

NeuroMatters

Connecting YOU to the Research

Living with a Brain Injury

Finding out what it is really like

An anxious caregiver, responsible for an individual with a brain injury, often asks the question: "When I'm no longer around, when I can't provide the right level of care, what's going to happen to my loved one?"

Aging caregivers is one of the key highlights from the recently released **OBIA Impact Report**. Statistical evidence gathered in recent years has added proof for the need to support people living with the effects of ABI, but the **OBIA Impact Report** delivers an in-depth look at brain injury from the perspective of individuals and caregivers. Compiled from both qualitative and quantitative information, this research and communication document not only provides hard data but also truly answers the question, "What's it really like to live

with a brain injury? And what's it like to actually care for someone with a brain injury?"

"The report is a powerful snapshot of the real impact of ABI," says Ruth Wilcock, Executive Director of the Ontario Brain Injury Association (OBIA). "We're already getting feedback from individuals, rehabilitation providers, caregivers, personal injury lawyers, etc. telling us that the report really illuminates the difficulties people are facing."

Two of the report's highlights are particularly noteworthy to Wilcock and ONF, which partnered with OBIA on the project.

Aging caregivers looking to the future

The survey found that most caregivers are over 50 years of age (the average age being 57), 75% are female and 41% are parents. These are worrisome statistics, given the few alternatives available for individuals with an ABI if they cannot be cared for appropriately at home.

"This backs up what we've noticed," says Wilcock. "Frequently, OBIA gets telephone calls from caregivers asking what to do. For many years they've

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cared for their loved one – very often their son or daughter – and they are desperate to know what will happen after they're gone".

These findings point out another key issue, the importance of appropriate placement of people living with ABI and the growing need for additional support services. With limited space and long waiting lists in supportive housing and ABI programs, many risk being placed in a long-term care facility which may not be appropriate for the individual and where currently, little training is given to staff about brain injury.

Impact on mental health

A further significant finding highlights the mental health issues that often accompany an ABI, i.e. depression, anxiety, mood swings, and the like.

- 76% have trouble with depression some or most of the time
- 80% have trouble with anxiety some or most of the time



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- 75% of ABI survivors report trouble with changes in sleep patterns
- 34% don't have access to family counselling or support services

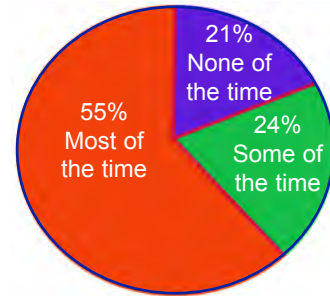
Knowing that there is a high incidence of mental health issues informs both the individuals with ABI and their caregivers about what to expect, and assures them that they are not alone. The research also sends a strong message about the increased need for support/counselling services and the training required to provide the right kind of care.

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Additional insights

There are additional highlights of the report. Early diagnosis plays a significant role in the recovery process, yet too often, a brain injury goes undiagnosed for months, even years. This impacts both physical recovery and mental health, leading to additional anxiety and frustration.

Findings in the **OBIA Impact Report** highlight mental health issues that accompany an ABI such as trouble with depression.



- 42% of survivors received a diagnosis of brain injury while in a hospital's emergency department, but nearly 15% said it took longer than 6 months to learn about their brain injury, 4%, more than 5 years.

ABI also creates a serious financial impact. In addition to the millions of dollars spent on medical care and rehabilitation, those living with ABI and their caregivers most likely face a substantial economic loss. An individual who has sustained a brain injury often is not able to return to their place of employment, and those providing care give up previous activities because of their newly-developed responsibilities.

- 79% of caregivers admit that the brain injury has impacted family finances
- 46% of caregivers state that the brain injury impacted their employment status

- 75% of ABI survivors reported that they were employed for pay prior to their brain injury and 87% said they were currently not employed for pay

The report as a communications piece

Designed as a communication document, Wilcock hopes the **OBIA Impact Report** will raise ABI awareness among politicians and policy makers, and help educate those working with individuals with ABI, especially "on the ground" at the community level. The research also should reassure caregivers and those with ABI that their challenges are being better documented and understood.

"ABI is not like having a sprained wrist where you recover in a few weeks and off you go," she adds, "There are life-long impacts with ABI that affect our social service system, our healthcare system, our families, our communities, and these just don't go away."

OBIA and ONF have always been interested in learning more about the personal costs of ABI. Understanding the difficulty in quantifying such costs, in 1989 OBIA began research through a questionnaire to caregivers. In 2008, ONF joined the project as a partner. ONF's support provided the resources to improve the survey, including convening an expert panel to review and improve the gathering tools. The OBIA Impact Report is the culmination of data collected between 2009 and 2011.

"With ONF as a partner, we were able to create more comprehensive information about long-term needs, issues and challenges facing people with ABI," says Wilcock.

Over the next 2 years, supplemental Impact Reports will focus on specific areas of interest.

The **OBIA Impact Report** is available on OBIA's website www.obia.ca.

The Centre for Family Medicine Mobility Clinic

A Model Project for Delivering Primary Care to those with SCI

This fall, Elizabeth Witmer, former MPP and presently Chair of the Workplace Safety & Insurance Board (WSIB), spent time at the Kitchener Mobility Clinic talking with health care staff from the Mobility Clinic team and ONF staff.

Witmer has consistently demonstrated a keen understanding of the challenges faced by consumers who need primary healthcare, and the needs of primary care providers, who must deliver care in high needs situations. For those living with a spinal cord injury (SCI), inadequate access and support to primary care is a major problem. The offices of family practitioners are often not accessible and both physicians and staff lack experience and understanding of the needs of those with SCI, such as the height of examination tables, adequate space in hallways and waiting rooms, and scheduling appointments around transportation availability.

The Mobility Clinic showcases new ways to more efficiently and effectively deliver care to SCI consumers, as well as to others with mobility issues. It does so by modelling true patient-centred care that is integrated so it works toward the best result for the consumer.

According to Dr. Joseph Lee, Clinic Director, "Our model highlights the importance of the interaction among people as the foundation of any therapeutic or healing activity."



Witmer, far left, visits the Kitchener Mobility Clinic.



Mobility Clinic and ONF staff with Elizabeth Witmer (seated at table).

The Clinic has built relationships within family health teams as well as rehabilitation institutions, academic institutions and persons with SCI so that while visiting the clinic, consumers are able to access services all in one site. These include a pharmacy, care by physicians, chiropractors,

nurses, occupational therapists and social workers.

In the words of one of the consumers, "They have helped me with different services, one thing just leads to another. I keep getting more and more good services."

www.family-medicine.ca

No Longer an “Invisible Injury”

New study on concussions in hockey players

There's some reassuring news for young hockey players and kids playing sports who sustain a mild traumatic brain injury (mTBI) or concussion. A new study shows that for most adolescents¹, adequate rest and management before returning to normal activities means that they should recover well over the long-term. The study also showed that for every additional concussion, symptoms are more severe from the beginning and last longer.



¹ It is still unknown as to the long term results of a concussion on children that already have a pre-existing condition such as ADHD or learning disability.

“These players need to rest, which means a gradual return to school and not returning to play too early,” explains Michelle Keightley, principal investigator for a 4-year study on the immediate and long-term outcomes following sports-related concussions in children and youth. “The problems come when children return to activities, including playing hockey too early. This causes a recurrence of symptoms, such as dizziness, headaches, loss of balance, etc. We also know that these get worse with each successive concussion.”

Tracking 11 hockey teams over three years

The study selected 7 boy's and 4

girl's minor hockey teams. Those who sustained any “hit on the head that caused a stop in play” became part of the study. Over a 3-year period, 2007-2011, they were followed on various aspects:

- 1) symptoms immediately following their concussion
- 2) memory
- 3) balance and
- 4) motor functioning

Overall findings include the following:

- The majority of injuries were sustained as a result of an intentional body check. They also mostly happened during tournament play. These findings help direct the hockey

community to areas that need improved injury prevention practices.

- The athletes noticed that their concussion impacted their hockey playing ability and skill level. There was an initial decline in balance and coordination post concussion, with a gradual improvement with recovery.

Pressure still exists for “returning to play,” and to minimize the injury. Some athletes associated their symptoms with the severity of their concussion, instead of understanding that a concussion of any kind is still a serious injury.

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Emotional impact of concussions

In addition to quantitative data, structured interviews were conducted with both players and parents about how they felt after the injury, their general moods and behaviour, and state of mind when it was time to return to school and sports. It became clear that a concussion impacted the confidence levels of some, making them more hesitant and nervous to go out on the ice.

“The emotional response from the kids themselves is particularly noteworthy, says Keightley, “those recovering from a concussion showed lots of anxiety over getting hit again, and often did not tell their parents because they didn’t want to add to their worries.”

“These findings help us to remember that a concussion is a traumatic event and kids need time to process it. Parents can assist by talking about it directly, helping their child process it, even supporting their children to leave hockey or play the sport at a

“Children and adolescents involved in organized sports are nearly six times more likely to suffer a concussion than those involved in leisure physical activities.”

different level, if that’s what they really want to do.”

Concussion as “serious”, not “invisible”

Viewing a concussion as “serious” continues to be a challenge. Although there’s been a shift away from a former viewpoint that “young” brains – those of children and adolescents – recover more easily, many continue to view a

concussion as trivial. Concussions also aren’t injuries you can “see”, like a broken leg; so some have difficulty finding obvious reasons to treat the athlete differently than a healthy player. One player, for example, referred to his concussion as an “invisible injury”.

New supporting studies show that there are critical points in the development of a child’s brain where injuries can do more damage. Given that concussion is one of the most commonly reported injuries in children who participate in sports, the study’s findings are important reminders that kids need to have supports in place at home and at school and their athletic coaches need to encourage rest, make sure they recover, and insist that they don’t return to normal activities until they are ready, that is, symptom-free. This applies to all those involved in children’s sports, as well as the management of concussed adolescents, whether it be at school, a medical clinic or the rink.



“During his recovery, he was at times emotional, not himself. He at times, you know, was I think a bit frustrated too, that he felt better and then he would engage in some form of mild physical activity and get a headache again and that would set him back. He is very athletic and very much wants to participate in sports.”

Parent interviewed for the study

The Jane Gillett Pediatric ABI Studentship

Announcing the first recipient

Ontario Neurotrauma Foundation is pleased to announce the recipient of the Jane Gillett Pediatric ABI Studentship, Vincy Chan, a PhD student at the University of Toronto in the Department of Public Health Science.

As the recipient of the studentship, Chan receives funds of \$69,000 over a period of three years to complete her PhD. Chan began her work this September, studying children and youth with ABI in Ontario, specifically looking at the service utilization patterns once they return home and to their communities following their injury. Questions include where they are

discharged to, where they receive services, and what types of supports they receive through OHIP and homecare.

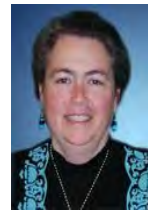
"The extent of ABI at the population level among children and youth and the subsequent utilization of publicly funded health services across the continuum of care is not well known." Chan says. "This study can inform planning of health care services for this vulnerable population".

ONF congratulates Chan for being selected. ONF also would like to thank the International Paediatric Brain Injury Society (IPBIS) for contributing towards this award by sharing the donations made to IPBIS in Dr. Jane Gillett's memory (www.ipbis.org).



About the Studentship

Dr. Jane Gillett was a dedicated physician who worked tirelessly to improve the lives of her patients with ABI and their families. She was involved with ONF for many years as a Board member and Chair of our Knowledge Mobilization Committee and was a well-known and valued leader in ABI. Following her death in 2011, ONF established the studentship award for Pediatric ABI research in her name.



5th Annual SCI Conference

A hit with consumers

The 5th National Spinal Cord Injury (SCI) Conference is a unique event because, unlike most such conferences, attendees include lay consumers in addition to professional researchers. Held every second year in Toronto, consumers have the opportunity to attend the conference, mingle with researchers and clinicians, engage in active discussions on current SCI research, and recommend what they would like as areas of research in future. The event took place October 19 and 20, 2012.

As one consumer commented,

"It was a very rewarding experience. It re-energized me as my husband and I deal with our spinal cord injuries. Thank you." This year's 500 delegates from across Canada included 6 consumer delegates from different areas of Ontario. Each had made an application online, which was then reviewed by the selection committee.

Consumer evaluation of this year's conference included comments such as: "The coordinator eliminated all stress and gave me every opportunity to have a most memorable

experience." The conference planning committee was also praised for making every effort to attend to individual personal needs as well facilitating conversation and social interaction between consumers and researchers.

Event evaluations will help shape the next conference in 2014, with hopes for more and even better research outcomes to share with our SCI community.

ONF is proud to be the lead sponsor for the National SCI Conference.

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SCI-related arthritis. These, along with issues of transportation and accessibility, eventually made it very difficult to continue to work."

Work environments often "unfriendly"

Although Cott praises the employers interviewed for their acceptance and support for employees with SCI, Ontario still lacks many workplace accommodations and disability understanding among other employees. Each individual has their own unique needs and way of managing them. For example, most offices have a washroom designed to meet the needs of a person with SCI, but that doesn't mean that the washroom itself is easy to get to. There also may be doors that are too heavy, poor access to the building, or office spaces that are just too tight. "These are often very simple things that if modified, would make the environment so much friendlier," says Cott.

Systemic Barriers Remain

Limited funding for retraining, particularly in more recent years, and lack of consistent and/or reliable transportation and personal care services continue to make remaining in the workplace difficult long-term. What if:

- the employee needs to get to an early meeting? Transportation and personal care schedules have to be changed, often resulting in unavoidable delays.
- the individual is encountering added health issues as his or her body ages, which reduce their stamina for performing the same job or working the same number of hours? Even with flexible work schedules, over time such barriers make it more and more difficult to stay in the workplace.

Employers interviewed continually praised persons with



SCI as hard working and committed to their work. The individuals themselves, however, are often reluctant to take sick days or ask for further accommodations as their body ages because they are determined "not to be a problem". Those with benefits also are afraid that reduced hours of employment may mean losing those benefits.

What's next?

As a physical therapist, Cott notes that the study illuminates the fact that rehabilitation and support cannot stop once someone returns to work. "We need to take a longer view," she says, "individuals with SCI need ongoing access to therapy." She adds that introducing interventions such as assisted devices and technology should be encouraged, despite the tendency to want to be able to manage without them.

One of the next steps will be creating a set of interventions to minimize job withdrawal. By sharing

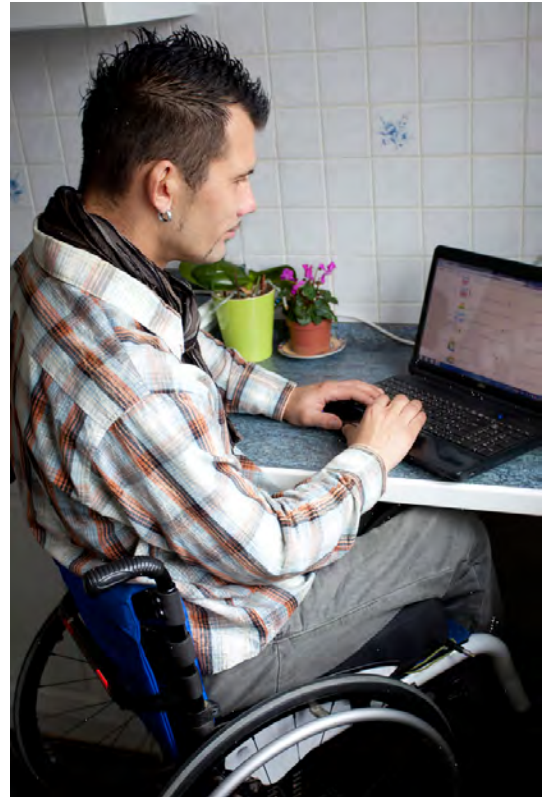
findings, it is hoped that the study will shed new light on aging with a disability, and remind policy makers, employers, rehabilitation providers, etc. that barriers to accessible workplace environments remain a serious issue in Ontario.

The above research project was a partnership between researchers at the University of Toronto, Spinal Cord Injury Ontario (formerly Canadian Paraplegic Association Ontario) and LaTrobe University (Australia). Those interviewed included persons with an SCI, community-based rehabilitation service providers, employment service agencies and employers.

Correction

In the spring issue of *NeuroMatters*, there is a correction to the article on page 7: MBCT uses a very different approach. By applying the skills of meditation and mindfulness to intentionally pay attention to the present moment, participants learn how to put aside their tendency to judge, to compare or wish for things to be different. This helps them view their changed lives with more equanimity, see more possibilities for problem solving, and regain a sense of wholeness.

Why Do People with Spinal Cord Injuries Eventually Lose Their Jobs?



A 30-year-old man returns to work following a spinal cord injury (SCI) and post injury rehabilitation. Despite challenges around transportation and accessibility, he manages well for several years through sheer determination and commitment to do his job. But 15-20 years later, his body cannot withstand the same physical challenges. He doesn't want to "ask for more accommodations" but getting to work and doing the job becomes extremely difficult, eventually impossible. He faces the reality of losing his job or perhaps having to contemplate early retirement as his only option.

Understanding Disability-Related Challenges

In our society, work is important not only because it earns an income but also because it helps define who we are and provides significant social interaction with others. Those who've sustained a spinal cord injury (SCI) and cannot return to work, soon begin to feel very isolated, which leads to depression and other related health issues.

There are consistent findings in research that people who are employed after SCI live longer, and report better health than people who are not working. By staying connected through work, self esteem and overall life satisfaction improves. This creates a positive impact on an individuals overall health, independence and feelings of self-reliance.

Difficulties remaining in the workplace long-term

An international study of job retention, post SCI, paints an unsettling picture. Conducted over 2 years in Ontario, Canada and Victoria, Australia, the research looked at why people lose their jobs after a spinal cord injury, not just in the first few months or years, but 10 to 15 years later. Several factors were identified:

- Recurrent health issues over time, as the body aged
- Lack of work place support and accommodations
- Systemic issues: Access to consistent and reliable transportation and personal care, and limited funding for job retraining

Those doing the study not only wanted a better understanding of all the reasons for losing jobs, but

also the kinds of work environments, support services and interventions that might help someone with SCI remain in the workforce, long term.

The conclusion? Staying in the workplace over time is very difficult for the person with SCI.

Aging with a disability

Dr. Cheryl Cott, Ontario lead for the project, was particularly struck by the number of individuals with SCI who had to take early retirement.

"They did so well through their rehabilitation, and were driven to get back to work and manage without help," she explains, "but all told a similar story 10-15 years down the road. Now they started encountering activities that presented challenges, perhaps because of a torn rotator cuff or

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