lot of our time.

Stop checking your emails regularly. Stop multitasking. Delegate more. Start saying NO from time to time. Keep yourself organized. Stop inviting interruptions like sending texts to friends while at work. They are a few examples of what
you can do to save up on time. You'll be surprised how much
time is wasted on trivial things.

Establish a Routine

Like any habit, it is hard to start and keep yourself motivated. There is no one-size-fits-all approach to the issue, but it is best to start with it the moment you arise in the morning. Wake up gently and happily, and don’t rush anything. Then you will be sufficiently energized to start your day properly, which is crucial when you are caregiving.

Don’t be too hard on yourself. Self-care shouldn’t be a chore, but quite the opposite. Make it an effortless experience by preparing your space ahead of time. Do not let yourself be tempted to check your emails or social media, as these are nothing more than distractions at this point.

Finally, you will need to give yourself enough time to complete the routine without rushing it. In the beginning, you may feel that you’ve “wasted” too much of your time by taking some for yourself, but don’t give in to that temptation. We suggest you start with around 20 minutes of self-care per day; then move to 30 to 60 minutes as you get more comfortable. You can even spread this time throughout the day into three 20-minute periods – one in the morning, one at lunch, and the other in the evening. It is only 4% of the day, by the way, which you dedicated solely to yourself. That doesn’t sound like much now, does it?

Conclusion

It’s the little things that make life beautiful, and self-care is just an expression of that. Do not be afraid to be happy and whole; otherwise, you’ll regret it.

Bio

Deb is a certified Og Mandino Executive & Life Coach, Professional Speaker, Author and Yoga Teacher. Her favorite role is being wife to John and mom to Christine and Laura.

Deb attended Brock University and The Richard Ivey School of Business for Entrepreneurship. Deb is a lifelong learner and an avid reader.

Deb has co-authored four books since 2015 and is currently working on her first solo book on self-care. Deb is the founder of the Women’s Self-Care Conference. Deb launched this conference in October 2018 and has taken it across Canada with a complete emphasis on self-care.

Deb’s passion is to help individuals prioritize their time and attention. Life is about progression, moving forward and not attempting to have perfection.

#IAmTheFaceOfBrainInjury

Do you have a story of survival? Do you have coping strategies to share? Are you a caregiver to someone with ABI?

To help spread the awareness of how brain injury impacts our lives, OBIA is pleased to share stories from our readership. The goal is simple:

Share ● Inspire ● Support

To share your journeys with our readers, email us at: stories@obia.on.ca
Indeed, it can be done

By John Fraser

“It can’t be done! said the tear. “That’s what my salt tells me!”

“Indeed it can be done,” said the bead of sweat. That’s what my salt tells me!” **

Just over five years ago, my wife Mary suffered a traumatic brain injury, sustained in a car crash. Life changed very quickly and dramatically for both of us and the journey continues.

After Mary’s original surgery, the next hurdle was whether or not Mary would qualify for admittance to the Regional Rehabilitation Centre in Hamilton Ontario, or would she go directly to long term care. It was touch and go. After all, Mary was a senior – late 60s with a poor prognosis. Fortunately, she was admitted to a three-month ‘slow to recover’ program. This program was excellent but, of course, Mary needed much more time to recover. Without going into detail, later that same year, after surgical replacement of the bone flap, Mary began to show very positive signs of further recovery. Mary needed further intensive rehab at the regional centre. We were first told that this just did not happen. But a combination of Mary’s determination and caregiver advocacy proved successful. After an agreed reassessment, Mary would go back but conditionally - only for one month. The timeframe actually proved to be flexible enough to last three months. At time of discharge, Mary was able to use a walker and could transfer to my car. Mary was coming home! The dedicated staff and the care Mary received at the centre were exceptional. But, things could easily have turned out very differently.Mary has been able to live at home for the past four and a half years, with some intermittent hospital stays and a few months in long term care. We have been very fortunate to have a private health care team – case manager, physiotherapist, psychologist, occupational therapist, and speech-language pathologist, providing a multi-disciplinary care approach. They have been a critical component in Mary’s care and I believe this has made it possible for Mary to remain at home.

It is important to note that although Mary was able to come home, for her it is still not really home. She has lost her independence and, to a large extent, so have I. We have had to accept that our home is now a shared one, with many people coming and going. Scheduling caregivers has been challenging and in the case of agency support, often very limited and inconsistent. Mary still tries to keep her kitchen organized but she can only do this from a fixed position – not very satisfactory. Discouragement can easily creep in.

We have learned that minor irritations and inconveniences to the average individual can become major obstacles for someone suffering from acquired brain injury (ABI). Still, it is through pure determination that we have been able to accomplish so much. We have suffered setbacks but have also been privileged to see almost miraculous progress. Being a caregiver is humbling but enabling as well. It is a role that
must be taken on with enthusiasm and perseverance.

For myself as caregiver I have now many new and expanded roles:

- PSW scheduling and payroll (24/7 care needed)
- PSW back-up
- handling medical appointments
- grocery shopping
- banking
- Providing transportation for Mary and... well the list goes on.

Being a caregiver requires an intensity of purpose and is in the truest sense a vocation — a calling. It demands a high degree of determination, a no-nonsense attitude, and not a ‘few beads of sweat.’

Yes, there have been setbacks – medical emergencies – seizures, respiratory issues, and severe pneumonia. Yet Mary continues to recover. This is in spite of very depressing and often very blunt medical predictions:

- ‘Too much damage to the brain – no possibility of ever walking again—further recovery unlikely’
- Following a setback – ‘This is likely Mary’s new baseline’ or ‘Mary is probably now on a downward trajectory’ and ‘Mary should really be in LTC where they have the facilities and expertise to provide the care that Mary needs.’
- Often a tendency to label – e.g. dementia or sundowners – Such labels can often colour the type of care provided.

The unfortunate reality is that there is much lacking in our health care system, especially in terms of treating persons living with ABI. This is particularly amplified in the case of seniors.

Notwithstanding, we have been very thankful for the many dedicated and hard-working health care workers that have been and are part of our lives. They are everywhere - in our hospitals, in long term care facilities, and in private care. However, these same workers openly admit that there are many examples of inequality and deficiencies within our medical system. At times, it has been a struggle to ensure that Mary has the best care possible.

My chief role as caregiver is to be an advocate for Mary. This means continuously looking out for her welfare. It means searching for the best possible care, wherever that may be. It often means doing one’s own research. Sometimes it means requesting a second opinion when advice comes from a doctor or other medical professional. At all times, it means having an open mind and being willing to accept help and support from many different places: medical care teams, friends and family, and various support groups and agencies. However, in the end, one has to listen to one’s own heart.

Although my wife and I know that our lives will never be the as they were, we are both still committed to each other and in our own way doing the very best we are capable of. ‘Indeed, it can be done!!’

** Jacob M. Braude, Braude's Handbook of Stories for Toastmasters and Speakers, Prentice Hall, 1957, #1864 p.267

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**BRAIN IMAGING STUDY**

**HAVE YOU SUFFERED FROM A TRAUMATIC BRAIN INJURY?**

If so, you may be eligible to participate in a study at the CAMH Research Imaging Centre investigating brain inflammation in people with traumatic brain injury and depression REB#051-2018

**Eligibility**

- Brain injury/concussion within past 5 years
- Age 18 to 60
- Women: not currently pregnant
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- Otherwise healthy

**Results and Compensation Provided**

To learn more, please call (416) 535-8501 ext. 36450 or email TBI.study@camh.ca

Calls typically returned in 1 week and messages will be left if permission indicated

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**camh Centre for Addiction and Mental Health**
As Monday mornings go, sunny ones in May are the most heartening, especially for teachers. The weather is warmer, the world is greener, our students seem happier and summer is on its way, with all its plans and promises of freedom from early morning starts.

May 2, 2016 was that kind of morning, until my life changed, five minutes away from my destination, my school. While waiting at a green light for the traffic to clear so that I could turn left, I heard a terrible crash, and then felt the impact. I did not know then that this sound heralded a change to not just all my summer plans but my future life.

An inattentive driver, returning from his night shift, asleep perhaps, or fiddling with his cell phone, or his attention faltering from some other distraction, hit the car behind me and pushed it into mine at high speed.

It was not just my vehicle that sustained damage. The first responders were very kind, taking the victim behind me to the hospital and offering to call a second ambulance for me. I was diagnosed by the paramedic as being in shock, but I wanted to go home, not to a hospital, and he allowed that, once my legs would hold me upright and the shaking stopped. He exacted a promise from me that I would see my doctor.

Within 24 hours the symptoms began taking over. Pain in my neck, back and head indicated something was very wrong. I was diagnosed with whiplash to the back and neck, and a concussion. May and June are months I hardly remember, with doctor and therapy appointments filling my days, phone calls with insurance adjusters, and an activity-pacing program, prescribed by my occupational therapist, dictating my every minute. Ten points allotted per day, with therapy taking up three, allowed for very little of my normal life to continue. I saw a physiotherapist, a kinesiologist and an occupational therapist, attending sessions three days per week. I experienced the frustration of a shut in. As friends, family and co-workers enjoyed a beautiful spring, I was at home, or at therapy, unable to tolerate sound or light, was motion sick, irritable and crying most days.

In my work as a guidance counsellor, many students presented themselves to me with sports-related concussions requiring an accommodations list for return to learn and return to play. I have seen students who came back to school the day after their accident, nauseous but determined to be at school, who
we had to send home. I knew students with total personality changes, constant sleepiness, irritability, emotional issues and sometimes depression, because of concussions. I worked with concussed students who could no longer do Math, and whose marks plummeted. I thought we were doing at least an adequate job supporting them. Our school board set up protocols; we followed them. I now understand that each concussion is different as is each recovery, so one set of protocols does not and cannot help all.

I learned that the concussion of most 16-year-old athletes is not the concussion of a middle-aged female motor vehicle accident victim. I am a researcher at heart but facts were hard to find and testing was inadequate. There are many types of practitioners anxious to have some of the money available to treat concussed patients, but little proof that their treatments work. My frustration grew. Suggestions of best therapies or best practices came from the internet but not from medical doctors. I searched for answers and discovered concussion-based Facebook groups, sometimes offering tried and true help but often featuring people as confused as I was. I had no idea how intimate with this topic I would become.

I reconnected with a sports medicine doctor who had gained a lot of concussion experience since I had last been to her. I made the decision to trust her instincts since I was not substantially better after two months of attending therapy sessions at the clinic my car insurance sent me to. I had also been going to private therapeutic yoga sessions. My neck seemed to be getting worse rather than better. Cognitively, I was in decline. I was unable to read much, was struggling to remember words, or follow conversations, could not use a computer, and was very dizzy and nauseous. My sleep was very disturbed, and when I did manage to sleep, it was in short bursts, and when I dreamed it was in neon colours.

This doctor was very good at listening. She was able to understand that many of my symptoms, other than my neck and body pain, shared a common thread. They were easily activated by visual stimulus. I had just had an appointment with my optometrist, to have my two-year checkup, and it could not be completed because of the severe nausea it triggered. My concussion doctor sent me back to my optometrist for more testing.

One of the optometrists had been recently trained in neuro optometry and instantly recognized my symptoms as those of brain injury and knew what to test for and how. I started wearing eyeglasses with prisms in the lenses, which helped my nervous system to start to calm down, because my eyes were not being so taxed. Further testing was required but I refused, since it made me feel so ill.

I was still not improving, walking with my head facing down, very dizzy and nauseous, could not use a computer and still could not read. My doctor encouraged me to return to continue the testing, which I had been resisting because the testing made me feel so sick to my stomach, and left me dizzy for days. Clear nail polish was painted on the inside of the lenses of my glasses close to the nosepiece, to force my eyes to not look into the middle. That made things much worse, so it was removed, to be replaced in two weeks by slim strips of tape instead. These tape strips on eyeglasses are the universal language by which sufferers of post concussion syndrome recognize a fellow traveler. I either had to explain how I received my concussion when spotted, or attract unknowing stares.

The next step in this journey was more than 40 sessions of vision therapy, going to their office once a week, and practicing vision exercises every day. It was hard work, often very uncomfortable, but ultimately successful.

I was able to read again, at first with a coloured filter to minimize my discomfort, and only a few pages, depending on the font and the brightness of the page. I could use a computer for short periods of time, with a special monitor and was able to again write legibly. I went for walks alone, slowly, for short distances, but at least I could leave my house. I was able to build on all of these skills, pushing myself a bit more each day. I rode an exercise bicycle, five minutes, then seven, slowly working up to the 35 minutes I was used to. The black holes that would appear where words were supposed to be happened less often. I started to notice the negative effects of stress and fatigue on my recovery. Sleep improved, aided by magnesium supplements, which made me less forgetful, and less foggy. My dreams returned to a normal colour.

A concussion can rob you of the feeling that you are smart, that you are a capable adult, that you can be responsible and thorough. The confused state of mind that can occur, the forgetfulness, the fogginess, all of it can serve to make you feel incompetent. I have not been able to return to work. I could not be in a position where I was responsible for other people’s children when I had days when I was barely able to take care of myself. I retired, to take care of me.

I drive much less now, and when I socialize, it must be for shorter periods of time. I have always loved to hike, but at first, even on a short walk, if the leaves were blowing around me, or water lapping on a shore, it would be enough movement to start the nausea. My vision had three issues that needed correction, including my peripheral vision. Once my vision was set off by peripheral movement, I would become very light sensitive, sound sensitive. It could be caused by an uptick in traffic, people walking past me on a sidewalk, riding in a car, the aforementioned fall leaves blowing by, or a crowded, noisy grocery store. In all the concussion information that came my way as a teacher and counselor, I was never told about the possibility of a student’s vision being affected. They should probably all be checked by a neuro optometrist after a concussion but this is not suggested in the protocols our school board gives to counselors and coaches or by doctors who write back-to-school notes for concussed students.

My life has changed. I no longer ask doctors when I will be back to normal. When my neurologist asks me to state a number, a percentage of “normal” that I have achieved, it frustrates me. Instead of looking backwards, I am looking for a new normal, one that can allow me to feel complete again. I am concentrating on my recovery.
My vision has improved; my ability to be in a crowd or to socialize is still hampered by the effects of life’s stresses, but is better. Grocery stores, malls, crowded subway stations are often not comfortable places. Long lunches with a friend can turn negative if the stimulation of the restaurant is too much, or the conversation too intense. I have learned to sit away from windows in public spaces, so traffic going by does not set me off. I plan one thing per day, and try to have unplanned days around events so I can cope.

I have rediscovered meditation, yoga and creativity and this is helping me heal. I try to have creative activity in my life every week. I paint, I write poetry and nonfiction, and I may yet complete that book I started! I am attending physiotherapy still, especially cranial sacral work to ease my neck and head pain. I am seeing a therapist to help me cope with the anxiety and disappointment this brain injury has brought into my life. Soon, gardening will help me to be outside more. I am embracing my new me, a new life path, trying to understand what helps and what does not.

Here are some things that are helping my progress and may help yours:

- Sunglasses – for inside bright lights, outside glare and sun
- Ear buds and music – on walks, listening to music can increase balance
- Noise Cancelling Headphones – to limit airplane noise and outside noise
- Ear plugs for sleeping
- Musicians’ ear plugs: for grocery stores, malls, concerts, plays
- Cervical Neck Traction- Inflatable collar pillow, to help with neck pain
- Hat – large enough to obscure the periphery if that is a problem. Keeps out the sun and other sources of light.
- Kindle – great to read on; typeface changes, font size is adjustable, and the colour can be set to not cause eye strain
- IPAD – to take part in free painting lessons on YouTube
- F.lux – a free download that warms up the colour of a computer screen, easier on your eyes
- Parkwood Pacing Points Program – useful right after a concussion to limit stimulation
- Yoga- especially one-to-one therapeutic yoga, and meditation
- Cranial sacral therapy – very gentle movement to help head and neck
- Vision Therapy - prism glasses, vision exercises
- Exercise - daily walking, recumbent stationary biking, helps to rebuild balance and strength
- Creative activity – knitting, reading, writing, painting, drawing, gardening.
Seeking Participants for A Social Media Study

Investigator: Dr. Lyn Turkstra, School of Rehabilitation Science, McMaster University

Student Investigator: Reihaneh Ahmadi, McMaster University

We are seeking adults with traumatic brain injury (TBI) for a research study. The purpose of this study is to learn how people with TBI use social media, so we can develop technology to make using social media easier for people with TBI and other brain injuries.

You are eligible for the study if you

- Are age 18-65 years
- Are a native English speaker
- Had moderate or severe TBI more than 6 months ago
- Use some kind of social media
- Can see content on a standard computer screen and at a standard-height table

The study takes about 2 hours in one visit and is on the McMaster University Campus. We will pay you $25 and a $10 Tim Horton’s gift card for participating. We also will pay your transportation up to $30 or parking if you drive.

If you are interested in participating, please call

905-525-9140 X 22892
For more information on how to become a Corporate Champion, visit:

www.obia.ca
Call OBIA 1-855-642-8877
Toll-Free Support Line 1-800-263-5404 (HELPLINE)

Brain Injury Associations

**Ontario Brain Injury Association**
Phone: 905-641-8877 or 1-855-642-8877
Toll-free support line 1-800-263-5404
Email: obia@obia.on.ca  Website: www.obia.ca
  - www.facebook.com/OntarioBIA
  - www.twitter.com/OntarioBIA
  - www.instagram.com/OntarioBIA
  - www.LinkedIn.com/company/Ontario_Brain_Injury_Association

**Belleville**
**BIA of Quinte District**
Phone: 613-967-2756 or 1-866-894-8884
Email: info@biaqd.ca
Website: www.biaqd.ca

**Chatham-Kent**
**New Beginnings ABI & Stroke Recovery Association**
Phone: 519-351-0297  
Fax: 519-351-7600
Email: info@newbeginnings-cksl.com
Website: www.newbeginnings-cksl.com

**Dufferin County**
**Headwaters ABI Group (HABI)**
Phone: 519-215-1519

**Durham**
**BIA of Durham**
Phone: 905-723-2732 or 1-866-354-4464
Email: information@biad.ca
Website: www.biad.ca

**Fort Erie**
**BIA of Fort Erie**
Phone: 905-871-7789
Email: biafeoffice@gmail.com
Website: http://braininjuryfe.wixsite.com/biafe

**Hamilton-Wentworth**
**Hamilton BIA**
Phone: 905-538-5251
Email: info@hbia.ca
Website: www.hbia.ca

**London and Region**
**BIA of London and Region**
Phone: 519-642-4539
Email: info@braininjurylondon.on.ca
Website: www.braininjurylondon.on.ca

**Niagara Area**
**BIA of Niagara**
Phone: 905-984-5058
Email: pat@bianiagara.org
Website: www.bianiagara.org

**North Bay Area**
**BIA of North Bay and Area**
Phone: 705-478-8664
Email: contact@bianba.ca
Website: www.bianba.ca

**Ottawa Area**
**BIA of Ottawa Valley**
Phone: 613-233-8303
Email: contact@biaov.org
Website: www.biaov.org

**Peel-Halton**
**BIA of Peel & Halton**
Phone: 905-823-2221 or 1-800-565-8594
Email: biaph@biaph.com
Website: www.biaph.com

**Peterborough Area**
**Brain Injury Association Peterborough Region**
Phone: 705-741-1172 or 1-800-854-9738
Email: biapr@nexicom.net
Website: www.biapr.ca
**Sarnia-Lambton**
**BIA of Sarnia-Lambton**
Phone: 519-337-5657
Email: sarnia.biasl@gmail.com
Website: www.sarniabiasl.ca

**New Beginnings ABI & Stroke Recovery Association**
Phone: 519-491-2668
Email: info@newbeginnings-cksl.com
Website: www.newbeginnings-cksl.com

**Sault Ste. Marie**
**BIA of Sault Ste. Marie & District**
Phone: 705-971-1050
Email: braininjuryssmd@gmail.com
Website: www.soobraininjury.com

**Sudbury and District**
**BIA of Sudbury & District**
Phone: 705-670-0200
Email: info@biasd.ca
Website: www.biasd.ca

**Thunder Bay**
**BIA Thunder Bay & Area**
Phone: 807-621-4164
Email: biatba@yahoo.ca
Website: www.bisno.org/brain-injury-association-of-thunder-bay.php

**Timmins**
**Seizure & Brain Injury Centre**
Phone: 705-264-2933
Email: sabicrl@eastlink.ca
Website: www.seizureandbraininjurycentre.com

**Toronto (GTA)**
**Brain Injury Society of Toronto**
Phone: 416-830-1485
Email: info@bist.ca
Website: www.bist.ca

**Waterloo-Wellington**
**BIA of Waterloo-Wellington**
Phone: 519-654-0617
Email: info@biaww.com
Website: www.biaww.com

**Windsor-Essex**
**BIA of Windsor and Essex County**
Phone: 519-981-1329
Email: info@biawe.com
Website: www.biawe.com

**York Region**
**BIA of York Region**
Phone: 905-780-1236
Fax: 905-780-1524
Email: n/a
Website: www.biayr.org

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**Provincial Associations**

**Brain Injury Canada/Lésion Cérébrale Canada**
Phone: 613-762-1222, Toll free Line: 1-866-977-2492
Email: info@braininjurycanada.ca
Website: www.braininjurycanada.ca

**British Columbia Brain Injury Association**
Phone: 604-984-1212
Email: info@brainstreams.ca
Website: www.brainstreams.ca

**Central Alberta Brain Injury Society (CABIS)**
Phone: 403-341-3463
Email: cabis@telus.net
Website: www.cabis.info

**Saskatchewan Brain Injury Association**
Phone: 306-373-1555 or Toll free (in Sask) 866-373-1555
Email: info_sbia@sasktel.net
Website: www.sbia.ca

**Manitoba Brain Injury Association**
Phone: 204-975-3280 or Toll Free: 866-327-1998
Email: info@mbia.ca
Website: www.mbia.ca

**Ontario Brain Injury Association**
Phone: 905-641-8877 or 1-855-642-8877
Toll free support 1-800-263-5404
Email: obia@obia.on.ca
Website: www.obia.ca

**Newfoundland and Labrador Brain Injury Association**
Phone: 709-579-3070
Email: nlbia2011@gmail.com
Website: www.nlbia.ca/index.php

**Regroupement des associations de personnes traumatisées cranio-cérébrales du Québec**
Phone: 450-575-8227
Email: info@raptccq.com
Website: www.raptccq.com

**Brain Injury Association of Nova Scotia**
Phone: 902-473-7301
Email: info@braininjuryns.com
Website: http://braininjuryns.com/

**Brain Injury Association of Canada (New Brunswick)**
Phone: 506-721-8003
Email: biancb@icloud.com
Website: www.biancb.org

**Brain Injury Association of P.E.I.**
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Website: www.biapei.com
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(705) 647-6330

OTTAWA
Chateau Laurier (by Appt)  
(613) 234-1866
Events Calendar

Various dates
Caregiver Education Program
Support, Hope & Resiliency: An Education and Training Program for Caregivers of Acquired Brain Injury Survivors
Location: various locations across the province
Contact: Nancy LaJoie
Phone: 905-641-8877 ext. 248
Email: nlajoie@obia.on.ca
Website: www.obia.ca/caregiver-education-program/

January 13 - March 9, 2020
Online Caregiver Conversations Group
Online support group to exchange ideas and manage stress
Location: online
Contact: Katy Kumar
Phone: 905-641-8877 ext. 224
Email: kkumar@obia.on.ca
Website: www.obia.ca/online-caregiver-conversations-group/

January 29 - February 2, 2020
UHN presents
2020 Traumatic Brain Injury Conference: Promoting Well-Being Following TBI
Location: Marriott Downtown CF Toronto Eaton Centre Hotel, ON
Contact: Conference Services
Phone: 416-597-3422, ext. 3448
Email: conferences@uhn.ca

February 7, 2020
UHN presents
NDT Introductory Course in the Management of Adults with Stroke, Brain Injury and other Neuromotor Disorders
Location: Toronto Rehabilitation Institute, ON
Contact: Conference Services
Phone: 416-597-3422, ext. 3448
Email: conferences@uhn.ca

February 18-21, 2020
OBIA Training Program
Neurorehabilitation: Assisting Recovery & Function in Everyday Life Following Brain Injury (Level One)
Location: Brock University, St. Catharines, ON
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: training@obia.on.ca
Website: www.obia.ca

March 8-11, 2020
Rotman Research Institute Conference
Aging & Brain Health
Location: Metro Toronto Convention Centre, Toronto, ON
Contact: Paula Ferreira, Conference Coordinator
Phone: 416-785-2500 ext. 2363
Email: conference@baycrest.org

For more listings, check: www.obia.ca/calendar
Providing Quality Rehabilitation Support Services

At Lawlor, our business is providing rehabilitation support services to children and adults with an acquired brain injury or spinal cord injury in Central and South Western Ontario.

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Pathways to Independence specializes in providing services and supports to adults with an acquired brain injury (ABI). These services could be a place to call home or day services designed to support a person living with a brain injury to reintegrate into their community.

Pathways Service Plan supports a person’s rehabilitation and reintegration to the community following a brain injury. In addition to assisting with activities of daily living, Pathways employees actively work with the person to access social networks and community partners to develop and support the implementation of a person’s individualized service plan.

Pathways ABI programs and services are tailored to accommodate individual needs and provide a continuum of care.

Reach out to us to find out more about Pathways ABI Services:
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356 D Woodroffe Ave, Unit 202, Ottawa, ON K2A 3V6  T 613.233.3322
www.pathwaysind.com
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David B. Himelfarb - Managing Partner

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February 18-21, 2020

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- Introduction to Neurorehabilitation: Where brain and function meet
- Foundations of Neurorehabilitation
- Facilitating cognitive function in everyday life
- Behavioural challenges and facilitating participation in life roles
- Relationship building: Supporting engagement in social roles and developing adaptive social networks
- Risk management: Seeking a balance between protection and risk.

Location: Brock University
1812 Sir Isaac Brock Way,
Room: TBA
St. Catharines, ON

Date: February 18-21, 2020

Hotel: Four Points Sheraton 905.984.8484

Professors: Sherrie Bieman-Copland, PhD, C.Psych
Dawn Good, PhD, C.Psych
Deidre Sperry, MSc, SLP

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HELPLINE
1-800-263-5404
Calls answered Mon-Fri, 9am - 5pm EST

We want to hear from you.
Survivors and Caregivers are invited to participate in OBIA’s Annual Research Questionnaire.

Your participation will enhance our ability to provide a greater unified voice on behalf of people living with the effects of brain injury in Ontario.

In appreciation for your participation in our research study, you will receive a free one year dual membership with both OBIA and the participating local brain injury association of your choice and a Survivor Identification Card.

Contact OBIA’s support services to request a copy.

1.800.263.5404
www.obia.ca
WHAT WILL HIS FUTURE LOOK LIKE?

WE’RE COMMITTED TO HELP MAKE THE FUTURE A BRIGHTER ONE FOR YOUR LOVED ONES.

Our full-circle care promise means you won’t be handling these challenges alone and he’ll have the support needed when you’re not around.

Your clients cannot afford to compromise on their recovery, even when insurance limits are capped. We fight to ensure that your clients get funding for the care and treatment that they need.