

NeuroMatters

Connecting YOU to the Research

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Please Remain Seated

A look at preventing spills, falls and tumbles

It's bad enough that falls are one of the major causes of spinal cord injury (SCI), but studies have shown that wheelchair users are prone to subsequent falls, some with serious outcomes. For people with SCI, even a minor injury from a fall can result in secondary complications like pressure sores if not treated properly, so prevention and precautionary measures are needed to maintain good health. As well, compared to the general population, people with SCI have more fragile bones, making them more susceptible to breaking bones. That's because bone mineral density - especially in the hips and knees - tends to decrease after SCI because of people's inability to weight bear.

The Ontario Neurotrauma Foundation (ONF) has been looking at how to assist in the prevention of falls, including among people with SCI. This includes falls in the hospital setting and community.

For people in rehab soon after SCI the newness of their condition and its effects make them more susceptible to falls. Since about 30% of hospital-based falls result in serious injury, ONF started working with Toronto Rehabilitation Institute to reduce the number of falls among people with SCI.

Toronto Rehab has identified some of the best ways to prevent falls in hospitals. They include...

- consistent reporting (i.e. professionals should report on patient falls and injury rates, and they should classify the severity of the injury)

- post-fall assessments to identify what caused a fall and to eliminate or avoid the hazard
- better risk assessment (i.e. professionals should identify those patients who are at risk of falling and then work with them and staff to avoid possible risks)
- creation of comprehensive risk and injury prevention strategies to minimize the risk of a fall

- better equipment and supplies (e.g. adjustable beds, raised toilets, proper sized wheelchairs)
- training in wheelchair skills and safety
- prevention and management training for staff, patients and the families of patients
- a standard policy that incorporates the foregoing recommendations
- getting clinical innovation and research findings into the hands of those who can use them

Hospital leaders were called upon to help make the changes noted in the above recommendations, and Toronto Rehab has created an evaluation process to



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see whether needs are being met as these recommendations are put in place. The follow-through will result in the development of best practices that can be shared with other hospitals. ONF will continue to work with Toronto Rehab to identify practices that will specifically benefit people with SCI.

It is important to consider how the recommendations made by Toronto Rehab can be used in non-hospital settings - i.e. out in the community - where people with SCI spend most of their lives.

There has been a lot of research committed to issues related to SCI. ONF funded the Spinal Cord Injury Rehabilitation Evidence (SCIRE) project. It culminated in the 2006 publication of a comprehensive report on published research on rehabilitation strategies and community-based programmes to improve the functional outcomes and quality of life for people with SCI.

The SCIRE report has many key points highlighted and those that assist people in avoiding falls are as follows:

1. Bone Health

According to the SCIRE report, there is overwhelming evidence about the merits of addressing bone health issues as soon as possible after sustaining a SCI. If you have not had your bone mineral density tested and treated, you may be at greater risk for fragile bones, which in turn puts you at greater risk for falls. The SCIRE report also points to evidence that calcium and vitamin D supplements, some oral medications, and electrical stimulation can increase your bone mineral density. Talk to your doctor to see what treatments can help you.

2. Physical Fitness

The goal of rehabilitation is for you to be at your physical best so that there is less risk of injury or compli-

cations. Research in the SCIRE report indicates that there is a direct correlation between one's level of functioning and one's quality of life. Being physically fit will help in many ways, such as reducing pain and stress, improving balance, and making transfers less difficult. Strength will help move body weight, and muscles will act like cushions if you do fall.

According to the SCIRE report, here are some proven ways to improve your fitness level and strengthen your muscles:

- > Neuromuscular stimulation assisted exercise - where a healthcare professional will work a certain muscle
- > Cardiovascular fitness - aerobic exercise at moderate intensity - 20 to 60 minutes a day, 3 times a week
- > Resistance training (weights, resistance bands, swimming) at moderate intensity, 2 times a week

3. Age

Research has shown that the younger you are, the more likely you will recover quickly from a fall. People who are older and have had a longstanding injury not only take longer to recover, but also are statistically at higher risk of breaking their bones when they fall - or of breaking a bone and therefore falling.

4. Gender

Research shows that, in general, women have more bone breaks than men. Therefore, women are more likely to fall from a break - or to break a bone from a fall. During menopause, women with SCI have greater bone mineral density loss in their hips and knees than women without disabilities.

5. Sleep Issues

Studies have shown that people with SCI tend to have sleep issues (e.g., apnea, snoring, daytime

sleepiness). Falls can happen when people are not as aware as they want to be or need to be. So it makes sense to talk to your doctor about what you can do to improve your sleep.

6. Prior history

Research shows that a family history of broken bones prior to your SCI also plays an important role in your bone health and therefore your risk of falling. If you have a history of broken bones on your mother's side, or if you have had broken bones yourself, you already have weaker bones. Since research findings have shown that the majority of breaks happen after transfers or activities that involve minimal or no trauma, fragile bones are a risk factor for falls.

If you experience a fall, it would be wise to do a post-fall assessment, just like Toronto Rehab recommends in the context of hospital-based settings. See if you can determine why the fall happened and then remove or fix the problem, or change whatever you need to do, so that a fall does not happen again.

By keeping these suggestions in mind, and with Toronto Rehab creating best practices for fall prevention, the world should get a bit safer for everyone!

In the next issue of NeuroMatters, we will highlight two new bone-health projects:

- "Whole Body Vibrations for Treatment of Sublesional Osteoporosis after SCI", dealing with the prevention of bone loss
- A clinical trial on the drug Risebronate, which is being used to treat sublesional osteoporosis after SCI

Can You See Us

ABI organizations ban together to create awareness and education

Part of ONF's vision is to improve the quality of life for people with neurotrauma. So it made perfect sense for us to collaborate with the following organizations in the founding of the Ontario Alliance for Action on Brain Injury.

- Ontario Brain Injury Association (OBIA)
- Ontario Association of Community-Based Boards for Acquired Brain Injury Services (OACBIBS)
- Provincial Acquired Brain Injury Advisory Committee (PABIAC)
- Toronto Acquired Brain Injury (ABI) Network

The Alliance wants to make a difference in the lives of people living with ABI. It seeks to partner with government to develop a detailed strategy on how to support brain injury survivors and their families in the community. To this end, it has developed a public awareness campaign to educate people about what it means to have a brain injury.

Known as *People Living with Brain Injuries - Can you See Us?*, the campaign notes that people with brain injuries are not being noticed. A brain injury does not necessarily have a visible aid, such as a crutch or a wheelchair, and so people tend to think a brain injury is something you "get over" or they confuse mannerisms like lack of balance or slurred speech with other health issues like alcoholism or drug addiction. In fact, there are approximately 500,000 Ontarians who have an acquired brain injury (ABI), and 44 people in Ontario sustain a brain injury every day! There are more people with ABI than women with breast cancer or people with HIV/AIDS in the province. Included in the awareness campaign are public service announcements (PSAs) that the

Alliance has created in partnership with the Toronto Film School. The idea behind the PSAs is to show that a lot of people do not understand what it is like to live with an ABI. Each PSA shows how a person's life has changed since sustaining a brain injury. The people who do not understand what the person is going through have blindfolds on symbolizing their inability to "see" the disability. Each PSA touches on a different aspect of life such as education, work, and homecare showing that ABI is a life issue - not just a health issue.

Here are the scenarios:

- A young girl falls off a swing, and then starts having difficulty in school. The teacher cannot understand her student's challenges and threatens to keep her in for recess until her work improves.

having such a hard time keeping up with her tasks.

These PSAs are being aired on 27 different TV stations across the province. There is also a longer video that incorporates all of these stories.

As well, the Alliance has created a website, www.see-us.ca, where you can:

- access the PSAs and the video
- get more information on the partner organizations in the Alliance
- read personal stories about people affected by brain injury
- access a list of resources
- e-mail MPPs (<http://www.see-us.ca/mpp.php>) to let them know that you want better community services and a government policy for people with brain injuries.

The work of the Alliance represents the Alliance first push for

There are approximately 500,000 Ontarians who have an acquired brain injury (ABI), and 44 people in Ontario sustain a brain injury every day

- An elderly man has a stroke, and his wife becomes his sole, full-time caregiver. The caregiver's friend calls wanting her to go out with their group of friends. The friend doesn't understand why she doesn't make time for the group anymore.
- A young man falls down some stairs at work. He becomes unemployed, and ends up on the streets. Two passers-by refuse to give him money because they mistakenly think he is drunk.
- A young woman is involved in a car crash, and when she finally returns to work her co-workers don't understand why she is

change with the provincial government. People with brain injuries have been in the shadows for too long, and many areas of their lives are affected. The issues people with ABI face, without the proper supports, are overwhelming and even affect the people who are close to them.

The Alliance is a strong partnership that will push for important changes within the government. People with brain injuries, their friends and families are urged to e-mail their MPPs to be seen and be heard!

It Takes A Village

ONF research highlights that people with ABI are falling through the cracks

Research has shown that an acquired brain injury (ABI) can seriously impact a person's quality of life. For example, many people with ABI become unemployed, residents of nursing homes at an early age, inmates of prisons or socially isolated. As the Ontario Alliance for Action on Brain Injury points out, the needs of people with ABI are often not met. People with ABI are not seen, nor are the issues they face understood, by our policy makers and community leaders.

John Kumpf from the Alliance says: "Ontario's health care system does a great job of patching people up in the immediate aftermath of their injury. But once they're released from hospitals and rehab facilities, ABI survivors are often left on their own."

People with ABI are often isolated in the community; support and understanding can be in short supply. This overwhelming experience can affect their ability to function. And as daily living becomes increasingly difficult, health issues, psycho-social issues and coping can decline until they become serious. And some people - too many - end up living on the streets.

Previous research studies on the connection between homelessness and people with ABI showed that homeless people had a high rate of brain injury. These studies, however, had only a few participants - and most were men. ONF decided more research was needed.

ONF funded researchers Stephen Hwang at St. Michael's Hospital and Angela Colantonio at Toronto Rehab, the study surveyed over 900 men and women in Toronto homeless shelters and meal programmes, during 2004 and 2005. The participants were asked whether or not they had ever had a brain injury, and answered questions that allowed the researchers to define the injuries as mild, moderate or severe. The participants were also asked about their physical and mental health, as well as

any alcohol and drug problems in the past 30 days.

And the results? 53% of the participants indicated that they had sustained a brain injury, and 70% of these individuals indicated that they had sustained the injury before becoming homeless. Among those with brain injuries, 40% reported having sustained one injury, 21% reported having sustained 2 injuries, and an astonishing 20% reported having sustained 5 or more injuries!

The study also showed that participants with a history of ABI had other health-related problems, such as seizures, mental health

"Ontario's health care system does a great job of patching people up in the immediate aftermath of their injury. But once they're released from hospitals and rehab facilities, ABI survivors are often left on their own."

issues, and alcohol and drug abuse.

The study highlights the need for healthcare professionals to routinely ask their homeless patients whether they have a history of ABI. If patients do have such a history, then they can be referred to rehabilitation and other existing community-based programmes, and perhaps to providers of disability benefits. Knowing about a patient's ABI will enable the healthcare professionals to make their



patients aware of the supports and services that are available.

However, unfortunately, adequate supports and services are not yet available in most communities, and therefore people with ABI are still falling through the cracks. The Ontario Alliance for Action on Brain Injury (OAABI) is working with the government to implement the necessary community supports for ABI survivors and their families.

For all of us, where we live is an important expression of who we are. For people with ABI, supportive living environments are fundamental to feeling both secure and part of the community. With better community supports for people with ABI, it is very likely that the homelessness rate can be reduced.

Primary Healthcare Update for Individuals with Physical Disabilities

Toronto, Hamilton and Windsor are developing their models

ONF likes to think big picture and to take varied approaches to enhance healthcare access and delivery for those living with a spinal cord injury and other physical disabilities. As an example of this, earlier this year *NeuroMatters* discussed an ONF-funded pilot project on primary healthcare for people with spinal cord injuries (SCI).

Primarily healthcare is extremely important to people with SCI because they access the health-care system more than the general population does due to secondary complications (e.g., urinary tract infections, pressure sores). To recap, the key elements of primary healthcare are:

- access to care
- management of current health condition
- prevention of future illness
- informed and active participation by patients
- coordination of services along the continuum of care

The assessment of and responsiveness to community needs are integral to primary healthcare. Therefore, the delivery of services is unique to each community. In this article, we highlight the approaches of some of these communities.

In **Toronto**, the advisory team partners are Bridgepoint Family Health, Ontario Neurotrauma Foundation, The Centre for Effective Practice, Anne Johnson Health Station, Toronto Rehab, Sunnybrook Family Practice and University Health Network Family Health Team. This model plans to have a nurse coordinator manage the coordination and services for clients and liaison with other

providers. The hope is that by bringing stakeholders together, then people with SCI will have better access to family practice teams.

In **Hamilton**, the Hamilton Family Health Team, Hamilton Health Sciences, Ontario Neurotrauma Foundation, and Canadian Paraplegic Association Ontario are partnering to assess the Family



Health Team (FHT) approach to meeting community needs. In other words, doctors and other healthcare practitioners will be working together to share knowledge with their clients and each other. A nurse practitioner will coordinate the services. The FHT will be able to consult with a team of spine professionals (e.g. physiatrists, respiratory specialists, respiratory therapists, physiotherapists, occupational therapists,

advanced practice nurses, urologists, pain specialists). As well, the FHT plans to assess the physical access of its offices in order to identify and remove barriers.

In **Windsor**, the community will be creating a one-stop model of service delivery for chronic neurological and neurotrauma disability management. Its partners are Windsor Rehabilitation and Healthcare Center, the Windsor

Community Health Centre, Centre for Family Medicine, and ONF. It proposes collaboration between rehabilitation professionals, palliative care professionals, and the community health centre professionals. Coordinated by a primary care practitioner, individuals with neuromuscular and mobility issues will be served at this community health centre.

Ultimately, each of these approaches to primary healthcare offer much needed support to people

with SCI. The Toronto, Hamilton and Windsor communities are seeking to find the best ways to deliver primary healthcare. In future issues of *NeuroMatters*, look for what Ottawa, Kingston and Waterloo are doing on this front.

Reach Out and Touch Someone

Technology is bridging the gap between remote patients and healthcare professionals

Past issues of *NeuroMatters* have covered how difficult it can be for people who come home from the hospital after receiving treatment for a brain injury. Many people feel overwhelmed, and there may be few - if any - community supports to assist with the transition. Caregivers often feel the same way, too. Living with a newly acquired brain injury (ABI) is a huge learning curve: it is hard on people with ABI and their families, as everyone tries to deal with the changes.

So imagine if it were possible for those people with brain injuries (or their caregivers) who needed help as they adjusted to home life, were able to pick up a telephone or turn on their computer and - presto! - they could connect to a doctor, specialist, or other healthcare provider for answers to their questions, or for support and encouragement.

"Telehomecare" is a promising new technology for those who need support as they adjust to life at home after hospitalization, and for those who are finding it difficult to get to regular check-ups - because of geographical distance, transportation costs, mobility issues, etc.

Telehomecare works like this. A "patient station" is placed in a patient's home. It has a video screen, a camera, a stethoscope, a blood pressure machine, and other devices that a healthcare professional typically uses. At the time set for a "visit", the professional makes a call to the patient, who answers it by pressing a green button on the patient station. Technology does a bit of poking and prodding for the professional to help figure out how the patient



The Clinician's Station



The Patient's Station

is doing. After monitoring the patient's health and any changes, together, they talk about issues that may have arisen since the last visit and come up with strategies on how to manage day to day activities. The healthcare professional is in a great position to see how well patients are doing as they re-integrate into the community. If problems arise, supports can be put in place.

Telehomecare also enables the healthcare professional to speak with caregivers and family, to figure out how well the family is coping, and to offer support and education about living with, and managing, a long-term healthcare issue.

Telehomecare's website states: "The use of new technologies to provide remote healthcare is a growing trend in Canada, and parallels the availability of broadband networks for the delivery of education and training." Telehomecare has been used in studies with people who have diabetes, stroke, heart failure, and spinal cord injuries, to name a few. In these studies, patients reported improved health - and a high degree of satisfaction with the technology.

ONF became interested in this type of healthcare delivery to see how this technology could benefit people with ABI. It has recently approved funding for a two-year study led by Sonya Canzian and Dr. Avery Nathens, along with clinical experts from St. Michael's Hospital and researchers at York University.

Their study will be carried out in two phases from October 2008 until October 2010. In the first phase, the team will determine the key issues and concerns facing people with ABI within the first six months of returning home from the hospital. Participants will be asked what supports they needed at that time. The study will use the responses to develop a Telehomecare programme.

In the second phase of the study, the research team will use the information obtained from the first phase to determine what programmes and specialists would best serve the participants. The

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team will operate a virtual clinic, and work with the participants and their caregivers to improve health outcomes and to address coping issues. Each family will receive their own patient station. Researchers will look at whether this technology is more useful for people who live in rural communities compared to those who live in urban communities.

Telehomecare could prove to be useful for people living with ABI and for their caregivers. It is another way for them to feel connected to their healthcare providers and to receive needed support from a distance. We look forward to the results of this study.

Check out the
NEW and IMPROVED
ONF website
at
<http://www.onf.org/>

Things To Know

Neurological Health Charities Canada (NHCC) is a working group of organizations that represent people with chronic, often progressive, neurological diseases, disorders and injuries in Canada. ONF is working as a founding member to advance our interests in research and knowledge mobilization in the areas of Acquired Brain Injury and Spinal Cord Injury within this larger network that has both a federal and provincial focus.

For a more detailed description of NHCC please visit the website for the group at:

www.neurohealthcharities.ca

Conference Notes

The "Conference Notes" section of *NeuroMatters* enables people who have gone to a conference to share their thoughts, resources and findings.

By Tara Jeji

Conference: 21st Rehabilitation International World Congress: "Disability Rights and Social Participation: Ensuring a Society for All"

When: August 25-28, 2008

Where: Quebec City, QC

Overview: In its 21st year, this conference hosted attendees from around the world. It is the first time this conference has been held in Canada. It was fantastic to see so many people with disabilities at the hotel and in the streets of the city. Introduced was a treaty developed by the United Nations (UN) Convention on the Rights of Persons with Disabilities. The treaty provides the framework for the development of good policies, actions and projects which can have a positive impact on the lives of people with disabilities all over the world. Conference participants received a key that was symbolic



of opening the box that held the treaty - giving people *access* to the treaty. A picture of the box is above.

Comments on Keynotes: There were several interesting keynote speakers at this event. To read more about their accomplishments, please go to: <http://www.riquebec2008.org/> and click on "Keynote Speakers" under "News".

TELL a FRIEND

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research news, book reviews, upcoming events, consumer items for people with a spinal cord injury and an acquired brain injury as well as family and caregivers

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Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie
90 Eglinton Avenue East,
Suite 601
Toronto, Ontario, Canada
M4P 2Y3

Mark Your Conference Calendars

A busy fall lies ahead for ONF. In our ongoing efforts to serve the needs of people with neuro-trauma, ONF is involved in the following three conferences. Here's the scoop.

Toronto ABI Network Conference 2008 (Toronto, November 3 & 4)

ONF is one of the principal sponsors of this not-to-be-missed conference, which will be held at the Hilton Toronto. It will draw on the expertise of ABI professionals from the University of Toronto, Bloorview Rehab, and other organizations in the GTA. The two days will be jam-packed with four keynote speeches, workshop presentations, and poster presentations on topics such as:

- Support (e.g. community integration and services, culturally sensitive medical and legal support, client-centred decision-making in return-to-work scenarios)
- Children (e.g. media safety, communication)
- Health (e.g. lifespan issues for people with brain injuries and their families, art and music therapy when dealing with substance abuse)

As well, the conference will discuss creative and innovative solutions to improve the lives of people with ABI and how to best collaborate with service providers, clients and families.

To find out more about the conference, please link to: <http://www.abinetwork.ca/conference2008/>

Spinal Cord Rehabilitation: Innovation, Impact and Future Directions (Toronto, November 7 & 8)

This conference will share knowledge about recent North American research in the area of spinal cord injury. ONF is not only the Platinum conference sponsor; it is also funding a pre-course at the Lyndhurst Centre on November 6. The day will cover topics such as best practices in pain management, advanced therapies to prevent and treat pressure sores, and sensory assessment and motor measurement. Brian Kwon will deliver the keynote presentation on "Translational Research in Spinal Cord Injury: Clinical Trials and Tribulations". The subsequent conference at the Hilton Toronto will cover many more fascinating topics.

ONF has partnered with Toronto Rehab, Canadian Paraplegic Association Ontario, and Spinal Cord Injury Solutions Network to provide funding for those consumers who would like to attend the conference but for whom ability to pay is an issue. For more information about the conference, please link to:

<http://www.torontorehab.com/education/scic08index.htm>

Ontario Injury Prevention Conference 2008 (Toronto, November 16 & 18)

This conference at the Courtyard by Marriot, is organized by SMARTRISK in partnership with ONF, the Ontario Ministry of Transportation, the Ontario Ministry of Health Promotion, and the Ontario Public Health Association. ONF's Program Director of Injury Prevention, H el ene Gagn e, is the conference Chair and the emcee.

Through an interactive and practical programme, the conference will seek to engage stakeholders, encourage networking, highlight new research, and develop and share best practices. General topic areas for this conference include: policy, programming, environment, partnerships, transferability, social change, and sustainability. The conference will consist of three overlapping streams of interactive and skills building workshops, panel discussions, and poster presentations on a variety of injury topics. An additional stream will use All Terrain Vehicles (ATVs) as a case study to explore all of these components of best practice development and implementation. For more information about this conference, please link to: <http://www.oipc.org/>



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

90 Eglinton Avenue East, Suite 601,
Toronto, Ontario, Canada M4P 2Y3
Tel: (416) 422-2228 Fax: (416) 422-1240
E-mail: neuromatters@onf.org
Website: www.onf.org