Troy Lehman loves football. When he isn't working on personal injury cases involving municipal liability and other complex issues, this busy lawyer plays quarterback on the flag football field. Playing quarterback is all about strategizing, getting the ball to your teammates and working to get to the goal line.

As a litigator, Troy knows that careful planning, teamwork and focusing on his clients’ goals is the key to success. Troy is a litigation quarterback, planning the plays and involving the right experts to work in a tight formation. This approach keeps the case moving to the end zone.

There is one other thing you should know about Troy. Whether it is on the football field or in the courtroom, he can't stand to lose. In football, winning is about who scores the most points. In personal injury law, winning is about exceeding your clients’ expectations. As a personal injury lawyer, Troy wins the game when he obtains compensation for his clients that will help them rebuild their lives in a meaningful way.

To learn more about Troy visit www.oatleyvigmond.com/troy
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During this time of uncertainty, we are certain of one thing—we must continue to provide support to those living with brain injury.

By Ruth Wilcock  
Executive Director, OBIA

**RUTH’S DESK**

Connecting in Crisis:

**Finding Our Way Toward Resilience**

I must begin by saying how proud I am to be part of a community who is rallying to meet challenges in unprecedented times. There is no question that during the past several months our world has changed and everyone has been affected by the COVID-19 crisis. For some, home is now the place where work is conducted, while for others, this has meant the loss of their job. For all of the frontline personnel still working night and day, a whole new set of safety protocols, challenges and stresses have been added to their already challenging workload. Furthermore, services for people living with brain injury have taken a sharp turn in how they are delivered in order to strive to keep everyone safe.

At OBIA, we were able to pivot quickly and there was minimal interruption in our services. We have an incredible staff team to thank for their flexibility, ability to adapt quickly, and for their resiliency in a very challenging time. This well-positioned us to continue providing support to survivors of brain injury and their families.

I think of our 21 affiliated community associations across the province, and the public and private services providers, all whose mandate is to provide services and supports to their clients. I have been on numerous teleconferences with these organizations and it is so heartening to hear of the dedication and commitment to ensure that people can be supported, even in this very difficult time.

However, we do know that an extra layer of stress has been put upon caregivers and survivors of brain injury. We hear through our helpline, the new struggles that people living with brain injury are facing.

In-person day programs have been halted, reduced in-person supports and lack of respite for caregivers are some of the disruptions that have occurred. This has not been an easy adjustment.

Feelings of isolation have increased for everyone; however, there has been an exponential increase for those living with brain injuries—as one survivor
said, “welcome to our world”. For caregivers whose loved ones are in residential settings or long-term care facilities, they may feel that they are a world apart from each other.

And yet, somehow through this storm, people are finding new ways of being together and connecting. This is why our helpline is so important, why services being carried out virtually are paramount, and the personal calls being made from local associations to their members are literally a lifeline.

During this time of uncertainty, we are certain of one thing—we must continue to provide support to those living with brain injury. We must continue to bring awareness to the public about brain injury.

June is Brain Injury Awareness Month and in past years a variety of wonderful initiatives were carried out across the province. Walks, runs, art gallery showings, entertainment nights and events in parks are just some of the activities that took place, usually in public settings, as we endeavoured to make the “invisible visible”, bringing awareness and education about brain injury.

This year we continue to strive to make the “invisible visible” but it will be in different ways. Throughout the month of June, we are highlighting the Unmasking Brain Injury project. Each day, one mask, along with the story of the person who created the mask, will be highlighted on our website and social media.

We must continue to heighten the awareness of those living with brain injury. Even during this trying and challenging time, it is important to remember that as a brain injury community, we are stronger together. This is not a trite saying, but it is how we can maintain resiliency in the time of storm.

The road to recovery is right ahead.

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Scientific research helps to answer some of society's greatest challenges; however, much of it is conveyed with technical language in journals that many people cannot access. What is more, when research is communicated in the media, it is sometimes oversimplified or overgeneralized, giving false hope to the public.

It is important to have a realistic understanding of basic science to make informed decisions. Here, we describe three innovative Traumatic Brain Injury (TBI) studies that warrant further investigation by scientists in the coming years.

**Nanoparticle Treatment Could Prevent Brain Swelling in Traumatic Brain Injury**

Following a TBI, the body produces an inflammatory response to the injured brain cells. By causing brain swelling, this inflammatory response can inflict secondary damage to the brain.

Recently, researchers at Northwestern University identified a powerful nanoparticle therapy as a possible preventative treatment for brain swelling after injury\(^1\). The nanoparticles in this treatment were intricately designed to trick the body's immune system into attacking them rather than the injured brain cells. By delivering these nanoparticles into the brain, the researchers hoped to prevent the body's immune system from causing secondary brain damage.

In this study, mice with TBIs were given three injections of nanoparticles beginning two to three hours after injury. After treatment, these mice showed less brain swelling and damage compared to mice that were not treated with the nanoparticles. The treated mice also showed better functional outcomes, including improved long-term motor function.

If supported in additional animal trials and in human trials, nanoparticles could be an exceptional preventative treatment for individuals immediately after a TBI. Although this treatment would not undo the damage from the initial injury of the brain, it could significantly reduce secondary damage from brain swelling.

**Brain Chilling Shows Promise as a Concussion Treatment**

New research from the University of Wisconsin-Madison shows that in the future, concussions could be treated by simply chilling the brain\(^2\).

Following a traumatic impact to the brain, some of the damage is caused by biochemical signals in the cells that trigger deterioration in the brain and loss of function. In this study, researchers sought to determine if they could limit these damaging biochemical signals by chilling brain cells after injury.

To simulate concussed brain cells, researchers grew brain cells in a dish and then injured them with a mechanical force. They then tested these cells to determine if they could lessen some of the damage by cooling them.

Encouragingly, the researchers found that using a very specific set of guidelines, the cooling treatment was successful in preventing some of the damage. Specifically, the team needed to ensure that they hit a precise temperature of 33°C and that they did not wait too long after the injury to cool the cells.
Since this study investigated isolated brain cells on a dish, it is unknown if the cooling treatment would also be successful in complex living systems. It is also unclear how clinicians could limit the cooling to the brain while keeping the rest of the body at a normal temperature. Because of this uncertainty, brain cooling therapy must be further developed in animal and human trials before it can be offered to concussion patients in the clinic.

Investigating the Role of Genetics in Pediatric Brain Injury Recovery

In response to very similar TBIs, individuals often show strikingly different outcomes. However, the reason for this variation is largely unknown.

One possible explanation for some of the variation is differences in the availability of an important gene called Brain-Derived Neurotrophic Factor (BDNF). The BDNF gene provides instructions for making a protein that promotes the survival of brain cells. For unknown reasons, the BDNF gene can be chemically changed through a process called ‘methylation,’ making it harder to access and thereby produce the protective protein. The level of methylation is different from individual to individual.

While recovery can be unpredictable, those who have experienced significant childhood adversity tend to have worse outcomes following a TBI. Researchers predict that higher levels of BDNF methylation and a reduction in the protective protein is responsible for at least some of this poorer outcome.

To test their theory, researchers from the Children’s Hospital of Pittsburgh are currently conducting a study on 200 children aged 3-18 years with a TBI. Participants provide blood and saliva samples 6- and 12-months post-injury, allowing researchers to measure their levels of BDNF methylation. Using this information, the researchers plan to see if there is a connection between levels of BDNF methylation, recovery outcome, and childhood adversity.

Once it is complete, researchers hope that this study will help them to better understand why some children display a good recovery following a TBI, while others do not. Ultimately, this better understanding will lead to superior treatments and diagnostic tools.

References


The Changing Landscape of COVID-19

By Lauren Hough and Leah Mills, OBIA

Since January, daily life for Canadians has changed dramatically, leaving many people feeling isolated and alone. Although Canada has been fortunate to not have experienced the same devastation as many other countries; the closure of businesses and cancellation of in-home support to reduce the spread of the virus has left many more vulnerable than ever before. This is especially true for those living with a brain injury, caregivers and their family members. For many, the loss of in-home supports and day programming has led to a regression in recovery for those with a brain injury and added stress on caregivers to meet all of their loved one’s needs with minimal support.

What is COVID-19?

COVID-19 is part of a large group of viruses called coronaviruses. Humans have known of this family of viruses for many years and the virus typically does not cause more than mild flu-like symptoms. However, coronaviruses have been the source of widespread epidemics such as SARS-CoV and MERS-CoV (Public Health Agency of Canada, 2020).

COVID-19, typically causes mild respiratory symptoms to those who are infected; however, there are groups of our population who are much more vulnerable to this infection and may become severely ill. These include older adults, those with underlying medical conditions (heart disease, COPD, cancer, diabetes, etc.), and those who are immunocompromised (e.g. those with autoimmune disorders, people receiving chemotherapy, etc.) (World Health Organization, 2020).

There is one question that many people have – how is COVID-19 different from influenza? There are several factors that make COVID-19 more dangerous than the seasonal influenza. Firstly, COVID-19 has a longer incubation period ranging from 1-14 days in comparison to influenza, which typically has an incubation period of 2-4 days (World Health Organization, 2018, 2020). This means that the time between when a person is infected and when they experience symptoms is longer. As a result, individuals may be out in the community and spreading the virus before they know they have it.

What Can I Do?

As our neighbours, friends, family members and notable figures like Pink, Boris Johnson, and Tom Hanks are diagnosed with COVID-19, we are able to see that the virus does not discriminate. COVID-19 is spread by a cough or sneeze, close physical contact, or touching something a person with COVID-19 has touched before you. The following are ways you can help protect yourself, your family and your community during this pandemic.

Unfortunately, unlike influenza, a vaccine for COVID-19 has not yet been developed and currently no treatment is available other than supportive care. The above strategies will help you minimize your risk of getting the virus; however, if you are experiencing any of the following symptoms, please contact your local public health agency to determine if you should be tested for COVID-19 (World Health Organization, 2020). Symptoms of COVID-19 are as follows:

If you are suspected of having COVID-19, it is important that you self-isolate for 14 days immediately or until told otherwise by a health care professional. Self-isolating means remaining at home (except for medical care) and limiting your contact with others, including those within your home. If you are instructed to self-isolate, others in your home must remain at home in isolation as well (Public Health Agency of Canada, 2020).
Coping with the “New Normal”

As the months progress and social distancing continues, it is important to develop strategies to help manage the stress associated with our “new normal”. Below are some strategies that you and your loved ones can use to help cope during these unprecedented times (Centre for Mental Health and Addictions, 2020).

- Accept that your fear is normal during these challenging times
- Practice relaxation and mindfulness techniques
- Eat healthy and stay active as much as possible
- Get outdoors while maintaining a safe distance from others
- Seek accurate information:
  - The Government of Canada has released a COVID-19 app that keeps you up to date with statistics, resources, and news.
  - Other trustworthy sources of information are the World Health Organization, the Public Health Agency of Canada, and the Ontario Ministry of Health.
- Limit how often you seek updates about COVID-19 during the day as it can become overwhelming and unsettling
- Take measures to reduce your own and your family's risk of becoming infected
- Avoid substance use as a means of coping
• Seek support from friends, family or a support group:
  • Use the phone or video messaging to check-in with your friends and family.
  • Many local brain injury associations are still offering virtual supports to their members.
  • The OBIA Peer Support Program and Helpline 1-800-263-5404 are also available to help support you during this time.

• Brain Injury Canada has a Guide for Mental Health during COVID-19 on their website at: www.braininjurycanada.ca/guide-mental-health-covid-19

As we continue on this journey together, we need to come together as a community and help support one another through these challenging times. If you have questions or need a listening ear, please call the OBIA Helpline at 1-800-263-5404 for support.

References


There is hope, there is help!
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Two years ago, if you asked me what a concussion was, I probably would have said, “a sports injury that occurs when you hit your head.” Boy, was I ever naïve. May 28, 2018, one blow to the head changed my life. Since then, I have been listening to the stories of hundreds of others who have suffered head injuries, spent hours in treatment rooms and done everything in my power to change the future of brain injury.

I never really understood the implications that a concussion could have on quality of life. For the past two years, I have been living with post-concussion syndrome. Enduring chronic headaches, noise and light sensitivity, dizziness, extreme fatigue, brain fog, neck pain, mood disturbances, hormone imbalances, and poor concentration have impacted me greatly. Having a brain injury has shifted my sense of normality more than I ever imagined it would. It has affected my education, ability to work, social interactions and relationships. I had always identified as a strong student, someone who loved education and a person that could manage multitasking. I was the girl who worked two jobs, exercised daily, was working on two-degree programs and maintained a hearty social life. Suddenly, that was all taken away. I had to make the necessary adjustments to every aspect of my life in order to cope. Finishing my education was my biggest concern. When I acquired my brain injury, I was heading into my second year of Naturopathic Medical School. I had to move back home with my parents and adjust to new financial limitations. I had to make the very difficult decision to go part-time with my studies and get medically supported accommodations to ensure academic success.

I never imagined that I would be a chronic pain patient. In attempts to regain control of my life, I explored every available treatment opportunity and medical rehabilitation avenue. I have seen more than twenty different health care providers, including: physiotherapists, chiropractors, naturopathic doctors, neurologists, medical doctors, psychologists and massage therapists. I see value in seeing a diverse set of practitioners and exploring different approaches to medical care. I truly believe in a holistic approach to healing and individualized care. I am beyond grateful for all the healthcare providers who have guided me through this unpredictable and extensive journey. I encourage others to continue to keep an open mind to services and treatments, make educated decisions about healthcare needs and find practitioners who are knowledgeable about brain injuries.

After my accident, aside from the challenges I experienced with school and work, I struggled with leisure activities. The lifestyle I was living was no longer my reality. After many failed attempts of returning to activities I once enjoyed, my practitioners suggested I try something that wouldn’t require detail orientated brain function. I had never been a crafty person, but out of desperation and desire to find something that helped pass the days, I had my sister drive me over to the local craft store. Here, we wandered up and down the aisles looking for something I could do. All the unfamiliar options seemed overwhelming - colouring books, knitting, candles, scrapbooking, and painting. It was when I walked through the jewellery section that I thought, “maybe I could make bracelets?” I had always worn gemstone bracelets and I figured this was the perfect opportunity for me to learn how to make my own. I bought some cord and a few strands of gemstones and off we went. Needless to say, I became addicted. Every two or three days we would make it an outing, wandering back to the craft shop to refill my supplies. Each time I got a little more adventurous in my selections and I was picking up more and more materials. Beading became a saving grace for me; something that I looked forward to doing. When I was making bracelets, I was so focused on putting the bead on the string,
There is hope for a better tomorrow.

Thomson Rogers is dedicated to getting accident victims the compensation and support they deserve.
picking colours and matching the stones that I wasn’t focused on my pounding headaches. I felt good learning a new skill, a skill that I couldn’t compare my old abilities to.

Bracelets started to pile up; I was running out of friends and family to make them for. When I had started bracelet making, I had no intention of selling them. Quite honestly, I really didn’t think anyone would even want to buy them. My roommate from university had come to visit me and she convinced me to post them for sale. I reluctantly posted them on my personal social media and explained how this had become a new hobby of mine. The response I received was remarkable. So many kind people reached out to support my bracelet making and encouraged me to create a separate account for bracelets. This really got my wheels turning; I started envisioning this “business” I could create. This was an opportunity for me to continue to make bracelets, explain my experience with brain injury and use left over money to donate to foundations that could advance concussion research and recovery. I had no idea how to start a business… I was a science student. So, I started picking people’s brains, reaching out to companies to which I could donate and finally took a leap of faith and created an instagram page, @beadsforbrains.

I felt vulnerable exposing myself to the world on such a public platform. With time, I started to share my journey and the raw realities of living with a brain injury more openly. I continue to use this social page to post pictures of bracelets, share tips and connect to a whole world of individuals who are, like me, suffering. Bracelet making, which started as an outlet, has become an integral part of my recovery. The entire process, from the actual assembly of the bracelets, the content of each post, and the conversations that follow, has created a sense of support and community. I am so thankful for all the people that Beads for Brains has connected me to. With every bracelet sold and the abundance of heart-warming messages of encouragement I receive, I find strength to continue this fight.

I never imagined that so many people would resonate with my message. I didn’t foresee Beads for Brains being sold in shops, being mailed all around the world or that I would be writing this article. I am truly humbled. To date, through the sales of bracelets, we have donated over $4,000 to different organizations that support brain injuries and that are paving the way for the future of neurological conditions. Sharing my story, selling bracelets and donating money, has given me something that my brain injury took away from me: the feeling of purpose.

I like to think that I am functioning at 75% recovery, with full hopes of a complete recovery. I really saw a shift in myself once I learned the value of acceptance, patience and time. I have good days and bad days. When I start to overexert myself by committing to more than I should or shifting away from consistency, I find myself in a flare up. I have found peace and appreciation for this new pace of life. For anyone on this journey, I know it isn’t easy, but we have got to take initiative and accountability for our own health and well-being. Despite the challenges, I really do think that routine with diet, treatment, exercise and sleep is what allows me to function on a day-to-day basis. I often think that we underestimate the significance that we have in our own recovery—healing starts from within.

If I can give readers advice, it would be, “you are worthy of a full recovery.” Suffering from an invisible injury, can be extremely gruelling. You have to be your own advocate. My wish for you is that you won’t settle for mediocre health, that you’ll stop identifying with your challenges and that you find the strength to continue on. You aren’t alone and I encourage you to utilize the individuals and services that are available to support you through this process. Keep positive and optimistic. Try and accept each new day with the unique challenges and successes that may come. Celebrate the small things. Don’t compare yourself to others. Be okay with uncertainty. Be proud of who you are. Most importantly, remember you are resilient!
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.
Clinical Practice Guidelines (CPGs) are evidence-based statements to assist with the diagnosis and treatment of medical conditions. They help to ensure that patients receive appropriate and high-quality care (Institute for Quality and Efficiency in Health Care, 2016). CPGs include recommendations that are supported by “the best available evidence and are supplemented with clinical expertise and patient preferences” (Health Council of Canada, 2012, pg.3). In most cases, CPGs are developed for healthcare providers; however, the information they provide can improve patients’ understanding of their care and facilitate patient-provider communication.

As a leader in moving research to evidence-informed practice, the Ontario Neurotrauma Foundation (ONF) identified a need for CPGs for traumatic brain injury. Working closely with healthcare providers, researchers, and stakeholders, ONF steered the creation of three sets of clinical practice guidelines for the management of all severities of traumatic brain injury. These guidelines include recommendations, clinical tools, and resources for every stage of traumatic brain injury care including diagnosis, treatment, and rehabilitation. In 2012, ONF published the first edition of the Clinical Practice Guidelines for Mild Traumatic Brain Injury (mTBI) and Prolonged Symptoms (Marshall et al., 2012). The second and third editions of the CPG were published in 2015 (Marshall et al., 2015) and 2018 (Ontario Neurotrauma Foundation, 2018), respectively. Identifying a gap in concussion CPGs for children and adolescents (ages 5-18 years), ONF initiated the Guideline for Diagnosing and Managing Pediatric Concussion (Reed, Zemek et al., 2019). This guideline was first published in 2014, with the most recent update taking place in 2019. ONF’s third CPG, Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury, was released in 2016. To increase the accessibility of the guidelines, patient-specific guides and resources were also developed and ONF is working towards having CPGs available in French as well. Please see Table 1 for a summary of each guideline along with its resources.

Providing up-to-date and evidence-based guidance to healthcare professionals, service providers, patients, and families is one of ONF’s fundamental priorities. In recognition of the rapid increase in new literature related to concussion and traumatic brain injury, ONF is currently transitioning its three CPGs to a “living guideline” format. A living guideline involves the dynamic and continuous updating of recommendations as research supporting change in clinical practice becomes available. Our living guidelines will be developed and maintained in an interactive digital format through an ongoing process of review, evaluation and revision of research and clinical evidence by a group of clinical experts. In practice, this means the guidelines or parts of it could be updated as often as every few months. The Living Guideline for Diagnosing and Managing Pediatric Concussion was the first
The 2020 Awards of Excellence in Brain Injury Rehabilitation

The Ontario Brain Injury Association (OBIA) in collaboration with the Personal Injury Alliance (PIA Law) are pleased to present the 2020 Awards of Excellence in Brain Injury Rehabilitation. These awards are meant to recognize exceptional service to the brain injury community in the following categories:

- Hospital Social Worker
- Case Management
- Health Care Provider
- Community Brain Injury Association
- Rehabilitation Company

Nominations for the Awards of Excellence can be made online from June 1, 2020 to July 31, 2020.

Voting for the selected nominees will take place online from August 3, 2020 to August 31, 2020.

The recipients of the Awards of Excellence will be announced mid-September 2020.

To nominate, vote or for more information about the Awards of Excellence, visit: OBIA.ca or PIALAW.ca
of ONF’s CPGs to be converted in 2019, with plans to release the living Guideline for Mild Traumatic Brain Injury (mTBI) and Prolonged Symptoms and Living Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury underway (expected completion in 2020).

### Frequently Asked Questions

**Is it mandatory for healthcare providers to follow clinical practice guidelines?**

While they are not mandatory for healthcare providers (HCPs) to follow, clinical practice guidelines (CPGs) provide the most up-to-date evidence for HCPs to identify and treat traumatic brain injury (TBI) effectively. As the Ontario Neurotrauma Foundation’s CPGs transition to a living format, they will be updated frequently as new evidence emerges. It is recommended that HCPs adopt the CPGs as their guiding principles for diagnosing, treating, and managing TBI. This promotes consistency of care throughout the rehabilitation process and across different providers, which further supports the principles of equity and access to best practice care for TBI patients.

**How are clinical practice guidelines developed?**

The ONF CPGs were developed by experts in the field of brain injury through a rigorous review process. First, the existing scientific research was evaluated by multiple appraisers/individuals to determine the quality of the research evidence and to identify relevant CPG recommendations. The feedback and concerns of the end-users (TBI rehabilitation professionals and persons with lived experience) were then considered using a needs assessment, which guided the development of the format and components of the CPGs. Next, the relevant evidence was compiled and compared, and a consensus conference of professionals was held to develop the evidence-informed CPG. Further steps were taken to finalize the recommendations, determine recommendation priority, generate supplementary text to accompany the guideline recommendations and identify key supportive tools and resources. To learn more about the development process, please visit the website: [https://braininjuryguidelines.org/modtosevere/methods/steps/](https://braininjuryguidelines.org/modtosevere/methods/steps/)

**Can I use the clinical practice guidelines to diagnose and treat my TBI?**

Patients and clients should not use these guidelines for self-diagnosis or treatment. The CPGs are not a substitute for seeking medical care. Anyone with a suspected TBI should receive a medical diagnosis by a qualified professional (either a physician, nurse practitioner, or neuropsychologist). Patients can, however, use the CPG as a tool to educate themselves about their brain injury and advocate for their care. Patients can use these guidelines to understand what to expect throughout their brain injury rehabilitation, from the initial assessment to the long-term treatment and management of the TBI. If your healthcare provider is not using these guidelines, you can bring this information to them and discuss it together at your appointments.

**Where can I access the brain injury guidelines?**

The guidelines are available at [www.braininjuryguidelines.org](http://www.braininjuryguidelines.org). See full links to each guideline below:

1. **Guideline for Concussion/Mild Traumatic Brain Injury (mTBI) and Prolonged Symptoms – 3rd Edition, Adults (18+ years of age)**
   - **Link:** [https://braininjuryguidelines.org/concussion/](https://braininjuryguidelines.org/concussion/)

2. **Living Guideline for Diagnosing and Managing Pediatric Concussion**
   - **Link:** [https://braininjuryguidelines.org/pediatricconcussion/](https://braininjuryguidelines.org/pediatricconcussion/)

3. **Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury**
   - **Link:** [https://braininjuryguidelines.org/modtosevere/](https://braininjuryguidelines.org/modtosevere/)
About the Ontario Neurotrauma Foundation

The Ontario Neurotrauma Foundation (ONF) is a non-profit organization funded by the Ontario government that works to prevent neurotrauma and ensure Ontarians with spinal cord and brain injuries lead full, productive lives. ONF is the leader in moving research to evidence-informed health practices that improve the quality of life and health outcomes. Through collaborations and partnerships, ONF connects healthcare practitioners, researchers, policymakers and stakeholders including those living with neurotrauma to the information they need to make positive changes in health practices, outcomes and policies.

Acknowledgements

Many thanks to the executive committees, expert panelists, external reviewers, stakeholders, and persons with lived experience for their involvement and contributions to the Ontario Neurotrauma Foundation brain injury guidelines.

References


*these two authors contributed equally.

SUPPORT

ONLINE CONCUSSION SUPPORT GROUP

Have you recently sustained a concussion or suffer from post concussive syndrome? Are you struggling with headaches, fatigue, depression, anxiety, memory issues, or you “just don’t feel right?”

You are not alone! We are here to help!

Next sessions start in September, 2020.
For more information, visit: www.obia.ca/online-concussion-support-group/

Funding Provided by:
OBIA's online support group can be especially helpful for participants who are living with a mild traumatic brain injury, also known as concussion and persistent post-concussion syndrome, who need education, awareness, resources, and emotional support.

Most group members who are experiencing concussion symptoms, have had increased symptoms with the pandemic and it has impacted their physical and mental health. Almost all of them reported mood changes (anxiety and depression), increased confusion, and difficulty sleeping. One thing that many group members have shared is a feeling of added isolation and fear of unknown circumstances of the future. They are also looking for more support from community resources, friends, and loved ones. However, group members have stated that the online concussion support group has been one of the most important support systems to connect with others who share similar experiences.

With these groups, OBIA has created a safe place where group members can share their struggles and connect with others who have had similar experiences. A registered social worker facilitates the group and provides support in addition to resources to help with emotional recovery. The groups are limited to a small number to allow for greater discussion and interaction. The facilitator ensures that every member is respected and heard. These groups run for 60 minutes per week for eight weeks. Participants can join the group by computer or phone. Individual’s privacy is of the utmost importance and we use a secure online platform that maintains the confidentiality of groups.

Since September 2018, OBIA has hosted 31 separate groups. In these support groups, we have had a total of 330 individuals participate.

Focus Groups - Level Two- CBT/Anxiety

OBIA has continued to support level two concussion members with anxiety symptoms. This group is offered three times a year (September, January, and March) and participants must commit to attending all sessions.

Participant Post Survey feedback:

“As sad as it was to see others suffering with concussions symptoms, it was good to know that I am not alone and not the only one going through this. I could not have gone to a support group in person because it would ramp up my symptoms and I would crash for days afterwards. This is an excellent way to provide support for people who find the extra stimulation of meeting with a group, plus the travel to the destination, too difficult, and the cost too great to be able to attend in person.”

“Thank you so much Vijaya! It was so helpful to not only share experiences with others who have undergone a concussion, but the resources you provided are so incredibly helpful! I will go back and use them again as I work towards getting back to work in the summer/fall.”

“When I had my concussion six years ago, there was not much information readily available. I have spent the last couple of years stressing about my invisible injury that nobody could see or understand. I cried when I watched the video of what happens when you get a concussion. It made it real! I have had so many self doubts and such low self esteem; this group has really helped me learn there are others out there suffering as I am. You were a terrific facilitator and introduced so much helpful material. Thank you so much for helping me feel more “normal”.”
Get Connected with Peer Support

“I want to give back and help others who are trying to cope with their brain injury.”

“This program has made me understand I am not alone.”

OBIA’s Provincial Peer Support Program connects persons with lived experience (the Mentor) with an individual who is living with the effects of acquired brain injury and who requires support (the Partner). This program is available to survivors, family members and/or unpaid caregivers.

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PROUD SPONSOR OF SPINAL CORD INJURY ONTARIO AND THE ONTARIO BRAIN INJURY ASSOCIATION
Across the Province

OBIA Advisory Council (OAC) Report

The last meeting of the OAC was held on Saturday, March 25, 2020 and was held online.

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 on their status during the COVID-19 pandemic. Where reports for the OBIA Review were not available, the local information was taken from the OAC meeting minutes:

BIA Sarnia Lambton

Along with the rest of the world, COVID-19, has impacted most of our programs and services without warning. Within hours, our monthly lunch outing was canceled to err on the side of caution and prevention. Like so many others, some of our primary fundraisers have also been canceled or postponed. Our annual golf tournament, scheduled for the end of May is now set to tee-off on May 27, 2021. Our agency participation in a local fundraiser, Race to Erase has been tentatively rescheduled for September 26, 2020.

The highlight of this quarter was receiving a $5,000 Compassion Fund grant from the United Way of Sarnia-Lambton. This grant has allowed us to provide more than 100 individuals and/or families with food gift cards to help them through the challenging time of the COVID-19 pandemic. Words cannot describe the level of appreciation our members relayed in receiving this support. Funding was also earmarked for transportation needs, supplies and access to mental health supports.

In April, we participated in the Peer Mentor training, using the Zoom platform for the first time. It proved to be quite successful and met the goal of training new mentors, who are ready to support those with brain injuries. Exercise and mental health go hand-in-hand. During the month of May, we provided bike helmets to our members, in an effort to promote safety in our community.

On a weekly basis, we are connecting with our members via FaceTime, as a substitute for our Tuesday coffee hour. Regular contact is also being initiated by text messages, phone calls, emails and a good old fashion snail-mail greeting card. Our members continue to be amazing during this incredibly challenging time – resilient, grateful and optimistic for the future!

BIA Windsor-Essex

The Brain Injury Association of Windsor and Essex County has moved all its in-person meetings to virtual meetings through the Zoom platform. This has proven to be a bonus for some members who have had a difficult time going to regular meetings due to transportation issues.

We have added a new weekly “Coffee Chat” to allow members to speak with their friends and the acquaintances they have made at the support groups. This is quite popular and helps reduce social isolation. Members have commented on how much calmer they feel after these sessions. The last monthly Survivor Social was organized in the style of a “story slam” whereby participants prepared and presented a five-minute talk on a pre-selected topic. This month it was “My First Job”. It was delightful to listen to these stories and everyone felt quite entertained.

Volunteers have been calling members to find out how they are doing, listen to their concerns and comfort them in knowing that we care how they are doing through this pandemic. The Board of Directors has been using this down time for evaluating all our programs and planning our association’s strategy for the next five years.

BIAWE has a new office as of March 1 (photo above). However, two weeks after we moved in, we had to move out! We look forward to when we can return and host all our support groups and activities there. This location is on a bus-route, is wheelchair accessible, has parking and several rooms in which to hold our meetings.

Despite the current situation we all find ourselves in, BIAWE continues to thrive and enhance the lives of those affected by an acquired brain injury.

Hamilton BIA

We are open virtually to serve our members. We are operating a Warm Line, hosting virtual support groups and programming and launched a resource list on our website for our members to keep busy and engaged.
BIA Durham

Durham region is continuing their work remotely and the staff meet each morning virtually. By offering virtual programs through Facebook, BIAD is continuing to connect with and support their clients daily. Also, since food supply has become a problem, they are delivering food to their most vulnerable.

BIA Quinte District

The Quinte office is closed to the public, however, the Executive Director still works at the office every day. They are also working with Food Banks and they are starting a Facebook chat for their members to connect.

BIA Peel-Halton

Peel has canceled all programs until the schools go back. They are looking into using Zoom to offer virtual support groups. They are also looking into offering client supports virtually. BIAPH continues to check in with clients regularly. Their conference and fundraiser has been postponed until the fall and dates are still to be determined.

BIA Peterborough Region

Peterborough has had to cancel their in-person programs. All programs that can be, are run virtually. They are using Microsoft Teams and will be looking into Zoom for their groups. They have redeployed the staff. As with everyone, the staff are feeling isolated.

BIA Sarnia Lambton

Sarnia has also closed their offices. They will be checking messages and email daily. They will also look into Zoom for support groups. Community supports are helping their members while the office is closed.

BIA Waterloo-Wellington

Waterloo is working remotely. All in-person support groups and fundraisers have been cancelled. The staff meet weekly via Zoom, and Waterloo is looking into a live feed for their conference.

BIA Sudbury & District

Sudbury had to cancel their joint fundraiser with March of Dimes Canada. Their office is closed and they sent OBIA's contact information to their clients. They are monitoring calls and emails. Support groups are on hold but they are looking into other ways to have support groups. They are also looking at the makeup of their Board of Directors.

BIA York Region

York Region has always done things remotely. They thanked OBIA for offering the use of the OBIA helpline for their callers. They also had to cancel their fundraisers.

BIA North Bay & Area

The North Bay office is closed, however, they are working remotely and contacting clients. Their phones are redirected. North Bay is working on live tutorials for art classes. They have reached out to their mentors and partners participating in the Peer Support Program. Most Mentors are willing to work with their partners for longer as needed.

BIS Toronto

Despite the limitations of the 2020 pandemic COVID-19, we have remained resilient and continue to offer our members and the community a wide variety of programs and support during this difficult time.

Our multi-faceted services include offering free telephone support; which acts as a both a resource and warm line during weekday business hours. To ensure our members health and well-being is put at top priority, BIST staff has continued extensive communication with members via text, phone call, email, and video through the platform Zoom. In addition, we have various staff members, personally picking up and delivering resources to and from our clients’ residences, while ensuring we still practice social distancing. We have been fortunate to receive help from our community and have volunteers assist us in hosting virtual tax clinics for our members to access.

BIST has been providing educational webinars on pertinent topics such as Community and Government Resources, Mental Health & Coping Strategies, Fraud and Financial Abuse Education and Wellness, such as online yoga. All these webinars are available for anyone to see and can be viewed at www.bist.ca/webinars.

BIST is excited to share and announce that we have a new free online youth support group for ages 15-20 years, called W.R.A.P (Wellness Recovery Action Plan), facilitated by our very own Violence Impact Coordinator. If you’d like information on joining this group please contact isabelle@bist.ca

BIST’s support groups have moved online and we are continuously updating an abundance of resource materials on our website. These resources include: options of food delivery services, free food access programs, housing support, brain injury services, financial aid, mental health services, legal resources, self-care tips, leisure activities, educational courses, and COVID-19 health and safety tips. Questions about any of our programs? Contact info@bist.ca

Challenges that BIST has faced during the pandemic is in transitioning our in-person services, to now online support. We acknowledge the inevitable difficulties that come with transitioning the operations of services, and its effect on our community.

BIST unfortunately has had to reschedule our fundraising events to a later date, right now they are scheduled as follows: Mix and Mingle on September 9th, Birdies for Brain Injury Golf Tournament September 18th, and BIST Hero 5K Run on September 27th. Of course these dates will be continually re-evaluated to ensure we are following provincial protocols and keeping everyone safe.

Please continue to visit www.bist.ca for updated resources, programs, and updates.
Leah Mills began her position with Support Services in February 2020, with the completion of OBIA’s Neurorehabilitation: Assisting Recovery and Function in Everyday Life Following Brain Injury (Level 1) Brock Certificate Training Program. She is involved with the HelpLine, answering calls to provide ABI individuals, families and professionals with the information and support they require.

Before starting at OBIA, Leah completed a Bachelor of Science (Honours) at Brock University. She was involved with student practicums at the Brock-Niagara Centre for Health and Well-being and Hotel Dieu Shaver Health and Rehabilitation Centre where she assisted with stroke rehabilitation programs and discovered her passion for the ABI community.

Upon completion of her undergraduate degree, she enrolled in a Master of Public Health Program at Brock University to further her understanding of protecting and improving the health of people and their communities. She completed a student practicum and was subsequently hired at Behavioural Supports Ontario. In this role, Leah was involved with the Transitional Lead program that is designed to help individuals with dementia transition from their community home into Long-term Care. Through this opportunity, she discovered the challenges that individuals and families face with regards to navigating the health system in order to receive the appropriate support they require.

“It’s about empowering individuals by providing them with information on what services are available to support them and how to go about accessing them. That’s what is so great about the OBIA Help Line, it offers guidance to individuals and families who may be struggling with what services are available or where to go for help.”

Leah is passionate about OBIA and helping individuals and families navigate the health system so that they are able to access the necessary services to aid in their recovery with ABI. She looks forward to assisting you with any questions or concerns you may have about brain injury.

Solene Abdulla, Research Coordinator

Solene began her position at OBIA in February 2020 as a Research Coordinator, focusing mainly on OBIA’s community-based studies.

Before working at OBIA, Solene completed both a bachelor's and master's degree in biochemistry at McMaster University. At McMaster, Solene dedicated nearly four years to conducting stem cell and cancer research in the laboratory. In addition to laboratory-based research, Solene volunteered as a Research Assistant at Hamilton Health Sciences, where she also found a passion for clinical and community-based research.
While at Hamilton Health Sciences, Solene worked on a study that investigated brain injuries in elderly patients in the emergency department. This study illuminated the high incidence of brain injuries in her community and ultimately sparked her interest in acquired brain injury. Solene is extremely passionate about supporting her community through research and is thrilled to be one of OBIA’s newest team members.

When Solene is not at work, she enjoys trying new recipes, staying fit, and going on road trips.

Téa has always been interested in working in the Social Work field which led her to graduate from Canadore College with a diploma in the Mental Health and Addictions program. Afterwards, she began her career working with women fleeing violence at a women’s shelter. While working at the women’s shelter, she responded to crisis calls, provided direct support to women in a self-identified crisis and designed and delivered many presentations to the local schools to educate high school students entering post-secondary education. Téa has gained most of her experience working frontline with those who are homeless, experience intimate partner violence, and as a case manager.

She is currently studying at Carleton University to obtain her degree in Social Work and plans on continuing her education afterwards. She is very interested in learning more about acquired brain injury and is excited about her career with OBIA.

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Brain Injury Speaks Survey 2: Accessing Primary and Virtual Care

Summary of Qualitative Responses

Survey Overview

In March 2020, we asked members of the Brain Injury Speaks Stakeholder Engagement Network three questions about primary care and virtual care. Approximately 25% of the network (122 members) responded to the survey. A fourth, open-ended question was included at the end to provide participants with the opportunity to comment further about their experience with primary care/family doctors and virtual appointments. 75 participants used this open-ended question to describe their experiences.

Summary of Comments

The qualitative findings are presented in three sections: 1) Virtual Care, 2) Primary Care/Family Doctor, and 3) Other. The themes within each section and supporting quotes are described below.

Virtual Care (n=10). Two themes emerged: supporting virtual care, and hesitance about virtual care. Most comments were in support of virtual care, as most participants felt that virtual appointments would save time, reduce stress, improve access, and save money. Three participants highlighted the complex nature of brain injury as a barrier to accessing virtual care. One participant expressed that they are not interested in virtual care because of trouble with spending time on screens.

Quote – supporting virtual care: “Virtual appointments would be valuable given that I have not been able to find a primary care doctor in my city and have to travel to Toronto (a 1.5 hour drive) to see her for anything. During my worst times post-injury I had regular appointments every week. That would be very difficult now.”

Quote – hesitant about virtual care: “The virtual appointments with doctors should be in very limited cases. For patients with brain injury, who often cannot express and identify their problem due to cognitive issues, it is very important that a doctor might observe in-person what is going on. Being isolated already, the brain injury patients should choose if they prefer virtual or in-person, but virtual appointments can put them in more isolation that can lead to deeper depression.”

Primary care/family doctor (n=38). Comments about participants’ family doctors ranged widely. Three broad themes emerged: positive experiences with primary care, concerns about primary care, and neutral perceptions. See Table 1 for a summary of the themes and participant quotes.

Other (n=27). Many of the comments centred around accessing services and knowledge of available resources.

Quote: “The Guidelines for persistent symptoms from concussion are excellent but are not yet familiar to family physicians (FP). I gave a copy to my FP. She referred me to an ABI clinic that made several concrete and useful recommendations but only after a 12 month wait. My FP helped implement many of these recommendations for potential therapies and pharmaceuticals but the wait time meant a wasted year. A compounding problem was additional wait times from ABI referrals (eg another year for an audiology clinic). Other significant issues include: 1) lack of coordination among providers. Coordination defaults to the compromised patient. Paper reports rarely reach other providers files, even with consents. 2) Conflicting recommendations from different providers (blind men and the elephant problem – each provider treating a symptom in isolation). 3) The busy environment of hospitals and health providers offices which aggravate symptoms. Telephone appointments would be much easier.”
### Table 1

**Primary Care/Family Doctor – Themes and Participant Quotes**

<table>
<thead>
<tr>
<th>Theme: Positive experiences with primary care</th>
<th>Theme: Neutral Perceptions</th>
<th>Theme: Concerns about primary care</th>
</tr>
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<tbody>
<tr>
<td><strong>Subthemes</strong></td>
<td><strong>Subthemes</strong></td>
<td><strong>Subthemes</strong></td>
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<tr>
<td>- GP is very supportive and willing to learn/</td>
<td>- Family doctor has minimal</td>
<td>- Resorting to finding resources</td>
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<tr>
<td>attend extra training about brain injury</td>
<td>knowledge about brain injury</td>
<td>and helpful information</td>
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<td>- GP is thorough and conscientious</td>
<td>but is willing to make</td>
<td>online or from other sources</td>
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<td>- GP addresses basic needs and finds the</td>
<td>appropriate referrals</td>
<td>because family doctor</td>
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<td>right specialist or service to refer to</td>
<td>- GP is inexperienced with</td>
<td>has not been helpful (e.g. GP has</td>
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<tr>
<td>- GP has been helpful and supportive in</td>
<td>brain injury care, but I</td>
<td>never treated anyone with TBI</td>
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<td>doing the associated paperwork</td>
<td>have specialists who provide</td>
<td>before)</td>
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<td>treatment for me (e.g.</td>
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<td>physiatrist)</td>
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<td></td>
<td>- Other rehabilitation</td>
<td>- Primary care visits focus on</td>
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<td>professionals (chiropractor</td>
<td>other issues (e.g. diabetes) and</td>
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<td>or physiotherapist) provide</td>
<td>do not address underlying brain</td>
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<td></td>
<td>primary care</td>
<td>injury symptoms (e.g. fatigue)</td>
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<td>- Seeking care from alternate</td>
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<td>providers (e.g. chiropractors or</td>
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<td>physiotherapists) because family</td>
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<td>doctor does not have knowledge</td>
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<td>about brain injury</td>
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<td>- Challenges getting appropriate</td>
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<td>referrals and length of time to</td>
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<td>make referrals</td>
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<td>- No support provided for</td>
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<td>navigating the system/available</td>
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<td>resources</td>
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<tr>
<td><strong>Quote:</strong> Although we attend a clinic</td>
<td><strong>Quote:</strong> My family doctor</td>
<td><strong>Quote:</strong> My experience is that</td>
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<td>setting associated with McMaster University</td>
<td>is inexperienced with</td>
<td>primary care providers know next</td>
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<td>we have always seen the same person. My</td>
<td>brain injury and treatment</td>
<td>to NOTHING about brain injuries,</td>
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<td>son’s physician is a very caring and</td>
<td>but I luckily have a</td>
<td>and generally do more harm than</td>
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<td>patient young man who is interested and</td>
<td>physiatrist that I see</td>
<td>good. The ER can tell you if you</td>
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<td>highly motivated in dealing with ABI</td>
<td>that deals with brain</td>
<td>’ve got a bleed or an actual</td>
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<td>issues. If he does not know the answers</td>
<td>injury treatment. The</td>
<td>crack but not much else. They don’t</td>
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<td>he seeks assistance, he listens and guides</td>
<td>physiatrist is knowledgeable</td>
<td>recognize that whiplash is also</td>
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<td>my son. We have never felt slighted or</td>
<td>and continues to investigate</td>
<td>brain injury and tell you you don’t</td>
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<td>overlooked, misunderstood or rushed, and an</td>
<td>new treatments but he deals</td>
<td>have a brain injury when you do.</td>
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<td>exemplary trusting relationship has</td>
<td>mostly with pain and</td>
<td>Basically I know way more than any</td>
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<td>developed.</td>
<td>symptom control.</td>
<td>primary provider. I’ve had to</td>
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<td><strong>Quote:</strong> I am ‘fortunate’ that the sister</td>
<td><strong>Quote:</strong> My primary care</td>
<td>learn it on my own, and thank god</td>
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<td>of my family doctor also has a brain injury/</td>
<td>family doctor is very</td>
<td>for Facebook groups where I have</td>
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<td>post concussion syndrome as this gave my</td>
<td>supportive but I had to</td>
<td>gotten the most help. I’ve gotten</td>
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<td>doctor motivation to learn as much as she</td>
<td>bring ideas to him for</td>
<td>the most help from several different</td>
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<td>could, and also makes her very</td>
<td>services available to me.</td>
<td>types of chiropractors who have</td>
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<td>understanding and supportive of me as her</td>
<td>He never questioned the</td>
<td>been actually trained in dealing</td>
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<td>patient.</td>
<td>symptoms I reported to him,</td>
<td>with brain injuries (unlike primary</td>
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<td></td>
<td>thankfully. But I believe</td>
<td>providers!). The REAL help in</td>
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<td></td>
<td>that family doctors should</td>
<td>dealing with post concussion issues</td>
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<td></td>
<td>have more information about</td>
<td>is not paid for by OHIP.</td>
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<td>brain injuries.</td>
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◊◊◊
Brain Injury Speaks is a network of brain injury survivors and their caregivers/family members. The goal of the network is to empower those who are living with brain injury to share their experiences and inform the future direction of brain injury care in Ontario.

In this survey, we wanted to find out how people living with brain injury and their family access primary care. Over 120 people responded to the survey! Overall, most survivors see the same primary care/family doctor every time. The majority of survivors feel that their doctor does not have enough knowledge about brain injury. Most survivors said they would try virtual care for their brain injury care if it was available to them. The 3 questions from the survey are summarized in detail below.

**Access to Primary Care for Brain Injury**

Participants were asked where and how they access primary care

![Diagram showing responses to primary care access questions]

- Visit a family health team that has many health care practitioners: 41%
- Access both in-person doctor support and online materials: 8%
- Only use information from online sources or family/friends: 9%
- Visit the same family doctor every time: 40%
Primary Care Doctor's Knowledge about Brain Injury

When asked about their family doctor’s level of knowledge about brain injury:

52% said doctor has **limited knowledge** and that they knew more than their doctor

38% said doctor **does not** have experience in brain injury care, but provides for brain injury needs

10% said doctor is **experienced** in brain injury care and is highly educated about brain injury

Accessing Virtual Care for Brain Injury

When participants were asked about virtual care:

60% of respondents said they **would try virtual care** for their brain injury concerns if it was available to them!

26% said they are **not interested** in trying virtual care.

8% said they are **hesitant to try** virtual care.

Thank you to everyone who responded to the survey. If you have any feedback about the format of this summary, or if you have anything else to share about your experience with virtual or primary care, please email Gazal Kukreja, Stakeholder Engagement Coordinator, at gkukreja@obia.ca
When someone sustains an Acquired Brain Injury (ABI), the impact can be far-reaching, similar to the ripples that radiate from a stone skimmed across the water. Any family member or friend who helps take care of the person with a brain injury can be considered a caregiver. Caring for someone with an ABI can be challenging. As a multi-faceted role, there’s often a lot for the caregiver to learn and manage. But you don’t have to be alone on this journey.

Our free Caregiver Conversations Support Group is there to help. We offer a safe, confidential virtual space to meet other caregivers, exchange ideas, and manage stress. Each group includes approximately 10 participants who meet online once a week for eight weeks. The group is facilitated by a social work student, under the supervision of a registered social worker. We cover a wide range of topics from managing challenging behaviours to stress management to self-compassion.

Due to the high demand, we currently have three groups that are underway, ending in June. Our next session will begin in the Fall. Groups fill up quickly so please be sure to check our website for details. For more information call 1-800-263-5404, ext. 224 or email our group facilitator Katy Kumar directly at: kkumar@obia.on.ca

Caregiver

By: Linda Gaudette Pecore (support group participant)

I’m a caregiver for a son with a brain injury
I struggle to help you with your memory
Some days are good some are bad
As I watch you fight it makes me sad
All I can do
Is help you through
It’s hard to explain
I don’t want to complain
I lost my independence
In a simple sense
Not that I want you gone
Just want back my son
I know you’ll never be the same
Some days I feel that’s a shame
You had a bright future
Now success is when you remember
Day after day we repeat

Nothing can change in a heartbeat
I get exhausted
I get frustrated
It’s hard for you
But think of what I do
I wish we could go back in time
To see the way you used to shine
I get tired, I get mad
Remembering the good times we had
We still have them in a different way
Your ambition has gone away
Friends and family disappear
They just can’t seem to face the fear
I feel like I’m standing all alone
Everyday I turn a new stone
I know there are some worse off than us
It still feels good to yell and cuss
Just to step out and go for coffee
To have a day I can feel free
Those days are gone as I care for you
It’s the choice I made that much is true
I didn’t imagine it to be so hard
Never thought I’d pick this card
I don’t regret the decision I made
To care for you for the next few decades
All I can hope for is a little time
To find myself overtime.

◊◊◊

By Katy Kumar, Social Work Student, OBIA
“McKellar helped me regain financial independence.”

STEVE NOYES
I.T. Consultant Volunteer

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Vision after Acquired Brain Injury or Concussion: The Elephant in the Room

By Pamela Chinchilla, O.D., COVT, PVT, Clarity Optometry

For many of us, involved in the areas of vision therapy, developmental optometry or neuro optometric rehabilitation, it is not uncommon that we get asked by our patients, “How is it possible that after so many years, so many specialists, so many treatments; nobody ever told me about you?” “You understand my symptoms!!”, “So, you don’t think I am crazy?”

Visual problems may be overlooked during initial treatment of Acquired Brain Injury (ABI), and a regular eye exam often does not reveal the extent to which the visual process has been affected. When patients are examined and there is no clinical finding suggesting evidence of an ocular emergency (e.g., retinal detachment, ocular penetration by a foreign body, etc.), no obvious pathology, healthy eyes, and vision is not drastically reduced, those patients are frequently sent home with the promise that the visual discomfort will pass.

Visual symptoms are observed in 75% of ABI cases. These symptoms can be caused by decreased visual function, disorders of the binocular vision system, changes in ocular health and higher-order processing disorders.

The patients I see in my office, most often present with the following symptoms:

• **Eye focusing** – Blurred vision or the ability to shift focus between objects between near and far distances may be compromised.

• **Eye teaming** – Their eyes may not work together properly as a team, even to the point of experiencing double vision.

• **Eye movements** – They may experience difficulty with eye movements when reading (losing their place while reading is a common complaint), or trying to follow a moving object (like a ball being thrown).

• **Motion sensitivity** – Vision plays a significant role in our ability to balance, orient ourselves in space, and process movement of things in our environment. If affected, functioning at work or school, or performing routine daily

Studies have shown that between 50-90% of patients who suffer an ABI will have visual dysfunction. Dr. Charles Shidlofskky reports that between 80-90% of his patients attending his neuro-optometric clinical practice have visual alterations.

Symptoms may vary among individuals. Some typical symptoms may include: headaches, double vision, oculomotor dysfunctions (eye teaming), inability to maintain visual contact, poor depth perception, light sensitivity, unilateral spatial inattention, or if severe, marked visual defects.

Common Vision Problems and Symptoms Following ABI

Visual problems are often not the main concern during initial treatment of a brain injury and, in some cases, symptoms may not manifest until some time following the injury (2-3 weeks, in some cases).
tasks in environments with excessive visual stimulation, such as a grocery stores or shopping malls, may be difficult. Symptoms can include discomfort and even dizziness when scrolling on a computer screen or phone, or when in busy environments such as social settings, or sporting events.

- **Visual Field Loss** – Partial or complete vision loss can also occur after a head trauma. The area of the brain that has been affected, as well as the extent of the damage, will determine your field of view. This may cause such problems as bumping into objects, being struck by approaching objects, or sudden falls.

- **Eye Pain and Headaches** – Whether it is a stabbing pain, dull ache around the eye, or even redness, burning or itching, they may experience eye discomfort following head trauma. Headaches can be long-lasting, even longer than a year after the injury. These symptoms can make it hard for them to carry out daily activities or can cause them to have more difficulty thinking and remembering things.

- **Sensitivity to Light** - Brain injury can be accompanied by increased light sensitivity and general inability to tolerate glare. Photophobia, or sensitivity to light, can be exacerbated by specific light sources, such as bright sunlight and fluorescent lighting. Recent studies have also suggested that LCD screens (e.g. computers or smartphone devices) can be particularly bothersome after a concussion.

- **Vertical Imbalance** - Normally, the eyes work in perfect synchrony. In this instance, one eye will aim higher than the other. In an effort to adjust for the vertical misalignment of the eyes, the person will frequently tilt their head to help align their eyes. This, in turn, can cause disorders in the vestibular fluid of the inner ear and lead to dizziness and balance disorders.

- **Binocular Vision Dysfunction** refers to the inability of the eyes to work together as a team. The eyes need to aim together and focus accurately at a point in space, and be able to quickly change gaze between closer and further objects. Both components of near viewing (pointing and focusing) are controlled by neural connections in higher brain centres. Brain injury to these neural centres can lead to eye teaming and focusing issues, resulting in double vision and/or blurred vision – setting the stage for dizziness and balance problems.

If you or someone in your family notices changes in their vision following a concussion or some other head trauma, don’t ignore the elephant in the room: Immediately contact your eye care professional.

It is always best to consult with your eye care professional on managing any vision problems you may be experiencing. Following a concussion or other brain trauma, a neuro-optometric rehabilitation optometrist, trained to evaluate and treat vision problems after a brain injury, can offer specific advice tailored for your particular situation. Evidence and multiple data strongly recommend early intervention.

**What Is A Developmental Optometrist or a Neuro-Optometrist?**

Very few in the health care professions, including head trauma rehabilitation centres are adequately aware of visual problems resulting from ABI and the visual-perceptual consequences. Unfortunately, this creates a gap in rehabilitative services, resulting in incomplete treatment and frustration for the patient, family and treatment team.

Developmental optometrists, offer specialized eye care options. In addition to providing general eye care, they examine a patient’s skills for functionality and how it affects their daily activities and overall lifestyle. They have access to more comprehensive tools that test for vision problems that may remain undetected by standard vision exams.

After evaluation, examination and consultation, the neuro-optometrist determines how a person processes information after an injury and where that person’s strengths and weaknesses lie. The optometrist then prescribes a treatment regimen incorporating lenses, prisms, and/or vision therapy, designed to improve control of a person’s visual system and increase vision efficiency. This in turn can help support many other activities in daily living.

**What Is Vision Therapy or Neuro-Optometric Rehabilitation?**

Vision Therapy is an individualized treatment regimen for patients with visual deficits as a direct result of physical disabilities, traumatic brain injuries, and other neurological insults.

It is a process for the rehabilitation of visual/perceptual/motor disorders. It includes, but is not limited to, acquired strabismus, double vision (diplopia), binocular dysfunction, convergence and/or accommodation paresis/paralysis, oculomotor dysfunction, visual-spatial dysfunction, visual perceptual and cognitive deficits, and traumatic visual acuity loss.

Patients of all ages who have experienced neurological insults require neuro-optometric rehabilitation. Visual problems caused by traumatic brain injury, cerebrovascular accidents, cerebral palsy, multiple sclerosis, etc., may interfere with performance causing the person to be identified as having a learning disability. These visual dysfunctions can manifest themselves as psychological sequelae such as anxiety and panic disorders as well as spatial dysfunctions affecting balance and posture, which may end up leading to recurrent ABI’s or concussions.
A vision therapy or neuro-optometric rehabilitation treatment plan improves specific acquired vision dysfunction determined by standardized diagnostic criteria. Treatment regimens encompass medically necessary, non-compensatory lenses and prisms with and without occlusion, and other appropriate medical rehabilitation strategies.

To find a qualified vision therapist please visit Vision Therapy Canada “Find a Doc”:

https://www.visiontherapycanada.com/find-a-doc/

References:


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

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- Brain injury/concussion within past 5 years
- Age 18 to 60
- Women: not currently pregnant
- Not currently taking any street drugs
- 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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www.obia.ca
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: 905-646-2426
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
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

Alberta - Association for the Rehabilitation of the Brain Injured (ARBI)
Phone: 403-242-7116
Email: ana@arbi.ca
Website: www.arbi.ca

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

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

Newfoundland & Labrador Brain Injury Association
Phone: 709-579-3070
Email: nlbia2011@gmail.com
Website: www.nlbia.ca

Association québécoise des traumatisés crâniens (AQTC)
Phone: 514-274-7447
Email: aqtc@aqtc.ca
Website: www.aqtc.ca

Brain Injury Association of Nova Scotia
Phone: 902-422-5000 or toll-free 833-452-7246
Email: info@braininjuryns.com
Website: www.braininjuryns.com

Brain Injury Association of New Brunswick
Phone: 506-721-8003
Email: biacnb@icloud.com

Brain Injury Association of P.E.I.
Phone: 902-314-4228
Email: info@biapei.info
Website: www.biapei.info

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-cks1.com
Website: www.newbeginnings-cks1.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: 519-576-3535
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

Brain Injury Association of York Region
Phone: 905-780-1236
Fax: 905-780-1524
Email: n/a
Website: www.biayr.org
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Events Calendar

June - Brain Injury Awareness Month
OBIA presents
Unmasking Brain Injury - Mask of the Day
Location: OBIA’s social media platforms

June 11-12, 2020
OBIA presents
Mental Health, Addictions and Brain Injury (Level 2) Training Program - Virtual Classroom
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: training@obia.on.ca
Website: www.obia.ca

June 24, 2020
OBIA presents
Virtual Annual General Meeting
Location: Online, 6:30 p.m. EST
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: ddakiv@obia.on.ca
Website: www.obia.ca

November 12-13, 2020
OBIA and BIA Sudbury & District present:
Brain Basics
Location: Caruso Club, Sudbury, ON
Contact: Diane Dakiv
Phone: 905-641-8877 ext. 231
Email: ddakiv@obia.on.ca
Website: www.obia.ca

November 12-13, 2020
Toronto ABI Network presents
Conference 2020: Connecting, Learning, Inspiring
Location: Marriott Eaton Centre, Toronto, ON
Contact: Conference Coordinator
Phone: 416-597-7021
Email: info@abinetwork.ca
Website: http://www.abinetwork.ca/abi-conference-2020

June 2-4, 2021 (new date)
Brain Injury Canada presents
Brain Injury Canada National Conference
Location: Ottawa Conference & Event Centre, Ottawa, ON
Contact: Conference Coordinator
Phone: 613-762-1222
Email: info@braininjurycanada.ca
Website: www.braininjurycanada.ca

June 9, 2021 (new date)
BIST/OBIA presents
The 17th Annual BIST/OBIA Mix and Mingle
Location: Steamwhistle Brewery, Toronto, ON
Contact: Terry Bartol
Phone: 905-641-8877 ext. 234
Email: tbartol@obia.on.ca
Website: www.obia.ca

For more listings, check: www.obia.ca/calendar
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.

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- Physiotherapy
- Occupational Therapy
- Behaviour Management
- Speech Therapy
- Dietician
- Nursing
- Adult Education, Vocational Training or Upgrading
- Legal Services
- Family support

Reach out to us to find out more about Pathways ABI Services:
289 Pinnacle St, Belleville, ON K8N 3B3  T 613.962.2541  F 613.962.2657
358 D Woodcliffe Ave, Unit 202, Ottawa, ON K2A 3V6  T 613.233.3322

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Community based rehabilitation and life long support services for persons with acquired brain injury, neurological challenges and complex multiple disorders.

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Prerequisite Required: Neurorehabilitation: Assisting Recovery & Function in Everyday Life Following Brain Injury
NO EXCEPTIONS

June 11-12, 2020

Join our Live Online Virtual Classroom!

In response to COVID-19, OBIA continues to be committed to provide training for professionals working with people with brain injuries. Our certificate course will now be accessible through a live online virtual classroom.

Please note that this takes the place of the originally planned in-person, 2-day training program at Brock University.

About the Course:
This Level Two course is designed to increase your understanding of the relationship between traumatic brain injury, substance misuse and mental health challenges, and to assist you in developing a greater appreciation of the factors which make brain injury rehabilitation more challenging when a co-morbid disorder is present.

Professors, Dr. Dawn Good and Dr. Carolyn Lemsky will be teaching the program by live video conference.

For more information or to register visit:
www.obia.ca/brock-university-certificate-courses

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For more information, please contact: 416-66-REHAB or intake@neurorehab.ca
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