

NeuroMatters, Fall 2016



Welcome to the Fall Edition of NeuroMatters

Welcome to the new online edition of NeuroMatters, the newsletter from the Ontario Neurotrauma Foundation (ONF). NeuroMatters is the source for news and information about research and best practices in prevention, care and treatment of spinal cord injury (SCI) and acquired brain injury (ABI).

Working with healthcare practitioners, researchers, policymakers and stakeholders including those living with neurotrauma ONF is a catalyst for change that reduces risk of these injuries and improves the quality of life for those living with a neurotrauma. In NeuroMatters you can read the stories about those are doing this important work and the stories of Ontario people whose lives have been improved through positive changes in health practices, outcomes and policies.

Prevention of neurotrauma and care of those with neurotrauma comes at a high cost to our province's health care system. At ONF we are committed to the important role we play to bring research into practice that will improve lives and support a more efficient use of health care resources in Ontario.

Kent Bassett-Spiers, CEO Ontario Neurotrauma Foundation

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TBI Clinical Practice Guideline Available



Transforming Care for those with TBI:

Clinical Practice Guideline launched

Perhaps you are a clinician who specializes in rehabilitation for those with traumatic brain injury? You're using a tablet between visits with patients to look up a treatment option. Or you are a program director or a LHIN planner on your phone wondering if there is more you can do to incorporate best practices. Or perhaps you are a family member of someone with TBI and you're searching on your desktop computer about what rehabilitation is advised for a particular challenge your loved one is experiencing?

As of October 11 of these individuals are now able to find up-to-date, evidence-informed treatment protocols for adults with moderate to severe TBI, or answer questions about a specific impairment, or management option.

The massive project spanned almost three years and guided by researchers and stakeholders across two provinces. The [Clinical Practice Guideline for the Rehabilitation of Adults with Moderate to Severe TBI](http://www.braininjuryguidelines.org) (CPG) (www.braininjuryguidelines.org) was released today (October 11, 2016). Developed by two partner organizations, ONF and the *Institut national d'excellence en santé et en services sociaux* (INESSS), the CPG is extremely comprehensive (with a total of 266 recommendations for rehabilitation service organization and care), and a first of its kind for TBI healthcare in Canada.

The good news for anyone who may feel overwhelmed by the size and complexity of the resource is its electronic format. The CPG website is designed with built-in search capability and easy to follow sections, which makes the information easy to access and readily available.

Understanding the why, what and who of the CPG

The focus for the guideline is rehabilitative care provided in acute care, inpatient rehabilitation and outpatient rehabilitation. While not the specific focus, the guideline might be useful for those providing longer term rehabilitative care in the community. Areas addressed by the guidelines pertain to:

Components of the optimal rehabilitation system: Those working in rehabilitation and rehabilitative care will be able to determine if they are meeting best practices in the way their services are planned, organized and provided.

Assessment and rehabilitation of brain injury impairments: Clinicians will be able to use the guideline to address how specific effects of TBI should be assessed, and what management options of these impairments are available. Many of these recommendations can be applied across different stages of rehabilitation.

Tackling 266 recommendations

The recommendations cover various effects of moderate to severe TBI (e.g., cognition, behaviours, energy level and sleep and mental health) as well as how to help adults with TBI in the longer term (e.g., social participation, skill maintenance and community-based activity including return to work).

About half of the 266 recommendations are taken from guidelines developed elsewhere and carefully adapted as evidence permits, to make them relevant to the Canadian context. The remainder (126) have been taken from the Acquired Brain Injury Evidence-Based Review (ABIEBR) and developed as new, original recommendations. Much effort was taken to make the recommendation as evidence-based as possible. Where evidence was lacking, the experts used a consensus model to reach clinically relevant recommendations.

How to approach the Guideline

The guideline was created primarily for:

- Clinicians and program managers providing rehabilitation in acute care, inpatient rehabilitation and outpatient rehabilitation,
- Regional planners (LHINS) or organizations that want to understand what they should be providing, and
- Families and people living with TBI might also find the guideline helpful, in terms of understanding the different approaches to rehabilitative care.

Not all recommendations are relevant for everyone. Each user will approach the guideline differently, depending who they are and their situation. For example, a program manager organizing what is needed in outpatient rehabilitative care would look for different options than the family of someone with TBI looking to address an immediate challenge.

The next step: implementation

The guideline is the most up-to-date, evidence-informed clinically relevant guideline for moderate to severe TBI. Those working in rehabilitation have been doing tremendous work; the project partners believe that by identifying best practice and guiding implementation, organizations that provide rehabilitative care will know what to provide and what is needed to provide it.

ONF and INESSS are guiding implementation efforts, working with stakeholders in Ontario and Quebec. The goal is to support various sites during this final phase, helping them prioritize what recommendations would deliver value to them in their context.

The first step is complete. A survey has been sent to over 20 sites in Ontario (and the same number in Quebec) that provide rehabilitative care. We asked them to pinpoint the degree that some of the key recommendations are currently implemented, identify what is high priority for their site, look at the feasibility of implementing it and mention barriers to overcome. The project team and the governance committee overseeing the project will make decisions on priorities, based on survey results, provincial scope and interest.

The project team is also working with various professional associations and stakeholder groups to encourage them to notify their members of the guideline's release, and seek support for its use. This summer, ONF welcomed Judy Gargaro as Clinical and Systems Implementation Associate for the ABI program. Judy will be working with many of the Ontario sites to see how they want to implement, and how to move forward.

A remarkable achievement

The guideline is truly a remarkable achievement for the two partner organizations: ONF and the Institut national d'excellence en santé et en services sociaux (INESSS).

It involved more than 100 stakeholders, including researchers, clinicians, managers, consumers, associations, policy and planning representatives, administrators, and individuals with TBI and their families.

The scientific committee that led the development of the guidelines brought together top researchers and clinicians in TBI and guideline development: in Ontario Dr. Mark Bayley and Dr. Shawn Marshall working with ONF; and in Quebec, Professors Bonnie Swain and Ph.D. Marie-Eve Lamontagne, Ph.D. working with INESSS.

Diagnosing, treating and managing neuropathic pain

At last, some answers

Diagnosing, treating and managing neuropathic pain after SCI

Imagine a clinician's dilemma. An individual with SCI is asking again about the fiery pain in her legs that's keeping her up at night. The neuropathic pain isn't just disrupting her sleep. During the day, it's interfering with her rehabilitation therapy, keeping her from activities of daily living, and over time, leading to depression. She suggests to her clinician an alternate medicine treatment that she read about. The clinician isn't confident about the idea, and wishes there was a specific process for diagnosis, and a treatment recommended as a best practice.

Neuropathic pain (NP) has always been a challenge—for both the clinician and the individual with SCI. Difficult to diagnose and to treat, it is one of the most common complications after SCI, and if not adequately managed, seriously affects quality of life. Several years ago, ONF took the lead and identified the need for clinical practice guidelines that could be used by clinicians and individuals with SCI. Until the release of the new Clinical Practice Guideline for Managing Neuropathic Pain with Patients who have Experienced a Spinal Cord Injury this summer, there was no standardized document guiding care for those with SCI. (Although guidelines for managing NP resulting from other medical conditions did exist.)

“If you can keep pain levels under control, you will hopefully make a significant impact on quality of life,” says Dr. Eldon Loh, lead researcher for the team that created the unique guideline at the Lawson Health Research Institute in London, Ontario.

“The importance of these guidelines is that it gives something for clinicians to refer to in order to see if they are on the right track, and to ensure that they are aware of the current state of research and any standardized management protocols. They provide the steps to go through when treating someone with pain, based on the best evidence available.”

The complexity of NP

NP affects every person with SCI differently, and at different stages post injury. A few may never experience it. All these factors make NP very difficult to manage. Typically, it takes various pharmacological, surgical and alternate medicine approaches to find something that works for each individual.

This kind of complexity, and the individualized nature of NP pain for those with SCI, makes research in this area a challenge. For example, it became clear early on in the development of the guidelines that there was a lack of strong evidence for many treatments, including the use of therapeutic cannabis, acupuncture, and trans-cranial stimulation. There either hadn't been enough studies, or studies on a wide enough scale to determine that any of these options were evidenced-based, even though many may have tried them in their frustration to find a way to eliminate the pain.

For this reason, the guidelines list various treatment options for those with SCI, but beside each one indicate one of three conclusions: recommended, not recommended, or no recommendation at this time pending further research.

Implementing the Guidelines

The guidelines provide tools and resources for those working in rehabilitation care, e.g. clinicians, researchers, and administrators, as well as individuals with SCI and their families as part of managing their own care. Created over a three-year process, recommendations were made for:

- Diagnosis and screening for NP;
- Different treatments, both medication and non medication;
- Models of care, i.e. how to structure delivery of care.

The team is now working on different ways of implementing the guidelines to make them more widely known, and applied in clinical practice and care. They have been published in the [international journal, Spinal Cord](http://www.nature.com/sc/journal/v54/n1s/index.html), and are available on the ONF website. (<http://www.nature.com/sc/journal/v54/n1s/index.html>)

Dr. Loh points out that individuals with SCI are encouraged to make sure their own clinicians know about the guidelines.

The development and release of the guidelines is a reassuring sign that a common, extremely life disruptive condition is being addressed. It is expected that they will have a significant impact on managing pain that too often has been not properly diagnosed and treated. The guidelines also are an essential document moving forward for identifying gaps and setting priorities for future research and best practices implementation. This work begins at a summit to be held on November 4. ONF is both a supporter and participant in this summit.

Fall Prevention Month

We all have a role to play!

Every year in Ontario, 100,000 adults (65 and up) visit a hospital emergency room because of a fall—20,000 of these adults are admitted! The falls happen in an instant, and are usually the result of a common hazard. Someone suffers a bout of dizziness, trips on the stairs, or slips on a wet surface. The result may be a few bruises, but for many, particularly older adults, a fall can lead to more serious complications that impact mobility, independence, and long-term quality of life.

The Ontario Neurotrauma Foundation continues to lead the change in fall prevention. This year's **Fall Prevention Month** is promoting the message that each of us has a role to play in reducing these numbers and keeping older adults active, independent, and healthy as they age. Those responsible for fall prevention range from policy planners to health care providers, and to each of us in the home. It could be a municipality fixing a broken curb by a sidewalk, or an older adult keeping physically active. All of these falls can be prevented if everyone is just more aware of what they can do to make a difference.



With the support of ONF and its **Fall Prevention Month** partners, for 30 days during November, organizations in Ontario and beyond are being encouraged to coordinate their efforts in raising awareness of their members and the public about fall prevention. The idea is that each organization comes up with its own initiatives, but is welcome to use a wide range of resources, all available free in a downloadable toolkit. Everything is available in English and French on the [website](http://www.fallpreventionmonth.ca) www.fallpreventionmonth.ca. Resources cover planning, promotion, programming, events, and evaluation. Included are evaluation tools for reviewing initiatives and sending feedback at the end of the month to the planning team partners.

For example, if a community group is able to hold a public presentation, there is a ready-made PowerPoint presentation as well as materials for an information booth or table. If an organization wishes to provide staff training, there are webinars and educational resources. If groups are looking for recreational activities, there are interactive games and quizzes on fall prevention that can be incorporated into an existing program. For events that focus on older adults, the website includes information about the **Finding Balance Program**, which offers resources to help older adults and their caregivers prevent slips, trips and falls. And if a group isn't sure what to do, there's even a list of brainstorming ideas.

Any group that is arranging a specific initiative is invited to post their events on the [website calendar](#). There are various items for publicizing the month, which groups are encouraged to distribute as widely as possible.

Last year's **Fall Prevention Month** reported that 109 organizations participated in at least one fall prevention initiative, and at least 30 of these organizations partnered with at least one other organization to run their initiative. Because of these efforts, it is estimated that these initiatives over one month reached 6,165 individuals! This year, with the help of a dedicated website and more promotional activities, organizers are hoping to make an even bigger impact.

Thirteen partner organizations support this year's Fall Prevention Month and steering the overall planning and creation of resources. ONF provides both funding and three staff resources to the project. ONF also was instrumental in identifying the need for a coordinated effort in preventing falls, setting up the Fall Prevention Community of Practice in 2010, and bringing together the partner organizations.

It can happen to anyone...

The Ontario Neurotrauma Foundation has spent more than a decade getting the message across that a fall can happen to anyone, at any time—and we are all responsible for prevention. It was

therefore ironic this summer when our Chief Research Officer, Dr. Riopelle, tripped and fell while walking his large St. Bernard dog on a leash over a very hilly golf course.

When asked about his fall, Rick acknowledged, “I belong in the category of ‘it could happen to me, but’ The ‘buts’ in this case were to use the opportunity while vacationing to get into a regular routine of exercise to manage the vicissitudes of aging while enjoying the scenery of Western Newfoundland as well as looking for lost golf balls! Attention to the walking terrain, and the directions the dog wished to take were the least of my concerns!”



Rick’s incident also demonstrates another important focus of ONF’s work—research makes a much greater impact on individual lives when it is actually put into practice!

[Dr. Richard Riopelle](#) has spent a career in neuroscience, most recently as the Chair of the McGill Department of Neurology and Neurosurgery before coming to ONF.

Four Important Summits

Four Important Summits

This year, ONF is supporting four important summits that are focused on bringing research into practice:

- Developing Standards of Care in Concussion Clinics in Ontario, April 15, 2016
- Neuropathic Pain Care and SCI, November 4, 2016
- Urological Health and SCI Summit, November 11, 2016
- SCI Primary Care Summit, November 23, 2016

Although each of these summits is focused on an entirely different topic, the purpose for each gathering is the same. Bring together research and subject matter experts, clinicians and policy makers, gather input from those with lived experience, and develop strategies to implement practice guidelines. The results, in each case, lead to improved practice or standards of care, more effective collaboration, new partnerships, and most important, improved quality of life.

Two of this year's summits are summarized below:

Getting the Right Care, from the Right Provider, at the Right Time: An SCI Primary Care Summit

Dr. Joseph Lee sees the upcoming **SCI Primary Care Summit** as a natural evolution of the collaborative work, research, and learning to-date on how it is possible to deliver better health care to those with spinal cord injury, and in a more timely way.

Both Lee and the co-leader for the summit, Dr. James Mulligan, have witnessed the challenges faced by those with SCI when it comes to finding primary care providers in their community. Those with SCI are heavy users of the healthcare system. But in too many instances, they are forced to use more costly resources such as emergency care centres for medical issues, which should be considered fairly routine to treat.

“The playing field is not level,” explains Lee, “Individuals with SCI do not have the same access to primary care providers for treating what are considered fairly common health issues, e.g. a urinary tract infection, or accessing routine tests such as a pap smear.”

Such challenges to access primary care are costly to the healthcare system as well as distressful and risky for the individual. Someone with SCI may wait several hours in a hospital waiting room for a condition that should be quickly and easily treated by a primary care provider. As a result, conditions are often left untreated until they became worse, which then lead to a hospital visit that might have otherwise been avoided.

Quality of life is also impacted in terms of family and relationships, productivity, and caregiver burden. In order to better manage one's health and find treatment, an individual with SCI often ends up moving away from their home community where they have their support network and family in order to be closer to an academic SCI rehab centre.

Few resources, conferences address primary care and SCI

In recent years, Lee and Milligan both realized that none of the conferences they attended on various aspects of SCI placed much, if any emphasis on primary care. It led Lee and Mulligan to a decision to hold a summit with the specific purpose of taking the lead to guide the direction of primary care for those with SCI in Ontario. The summit topic aligns with the goals of the “patient first” agenda of the Ministry of Health and Long Term Care.

The November summit, supported by the Ontario Neurotrauma Foundation, is an opportunity for 90-100 individuals to hear what Lee and others have learned from their own experience with more effective models of primary healthcare for SCI. Much of this experience has come from Lee's own involvement as one of the leads for the PRISM project (Primary Care and Rehabilitation with Self-Management) and the **Primary Care Mobility Clinic at the Center for Family Medicine in Kitchener/Waterloo**.

Attendees from across the province have been invited. They include primary care providers, researchers, specialists, LHIN directors, and policy makers drawn to the value of integrated, coordinated care that delivers better results in terms of cost as well as quality of life. People with SCI are participating in the presentations and panels. Those expected to attend are national SCI partners such as the Rick Hansen Institute, one of Canada's top neurotrauma surgeons, Dr. Michal Fehlings, and leading physiatrist Dr. Cathy Craven. The Deputy Minister of Health and Long-Term Care, Dr. Bob Bell will deliver the keynote address to attendees.

Lee hopes that the summit leads to the creation of other regional centres. "We need to share what we've learned over the past several years," he says, "There is a model for delivering healthcare to those with SCI that is more effective, and it costs less. What's not to like about that?"

For the past three years, Lee, along with Mulligan and Dr. Dalton Wolfe, have co-led PRISM (Primary Care and Rehabilitation with Self-Management), a project aimed at breaking down barriers across rehabilitation specialist and primary care providers. One of the healthcare models further developed through PRISM was the primary care Mobility Clinic at the Center for Family Medicine in Kitchener/Waterloo. ONF has had an active role in supporting and encouraging the work of the Mobility Centre.

Concussion Standards Summit

Public awareness of concussions has increased in recent years, and with this increase, so has the number of clinics (public, private, and third-party funded) that offer treatment and advice. Those committed to effective, right care, have begun to ask questions such as, "What qualifications should a 'concussion expert' have?", "What are the features that must be included in clinics that offer concussion treatment?" and "What do patients need to know to empower them to know that they have the right provider(s)?"

A few concussions statistics:

In 2013 alone there were 148,710 concussion diagnoses in Ontario,

43% of the patients with diagnosed concussions are under 18 years of age.

44% are within working age from 18-65 years of age, thus impacting the workforce and the economy.

On April 15, 2016, ONF brought together 65 concussion clinic providers, traumatic brain injury experts, people with lived experience of concussion, and organizations and agencies with an interest in concussion from around Ontario. The purpose was to look at how to develop standards for concussion clinics in Ontario.

Those gathered discussed key issues around consistency, quality, access to, and coordination of care for persons of all ages in Ontario who are dealing with the effects of concussion. There are approximately 150,000 people diagnosed with a concussion each year in Ontario. Of particular

concern, are the approximately 22,000 with persistent post-concussion syndrome who experience a prolonged, challenging recovery.

Better information, more interprofessional co-ordination

The group's vision was unequivocal— every Ontarian should be assured of the right concussion management of the highest quality, delivered at the right time, by the right provider. It was agreed that regardless of age, cause of injury or place of residence, providers of concussion care need better information and more inter-professional coordination in order to ensure that every Ontarian receives the most appropriate concussion care.

The first important, and necessary step is the development of minimum standards for concussion clinics. Such standards apply to the early management phase as well as the longer-term management of persistent post-concussion symptoms.

Such an action would set up the “quality standard” across the province to ensure that no matter where someone lives, in a city or a rural northern community, they have access to the right care, delivered by an interdisciplinary group of qualified professionals. The care also has to be evidence-based, with appropriate management protocols that improves chances of recovery and minimizes persistence of symptoms.

As a result of the summit, a strategy has since been developed that revolves around specific objectives, and an action plan for working with various stakeholders, partners, and collaborators including Health Quality Ontario. ONF is leading this work, based on **the long-term vision**:

Having standards in place for concussion clinics in order that funders and planners know what resources are needed to deliver optimal accessible concussion care, in a timely fashion delivered by appropriate providers, and patients and families are assured that they are receiving the best care.

Over the next few months, working groups with key stakeholders will be developing action plans in order to move forward on the following objectives:

- Develop standards for concussion clinics throughout Ontario;
- Establish ‘collective competence’ in concussion care that facilitates networks for regional care. Collective competence focuses on how individuals work collectively as a team, with awareness of each other’s contribution;
- Build an improved system for management and referrals;
- Improve the knowledge of patients and families regarding what they can expect as optimal services
- Develop methods for assessment, coordination and measurement of standards.

To find out more about the developing standards, please contact [Corinne Kagan](#).

Happy Birthday Loop

What's Next?

It's been a year since the [Fall Prevention Community of Practice \(CoP\)](#) launched Loop, the online collaboration tool, directory and search engine for fall prevention. The most unique aspect of Loop that also offers the greatest potential is the way in which it helps individuals across the province, whatever their interest in fall prevention, to collaborate more effectively. Using Loop, CoP members are able to:

- Exchange information on fall prevention;
- Discuss and collaborate on how to implement the latest evidence-based research and interventions in fall prevention;
- Network to find a mentor, partner or subject expert.

Loop is funded and staffed by the Ontario Neurotrauma Foundation but made possible through the active leadership of more than a dozen partner organizations.

This past year, for example, one Loop member was contacted by a local Community Care Access Centre (CCAC). Serving a rural area, the CCAC was about to initiate a fall prevention protocol for staff, and one of the directors was hoping to find a suitable presentation so she wouldn't have to



duplicate the effort. Not only was the Loop member able to fill her request, she connected the CCAC to others in the province who had done similar work.

Loop was evaluated over the summer via a membership survey. The results indicate it's been a great start for the interactive platform, with the over 1,000 Loop members enthusiastic about its benefits and potential. The next step is to get the word out about Loop's value, particularly for connecting and networking, and provide better orientation to new CoP members about Loop's services and supports.

Highlights of the survey include:

- As of September 9, there were 1,092 Loop members from all across Canada, both English and French.
- The majority are from Ontario, but the CoP is confident that over time numbers will increase country-wide.
- Loop successfully attracted a diverse membership. Most are from Community Care, Public Health and Long-Term Care sectors.
- The top 3 reasons for joining Loop were (in order): access to information (evidence-based research), professional development, and networking.
- Three quarters of respondents were enthusiastic about Loop because they see the benefits of working collaboratively.
- Webinars offered by the CoP and advertised through Loop were very popular.
- Library services were appreciated but underutilized.
- A small number of survey respondents noted the positive impacts of the CoP on policy (a very encouraging sign!).

For those who know about Loop and use its services, the platform is valued, and it is having a positive influence on the work of survey respondents. The next step for those in the CoP, in addition to everyone committed to fall prevention, is clear: spread the word about the CoP and Loop!

Comments to include from survey:

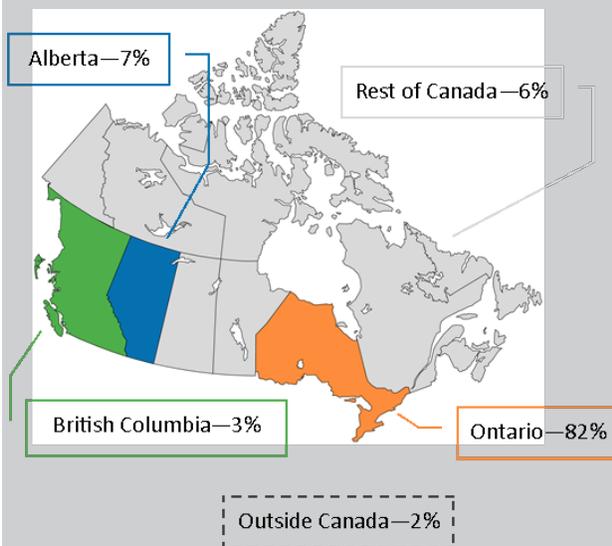
“Loop has connected our fall strategy stakeholder group with other provincial partner's doing similar work thus avoiding duplication and providing contacts for further inquiries.” “

[Loop] brought to light questions I hadn't considered before.” “

[Loop] community is friendly and supportive.” “

It is nice to know that others are working on some of the same aspects of fall prevention and that there is a place to connect with other like-minded individuals should you need to.”

Most Loop members are located in Ontario.



Meet Judy Gargaro

Judy Gargaro is the newest member of the ONF family. With 25 years experience in brain injury and spinal cord injury research, Judy is excited about her role as Clinical and Systems Implementation Associate.

“It's the perfect evolution for me,” she says, “For years I contributed to evidence-based research for clinical practice and programs. Now I have the opportunity to ensure best practices become a reality!”



Judy recognizes the challenge as well as the importance of effective implementation. It is estimated that less than 20 percent of best practices are ever applied because it takes both specific funding and effort to be able to effectively plan and sustain implementation activities. “It is not a case of lack of willingness,” she says, “But rather, budgets are so tight that without additional funding and a dedicated person, nothing gets started, or sustained.

“ONF is showing great vision in creating this dedicated position. It brings such value across the province to the entire system.”

Judy’s first assignment is supporting the implementation for two initiatives that have far-reaching impact across the province: the new Clinical Practice Guidelines for Moderate to Severe TBI, and the Standards of Care for Concussion Clinics.

Judy’s most recent work includes research coordination in brain injury and clinical program evaluation at West Park Healthcare Centre, Community Head Injury Resource Services (CHIRS), and Cota, a community-based support service for adults with mental health and cognitive challenges.