This report is a resource for patients suffering with Post-Concussion Syndrome. It looks at the condition, the symptoms, diagnoses, and treatment plans. Ontario currently has no comprehensive strategy for adult concussion care, making treatment inaccessible and unreliable. The report looks at the policy of the Ontario Ministry of Health and Long-Term Care with regard to concussions, and examines the research being done by various charities and private organizations in Ontario. Finally, the report provides a list of resources for patients, and makes recommendations for further study.
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Introduction
Every year, nearly 150,000 Ontarians are diagnosed with concussions. Also known as mild Traumatic Brain Injury (mTBI), this is the most common form of brain injury. Most people recover within a few days to a few weeks, but 15% - 20% of patients experience persistent symptoms such as headaches, dizziness, fatigue, cognitive impairments, and depression which can have a profound impact on their daily lives (http://concussionsontario.org/). When symptoms persist longer than a few weeks, patients are diagnosed with Post Concussive Syndrome (PCS) and can face an uphill battle in seeking and receiving appropriate treatments.

Although Ontario has a comprehensive strategy to address children’s concussions and their prevention, the province has no strategy to deal with adult PCS patients. Diagnoses and treatment plans are inconsistent and widely variable. There are no provincial standards to provide guidance to medical practitioners, and there is a lack of information and resources to pass on to patients.

Several private and charitable organizations are conducting research on concussions in Ontario, but there is little immediate help for patients who are looking for specialized assessments and symptom relief.

This report aims to provide information about Post-Concussion Syndrome, to examine the state of concussion care in Ontario, and to provide a list of available resources for PCS patients.
Who is this Report For?

This report is for adult Post-Concussion Syndrome patients and their families and caregivers in Ontario. Patients who are suffering the effects of concussion may have already endured months of suffering and disruption to their lives, and may be surprised at the seeming lack of consolidated information available. They may be stressed over the uphill battle to gain access to treatment and support. They want to know what’s being done, and they want a resource which can point them in the right direction.

The report may be used by physicians, politicians, and ministry staff who have to deal with an increasing number of concussion patients and an inadequate system for treating them.
Concussion

Concussion, or mild Traumatic Brain Injury (mTBI), occurs when the brain is thrust against the skull as a result of a blow to the head or body, or as a result of a whiplash effect, even if the head does not receive a direct impact. Common causes of concussion include motor vehicle accidents, sports injuries, and slips and falls.

Post-Concussion Syndrome

Post-Concussion Syndrome (PCS) occurs when damage to the brain causes a host of physical, cognitive, and emotional changes which persist after the initial few days or weeks. These changes can last from days to months, and in some cases, years. Symptoms can be minor, or severely disruptive to daily routines. Each person is unique.
Symptoms

Any number of problems can occur as a result of brain injury. This is not an exhaustive list. PCS can cause physical, cognitive, and emotional disruption. Patients may experience one, or several symptoms, and these may change over time. The most common symptoms include, but are not limited to the following:

<table>
<thead>
<tr>
<th>Physical</th>
<th>Cognitive</th>
<th>Emotional</th>
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<tbody>
<tr>
<td>dizziness</td>
<td>inability to focus</td>
<td>depression</td>
</tr>
<tr>
<td>nausea &amp; vomiting</td>
<td>memory loss</td>
<td>feeling weepy or teary</td>
</tr>
<tr>
<td>headaches</td>
<td>problems making decisions</td>
<td>anxiety</td>
</tr>
<tr>
<td>tinnitus</td>
<td>problems concentrating</td>
<td>frustration</td>
</tr>
<tr>
<td>vision problems</td>
<td>feeling “cotton-headed”</td>
<td>feeling isolated</td>
</tr>
<tr>
<td>sensitivity to light or sound</td>
<td>difficulty engaging in conversation or social situations</td>
<td>feeling misunderstood</td>
</tr>
<tr>
<td>sleep disruption</td>
<td>fatigue</td>
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</table>

In the long term, PCS patients are at higher risk of subsequent brain injuries as well as degenerative conditions such as Alzheimer’s disease and Parkinson’s disease.
Diagnosis

It is important to receive diagnosis and treatment as soon as possible after concussion, as this can affect recovery rates and times. Health care providers have access to tools and processes to help them make a diagnosis of PCS. Primary care must first monitor and rule out any severe or life-threatening complications like intracranial bleeding, but most patients will not experience this complication. Diagnosing PCS can be difficult because there may be no visible physical indications. Skull x-rays are insufficient to detect concussion, and MRIs and CT Scans are primarily used to exclude significant lesions in the brain. Because symptoms can appear weeks after the event, patients often do not seek treatment right away, making it difficult to assess the injury. After the initial trauma, primary care providers will conduct the following assessments:

- medical history
- physical examination, including a full description of the injury
- symptoms checklist using a Post-Concussion Symptoms Questionnaire
- risk factors assessment, including concussion history, headache history, developmental history, and psychiatric history
- careful observation of Red Flags which indicate a deterioration of neurological functions. These may require a CT Scan to rule out intracranial bleeding.
- monitoring of ongoing symptoms

When a diagnosis of PCS is made, a follow-up action plan and referrals for ongoing treatment will be made.
Prognosis

Each patient is unique, and it is difficult to predict recovery outcomes. Patients can generally return to work and daily activity, but it may be advisable to do so slowly, with careful monitoring of their tolerance for the activity. Rest is important, and overexertion is a risk. Symptoms may be aggravated by stress and activity overload. Pre-existing medical conditions and personal, psychosocial, and environmental factors can all have an effect on recovery.

Because symptoms can be long-term and unpredictable, it is advisable to work out a plan with doctors, work, and school to ensure that there are strategies in place to aid in recovery. Patients may require a reduced workload, or extra time to complete tasks.

In as many as 20% of cases, symptoms can persist and patients are advised to learn management strategies or seek alternative therapies to deal with ongoing issues.

Treatment Plans

Most patients make a full recovery, but for those with persistent symptoms, monitoring and treatment are critical. Interventions should be advised as symptoms arise. Primary health care providers can make referrals to specialists and multidisciplinary treatment clinics. Secondary symptoms such as chronic pain, chronic fatigue, depression, and anxiety should be referred to specialists as needed. Comprehensive and coordinated treatment plans can significantly improve recovery rates.
Ontario’s Policy
In 2016, Ontario passed Rowan’s Law – a set of protocols to prevent concussions in children, and protect them from the long-term effects of concussion (http://news.nationalpost.com/sports/ontario-passes-rowans-law-but-its-just-one-step-in-protecting-kids-from-concussions). The law was developed after the death of Rowan Stringer who suffered multiple concussions while playing high-school rugby. Ontario is the first province to initiate such a law – surprising given that 50 US states have concussion laws in place.

The Ontario Ministry of Health and Long-Term Care provides a wealth of information on concussions for parents regarding children’s sports injuries (http://www.health.gov.on.ca/en/public/programs/concussions/). There are numerous guides for prevention as well as concussion awareness training for teachers and coaches. There are links to pediatric societies and even a “Sport Concussion Library”, but there is no provincial strategy to deal with adult concussion issues, treatments, or resources. Nor is there any acknowledgement that concussion can be non-sport related.

While it is commendable that Ontario has a well-developed concussion strategy for youth, it is frustrating that there are no provincial resources which address adult needs.
Research

While there is little information about PCS available to the public, there are a few institutions conducting research behind the scenes. It remains to be seen how this research will affect those who are seeking immediate help with concussion symptoms. The most prominent research is as follows:

Ontario Concussion Care Strategy (OCCS) is a clinician-driven initiative shared between Toronto’s St. Michael’s Hospital and the Ottawa Hospital Rehabilitation Centre. This research is focused on adult concussion, but it is also done in collaboration with the Canadian Pediatric & Youth mTBI Common Data Elements (CDE) Study at McGill University.
http://concussionsontario.org/access-to-care/concussion-data/

http://concussionsontario.org/adult-concussion-guidelines/

The Ontario Neurotrauma Foundation has commissioned several studies on the state of concussion care in order to find the gaps in access and care. They found wide variations in services and treatments. Their 2016 report is forthcoming.
ONF has developed a comprehensive set of guidelines for health practitioners in an effort to standardize treatment options across the province.

The Canadian Concussion Centre is based at the Krembil Neuroscience Centre at Toronto Western Hospital. They research the effects of repeated concussion and its degenerative effects with the goal of improving diagnoses and treatments.
http://wwwuhn.ca/KNC/Research/Projects/Canadian_Concussion_Centre

“It is insufficient to know that concussion management is variable and that there are no standard approaches that can be held as optimal concussion care in Ontario”.
(http://onf.org/)
It can be frustrating for patients seeking information and treatment. Because there are no provincial guidelines and no standardized protocols, physicians themselves are often at a loss when it comes to persistent concussion symptoms. Patients can spend months pursuing leads before getting a diagnosis, and many months after that trying to track down treatment plans. Even the organizations which are trying to improve the situation are hard-pressed to provide concrete answers or patient interaction. They acknowledge that resources and data are limited and each one seems to refer patients to one of the others. Patients are caught in a circular loop.

The effects of brain injury can be lifelong. People with ABI may need assistance at home or supportive housing. They may need help returning to work or school. Or they may benefit from peer support or recreational programs.

- Toronto ABI Network
The Ontario Ministry of Health and Long-Term Care offers a wealth of information on children and concussion prevention in school athletic programs.


The Ontario Brain Injury Association (OBIA) has offices and a Peer Support program, but at the time of this report, the website is down, so patients must contact them by telephone (1-800-263-5404).

http://obia.ca/peer-support2/

The Ontario Neurotrauma Foundation offers extensive guidelines for physicians, but patients may find useful information there as well.


http://onf.org/

Toronto Acquired Brain Injury (ABI) Network acknowledges that “There are very few specialists or programs that specialize in concussions and post-concussive symptoms. Waiting lists for services covered by OHIP are usually long” (http://wwwabinetwork.ca/concussion-care-1). They provide a list of resources in Toronto and the GTA.


The Brain Injury Society of Toronto (BIST) offers complete programming, peer mentoring, workshops, community events, and social drop-ins in partnership with OBIA and Toronto ABI Network.

http://www.bist.ca/
Conclusion

Post-Concussion Syndrome is a serious public health issue which affects 150,000 Ontarians every year. Though most concussion patients make a full and quick recovery, about 20% continue to experience physical, cognitive, and emotional symptoms which disrupt their lives. The Ontario Ministry of Health and Long-Term Care has devised a province-wide strategy and laws which address concussions in youth, but there is no centralized strategy currently in place to assist adults experiencing PCS.

Statistical data on concussion care in Ontario is scarce, and the Ontario Neurotrauma Foundation (ONF) has yet to publish the results of its 2016 report. Other private and charitable organizations are conducting research into adult concussions, but so far, there is little guidance available to patients who must navigate the health system on their own. The Ontario Brain Injury Association (OBIA) provides peer networks and counselling for patients who seek them out, but physicians do not generally provide this information. The Ontario Neurotrauma Foundation has developed a set of concussion guidelines, but the dissemination of information to patients remains a challenge. Patients must be proactive in seeking the treatment they need.

We do not have any data regarding the economic losses of individuals, or the effects on the economy due to lost productivity. Nor do we have data regarding wait-times for treatment, or the effectiveness of treatments for PCS. The organizations that are working toward improving our knowledge are truly trailblazers, but more information regarding treatment and long-term care needs to be made available to patients. The Ontario Ministry of Health and Long-Term Care must take steps to ensure that the needs of injured Ontarians are being met.
References


