

NeuroMatters

Connecting YOU to the Research

IN THIS ISSUE

- 1 Delivering Primary Care
- 3 Will I be Able to Drive Again?
- 5 A Tool Kit to Stay Active
- 7 Upcoming Events
- 8 New Canadian Guidelines for TBI Rehabilitation



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

Delivering Primary Care to the Community

New eLearning resource launched for family physicians

Visits to a family physician are essential to maintaining one's health. But routine visits for a person with a spinal cord injury (SCI) are difficult, and in many instances, not even possible. The appointment may be a routine check-up that includes some specific tests, or it could be because someone is sick, hurt, or feel they require medical attention. But for a person with a spinal cord injury, such visits are not easy to arrange. In many instances, they are not even possible.

The reasons often are related to the facility itself. Many offices do not have a wheelchair ramp, an accessible bathroom or an examination table. The training and experience of the doctor is another issue. In Canada, medical students and family medicine residents

receive minimal or no training in SCI treatment and management. As a result, many SCI patients visit emergency rooms for medical complications. The reason may be a urinary tract infection or something more routine like the flu. But emergency departments are not a

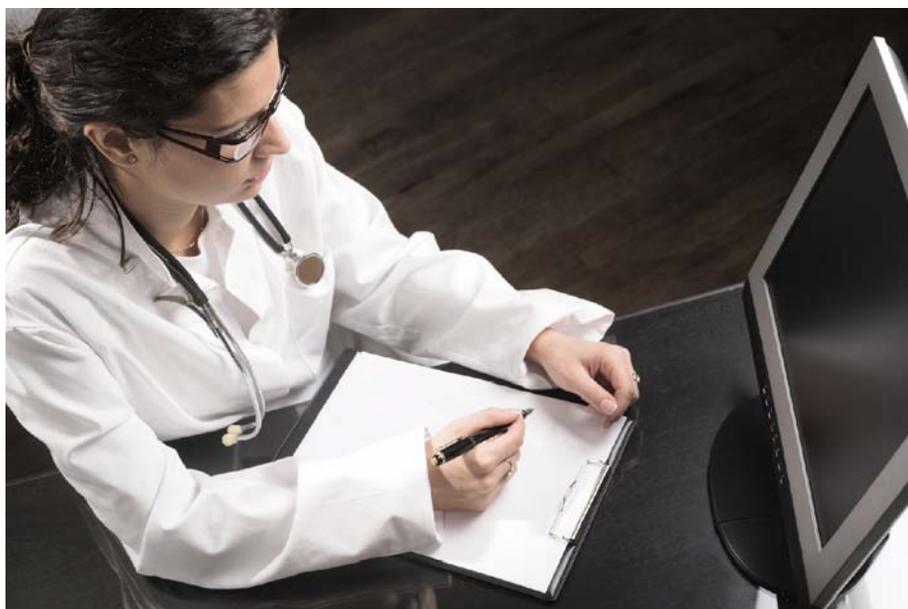
satisfactory substitute for a family physician. These visits are more costly to the healthcare system and they increase wait times.

Meeting an immediate need through eLearning

A team from the University of Ottawa in partnership with Ontario Neurotrauma Foundation recently launched an eLearning resource to address this problem. *Caring for Persons with Spinal Cord Injury: An eLearning Resource for Family Physicians* provides family physicians with information on how to care for patients who have a SCI. The online resource provides everything from a general overview of specific SCI topics to identification of symptoms, treatment, and overall health management.

"Even if family physicians have only a few SCI patients, they need to know how to treat them properly

...continued on page 2



...continued from page 1

and know how to train their staff to do the same," says Dr. Colla MacDonald from the Faculty of Education at the University of Ottawa. Dr. MacDonald is the lead researcher for the project, and an expert on curriculum design, evaluation and elearning in medical education. It is expected that the resource will support a physician in becoming more confident about accepting and treating patients with SCI.

Practical, comprehensive and easy-to-assess

The resource is designed around specific medical needs of a person with SCI and organized into five areas: Autonomic Dysreflexia, Neurogenic Bladder, Neurogenic Bowel, Respiratory Complications and Pressure Ulcers. Each section provides an overview as well as specifics on diagnosis, management, recommendations and follow-up. For example, in the Neurogenic Bladder section, physicians are given the signs of urinary tract infections, and cautioned that for individuals with

SCI, the symptoms may not be typical to what the physicians is used to seeing in their routine practice. Another section recommends the kind and frequency of various medical tests such as bone density scans and what to routinely screen for when doing an ultrasound. Helpful health promotion and preventative care recommendations are included. This could be advice a physician is able to pass on to patients about the importance of daily skin care checks to prevent pressure ulcers.

Designed with the user and the consumer in mind

When designing the resource, the experienced curriculum design team understood the challenge for doctors both in learning the material and then teaching it to medical students and residents. The resource is designed in bite-size pieces. An overview in each subject takes about 15-20 minutes, but there are layers of information. The learner can delve deeper into each area.

Prior to and during the content development, the team held workshops with family physicians, subject area specialists, physiatrists, SCI consumers and caregivers in order to get feedback and suggestions. "We worked together every step of the way in order to design a resource that would be relevant and authentic," explains MacDonald.

What may appear to be a minor issue in someone without a SCI may be a serious problem, even an emergency for a person with SCI. "A physician needs to know when to treat as well as when to refer to a specialist," adds MacDonald.

Caring for Persons with Spinal Cord Injury provides information on:

- Autonomic Dysreflexia
- Neurogenic Bladder
- Neurogenic Bowel
- Respiratory Complications
- Pressure Ulcers

Easy to use and ready to try

"The resource is designed as self-directed learning," she adds. "Physicians can also direct their medical students, residents, patients and their families to the site to learn more about caring for someone with a SCI. It is hosted on the ONF website and requires no passwords in order to facilitate easy access (<http://eprimary.care.onf.org>)."

Next steps will be to evaluate the resource, provide CME credits to physicians who complete it, and implement the resource within a family practice. It is hoped that in the near future the resource will become an integral part of the family medicine curriculum.

Caring for Persons with Spinal Cord Injury was funded by ONF, in partnership with the Department of Family Medicine, University of Ottawa.

"Even if family physicians have only a few SCI patients, they need to know how to treat them properly and know how to train their staff to do the same."



Will I Be Able to Drive Again?

New research to support the return to safe driving post TBI

Being able to drive again is a pivotal question for those who have sustained a traumatic brain injury (TBI). Driving represents independence: being able to get to work, visit friends and go places. But how do clinicians, responsible for determining driving readiness, evaluate whether or not someone still has the skills required to be on the road?

To date, there is no evidence-based assessment process for understanding driving ability post TBI. With no two injuries exactly the same, the signs can be difficult to assess, specifically in borderline situations. There is disagreement as to the best way to make assessments and concern that they do not take into consideration the sensitivity of the topic. Many individuals, post-TBI, are left with no option but to take a generic off-road driving test.

Understanding the nature of driving difficulties

To address these gaps, research is currently underway in a joint Ontario/Australian research partnership. The research mandate is to provide an evidence-based understanding of what happens to someone's

driving ability after a TBI. By looking at the nature and causes of driving difficulties, researchers expect to develop a more reliable and valid assessment procedure. It also is expected that the knowledge and evidence gained from the project will form the basis for skills re-training.

"We're not about taking away licenses," emphasizes Michel Bédard, one of two lead researchers on the project, *Safer Roads to Recovery*. "That is the last option we want.

"We want to understand how a TBI affects someone's ability to drive safely. We are asking, what do we know that supports safe driving and how do we evaluate how it may have changed following a TBI? And then, if someone has difficulties driving, how do we best support him or

"We're not about taking away licenses," emphasizes Michel Bédard, one of two lead researchers on the project, Safer Roads to Recovery. "That is the last option we want."

...continued on page 4

...continued from page 3

her, that is, what kind of retraining might be required to drive safely?"

Driving simulators test cognitive, physical and motor challenges

Driving requires noticing continually changing visual stimuli, fast information processing and correct motor ability. Bédard's team is using special research driving simulators to create on-road, naturalistic driving conditions that replicate the number of complex brain activities that take place when driving a car. Data is being collected from participants at three sites in Thunder Bay, Ottawa and Melbourne, Australia. Unlike actual road tests, simulators at these sites are programed to target specific challenges that cover these cognitive, physical and motor skills.



Driving simulators test cognitive, physical and motor challenges.

Helping TBI survivors return to safe driving is critical in their path to recovery and their ability to reintegrate back into their community.

"We are trying to understand how the decision making process is affected at various levels," explains Bédard. "We program into the simulators common and challenging situations a driver might experience, e.g. unexpected lane change requirement, braking for a pedestrian."

Safety and support first

Helping TBI survivors return to safe driving is critical in their path to recovery and their ability to reintegrate back into their community. TBI is currently the number one disabler of young Canadians under the age of 40, with the majority being young men between ages of 15 and 30. These individuals are particularly anxious to get back behind the wheel.

The research findings will contribute to safety for those who

return to driving (currently, about 50 percent) by making sure they are ready. If not, there need to be options for driver retraining, and as a last resort, support for the transition to non-driving.

"We have a responsibility to keep the roads safe, but our first approach is to enhance someone's skills so they are independent and safe on the road," says Bédard.

**Driving as a key to independence
Safer Roads to Recovery: Assessing Readiness for Driving after Traumatic Brain Injury**

is a joint research partnership between ONF and TAC (Transport Accident Commission) in Australia. Piloting is complete and data collection is expected to be finished this spring. A final report is expected in August, 2014.



**Go ahead, play a sport,
exercise, get active!**



Evidence-based research now shows that physical exercise improves strength and cardiovascular health for individuals with SCI. Stronger muscles and greater aerobic endurance translates into practical benefits. For example, it means an individual is able to do transfers more easily, wheel longer and enjoy more activities without feeling fatigued.

Following up on this research, in 2011 a team of researchers at McMaster University produced the first evidence-based physical activity guidelines for adults with SCI. The guidelines state that to improve physical fitness, healthy adults with SCI should participate in at least 20 minutes of moderate to vigorous aerobic activity two times per week, as well as strength training exercises two times per week.

The development of guidelines, however, raised some very important questions around implementation.

"Once the guidelines were published," says Dr. Kathleen Martin Ginis, Professor of Health and Exercise Psychology at McMaster University, "Members from the SCI community met with our research team and said that there was a lack of information about the specifics of exercise. We needed to answer questions such as, "How do I become more active?" "What is the best way to start an exercise program?" "How do I stay committed once I start?" "How do I know what exercises are right for me?"

Moving guidelines into practice

The SCI GET FIT toolkit kit is designed to help adults with SCI put the physical activity guidelines into practice.

"We needed to answer questions such as, "How do I become more active?" "What is the best way to start an exercise program?" "How do I stay committed once I start?" "How do I know what exercises are right for me?"

The toolkit packs a wealth of information into an easy-to-use format. Within four pages, there is practical advice about setting up and maintaining an exercise program. It lists exercises an individual can do in the home or at a gym, using either a manual or power wheelchair. There are tips on how to make your plan "sticky" as well as an example of an exercise action plan. Links throughout to more detailed online information include a portal where individuals can input the kind of activity they are looking for, e.g. basketball. Then by clicking "search", they will be directed to the nearest club or facility with adaptive equipment and organized teams for that activity.

Getting started, staying committed

Although targeted at individuals with SCI, the toolkit summarizes the benefits as well as safety tips and strategies to overcome common physical activity barriers. This makes it an invaluable resource for caregivers, fitness instructors, healthcare and rehab professionals as well.

...continued on page 6

...continued from page 5

"The barriers to starting an exercise program are high for anyone," explains Martin Ginis. "For those with SCI, these are even higher. First of all, even if someone lives close to a fitness facility, that facility may not be accessible from the street and the equipment maybe too close together for a wheelchair to fit."

Martin Ginis also recognizes that commitment to regular exercise can be a challenge. "Sticking with a program is difficult, especially when an individual gets sick and misses a few times. Fear can also be a factor. Many individuals with SCI, or their caregivers, are afraid that exercise might cause them to

get hurt. In order to keep up an exercise routine at an outside fitness facility an individual also needs to have access to transportation."

Spreading the word

As the toolkit has been introduced across Canada, response has been overwhelmingly positive. Many say that they are referring to it continually and searching on the suggested website links. Some have even taken the brochure to their fitness club to show what can be provided. A support line telephone service is expected to be available this fall, which will provide additional guidance and motivation.

SCI GET FIT TOOLKIT GO ACTION CANADA
A CANADIAN RESOURCE TO HELP ADULTS WITH SPINAL CORD INJURY MEET PHYSICAL ACTIVITY GUIDELINES

Experts recommend that all healthy adults with spinal cord injury set aside time to be physically active. This part of your day should be enjoyable, so choose activities that you like to do, and make it fun.
Try to incorporate both:
1 - AEROBIC ACTIVITY
2 - STRENGTHENING ACTIVITY

GUIDELINES AT A GLANCE
FOR IMPORTANT FITNESS BENEFITS, ADULTS WITH A SPINAL CORD INJURY SHOULD ENGAGE IN:
• At least 20 minutes of moderate- to vigorous-intensity AEROBIC activity 2 times per week, AND
• 3 sets of 8-10 repetitions of STRENGTHENING activity for each muscle group 2 times per week.

AIM FOR:

AEROBIC ACTIVITY
From Moderate to Vigorous.
Moderate means somewhat hard, and you feel like you could continue for a long time. You can talk, but not sing your favourite song, during the activity. Using a 0 to 10 scale, moderate-intensity physical activity is usually a 5 or 6.
Vigorous is really hard, and you feel like you can only continue for a short time before getting tired. You will not be able to say more than a few words without pausing for a breath. Using a 0 to 10 scale, vigorous-intensity physical activity is usually a 7 or 8.

STRENGTHENING ACTIVITY
You should feel quite challenged (without hurting yourself) by the end of the 3 sets. Take a 1-2 minute rest break between each set. Work each muscle group on alternate days.

ACTIVITY IDEAS
Wheeling, arm cycling, sports, swimming
Free weights, elastic resistance bands, cable pulleys, weight machines

If you are newly injured, are pregnant, prone to autonomic dysreflexia, or have other medical conditions, you should talk to your health professional to find out what types and amount of physical activity are right for you. A health professional might include a doctor, a physiotherapist, or a qualified exercise professional.

For a more detailed look at the guidelines and how you can get started, go to www.sciactioncanada.ca



One of the best outcomes is that many now realize what kind of exercise is available to them. As Martin Ginis notes, "People just didn't know what they could do; that they could do exercises in their home like yoga or strength-training, or that they could participate in sports like basketball, tennis, curling."

The guidelines, toolkit and all related resources are available for downloading on the SCI Action Canada website, <http://sciactioncanada.ca/guidelines/toolkit>.

ONF supported the development of physical activity guidelines as well as the implementation, which included the SCI GET FIT toolkit.

...continued from page 8

those in clinical care, and beneficial for TBI survivors.

The feedback from frontline clinicians emphasized the need for guidelines that are both "implementable" and "accessible".

"We certainly heard back that what they require needs to be practical," says Dr. Marshall. "Former rehab guidelines tended to give general, broad recommendations such as 'do a thorough assessment'. What clinicians really need are specific, relevant recommendations with associated tools for implementation. These could take various formats, depending on what is required. For example, it could be a checklist, a chart, an app, or perhaps a video that shows what to expect."

Clear and transparent

There is plenty of information available since the last TBI guidelines were prepared. Now that the survey of potential users is complete, the project is moving into the stage of pulling the

**"Feedback from
frontline clinicians
emphasized the need
for guidelines that are
both implementable
and accessible."**

evidence together. "Our job is to identify what is the most up-to-date, high quality and clinically relevant for TBI rehabilitation in Canada," says Dr. Marshall, "and adapt them for local applicability."

Good evidence-based guidelines are clear and transparent. This means that anyone using the guidelines to make a decision can apply them in light of the strength of that evidence and its relevance to their clinical setting. The new guidelines will explain to the user what the evidence says as well as be explicit as to the level (strength) of the evidence.

Next steps

The project spans 3 years, with the guidelines in English and French expected by Spring 2015. Once completed, there could be a "patient and family friendly version". This would help family members and caregivers gain a greater understanding of the rehabilitation process and the care being provided.

Throughout the process, the research team will continue to collaborate with all stakeholders, both in the development and implementation phase. A panel of experts will include clinical, research, consumer/family, policy and administrative experts from Ontario and Quebec. Pilot projects will take place at a few sites in each province, though ONF and INESSS are aiming at much broader implementation.

The Guideline for the Rehabilitation of Adults with Moderate to Severe Traumatic Brain Injury is a joint project between ONF and INESSS.

Upcoming Events



Watch Your Step! 2014 National Fall Prevention Conference

May 27th - 28th, 2014

Delta Chelsea Hotel, Toronto

Designed for those who work with older adults in all settings, researchers, practitioners and policymakers working in seniors' health and injury prevention.

<http://www.oninjuryresources.ca/events/item/national-fall-prevention-conference>

Bioinformatics Inform SCI Rehabilitation. Toronto Rehabilitation's 6th National Spinal Cord Injury Conference

October 2nd - 4th, 2014-

Allstream Centre, Exhibition Place, Toronto

www.sciconference.ca

Progress in Rehabilitation Research. 91st Annual ACRM Conference

"The ACRM Annual Conference is the best educational opportunity to learn about interdisciplinary care, the hallmark of outstanding rehabilitation."

October 7th - 11th, 2014

Metro Toronto Convention Centre, Toronto

<http://www.acrm.org/meetings/2014-annual-conference>

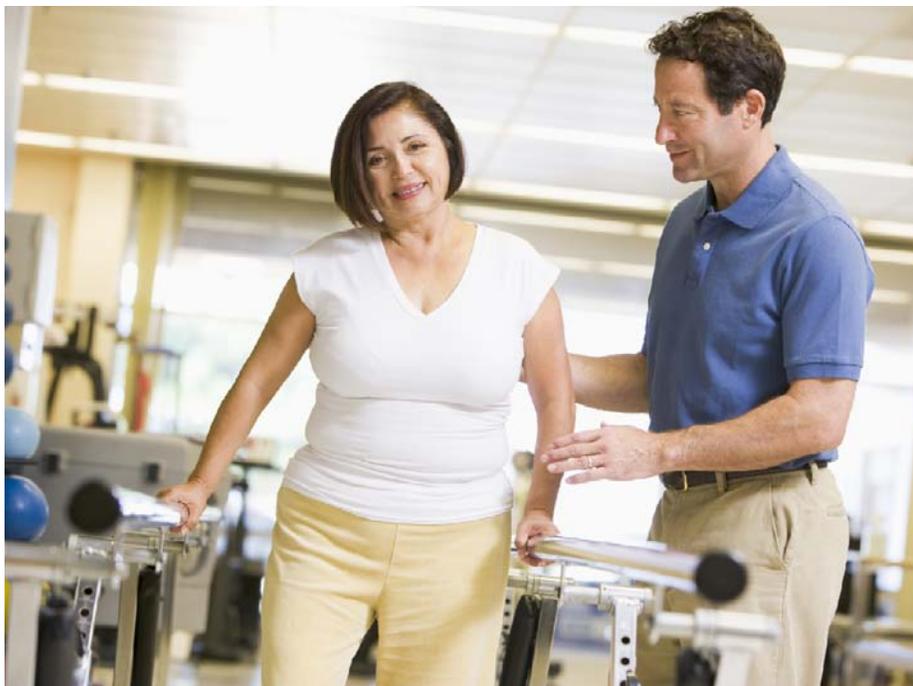
Toronto ABI Network Conference 2014

November 20th - 21st, 2014

Allstream Centre, Exhibition Place, Toronto

<http://www.abinetwork.ca>

New Canadian Guidelines for TBI Rehabilitation



Research now underway with clinicians' help

Each day front-line clinicians such as occupational therapists, physiotherapists and other health professionals spend hours helping individuals gain the best function possible, following a moderate to severe traumatic brain injury (TBI). Expert and committed to the work they do, these rehabilitation specialists know firsthand what happens through the rehabilitation process. They witness the challenges faced by patients and their families as well as fellow clinicians.

Front-line clinicians, program coordinators and managers working in rehabilitation settings and providing rehabilitation within acute care facilities in Ontario and Quebec were recently asked about their needs and expectations for an up-to-date and useful clinical practice guideline.

The guideline project team believes this kind of stakeholder and end user input is an important step in the development of new Canadian clinical practice guidelines for TBI rehabilitation. The feedback helps to evaluate needs at the beginning of the research. It also facilitates the eventual use

and integration of the guideline recommendations into clinical practice.

There are existing guidelines for TBI rehabilitation, but either they have been written for healthcare settings outside of the Canadian context or they have become outdated. There also were variations in approach among guidelines written a decade ago. Having guidelines that ensure consistent care across health care settings and provinces is key to making sure those who have experienced a TBI receive the best care possible.

"The rehabilitation experts surveyed have been particularly helpful in letting us know what would help them to provide consistent, high quality care," says Corinne Kagan, Senior ABI Program Director at Ontario Neurotrauma Foundation (ONF).

New Canadian guidelines that are relevant and up-to-date

The guidelines are being developed by a joint Ontario/Quebec team. Working with ONF in Ontario, the project is under the direction of co-leads Drs. Mark Bayley and Shawn Marshall. In Quebec, working with Institute national d'excellence en santé et en services sociaux (INESSS), the project is under the direction of Professors Bonnie Swaine and Marie-Eve Lamontagne.

An overarching goal of the project is to make sure that the new guidelines are evidence-informed, relevant and useful for

...continued - please go back to page 7

