

NeuroMatters

Connecting YOU to the Research

IN THIS ISSUE

- 1 Out and About
- 2 Events
- 3 Books
- 4 Caring About Health Care
- 5 Back in the 'Hood
- 6 Take Charge, Take Care
- 6 Conference Notes
- 7 Things to Know
- 7 What in the WWW is Going On
- 8 The Skinny on the Bowel

Out and About

Partners in fitness help people with ABI get more involved

We all know it is sometimes hard to exercise regularly and get involved in recreational activities. Sure, we know the benefits: strong heart, toned body, and feelings of confidence, satisfaction and happiness - but what if there was more to it? For people with traumatic brain injuries (TBI), there just might be.

The Ontario Neurotrauma Foundation (ONF) is funding a pilot programme that studies whether people with TBI become more involved in their community when they participate in a fitness programme.

Confidence, satisfaction and happiness are feelings developed by becoming good at a fitness activity, and these feelings are ultimately important if people want to reach out and get involved in their community.

Knowing that exercise programmes sometimes fail due to lack of motivation, and that people with TBI don't always feel comfortable in social situations, lead researcher, Dr. Dawson, and her co-researchers, took some steps to ensure that it would be easier for participants to get out and work out!

Participants in the study were asked to identify a significant person in their life (such as a friend, sibling or parent) who could participate in activities with them. Having a "fitness buddy" keeps participants motivated, and makes social situations more comfortable. Fitness buddies not only train with their partners, but also help them to meet people and to get involved in

other ways.

Researchers asked participants to choose their own activity in the community, so that the activity would be interesting, convenient, and something they would look forward to doing.

During the 16 weeks of the study, a research assistant will telephone participants regularly to ensure all is well and to measure changes. Participants can call the research assistant if they need support. A website will provide information about TBI, and a message board will enable participants to share their experiences, ask questions and motivate each other.

The research assistant will teach fitness buddies how to motivate their partners and how to get them to take important steps to reach their goal. Participants choose their goal and then, together with their buddies, plan how to make it happen. Together, they take the steps necessary to achieve the goal. After each step, they check to see if they are on track.

For example, if a participant's goal is

to join a bowling league, the research assistant would work with the participant and their fitness buddy to find a bowling alley close to the participant's home, and find out when the league played, after which the two of them would go bowling together. At the bowling alley, they might introduce themselves to others, or make enquiries about the league. Once the participant has joined the league, he or she may attend tournaments, holiday parties or other social events that will encourage the participant to continue to be involved in the community.



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

...continued from page 1

Hopefully, as participants achieve their own goals, and become more fit and involved in their community, they will have an increased sense of purpose and belonging. One participant who has already completed the study says: "I do feel ... increased self-confidence. I have increased self-confidence to resolve conflict and go out and seek meaningful relationships again, be it friendship or whatever. It's increased."

Previous studies have found that seniors think and remember better after they exercise, because the increased pumping of the heart sends blood to

the brain to nourish it. Another study found that people with TBI who exercised for four months had improved attention-processing speed. It will be interesting to see if the current study increases brain function in participants.

At the end of the 16-week study, the pairs will be left on their own to continue their activities. There will be a follow-up three months later to see if people have continued with their participation, and to measure improvements, including whether the participants are more involved in their communities.

"I have increased self-confidence to resolve conflict and go out and seek meaningful relationships"



Dr. Dawson and her co-researchers are still recruiting participants for this study, so if you are interested please contact Candace Ikeda-Douglas at 416-785-2500 ext. 3377. The researchers will be starting to look at results in a few months. The full results of this study should be available by the end of summer.

Events

March 27, 2008: 6:00 - 7 p.m.

Peer Connections: "Personal Attendant Services: Options, Tips and Skills" - The Canadian Paraplegic Association Ontario Ottawa office cover the need-to-knows about attendant services, Royal Ottawa Rehabilitation Centre. More info: peersupport@cpaont.org, 416-422-5644 ext. 242.

April 2, 2008: "Community Connections 2008" Information for people with disabilities, their families, caregivers and professionals within Waterloo Region. More info: 519-578-3660 ext. 2325.

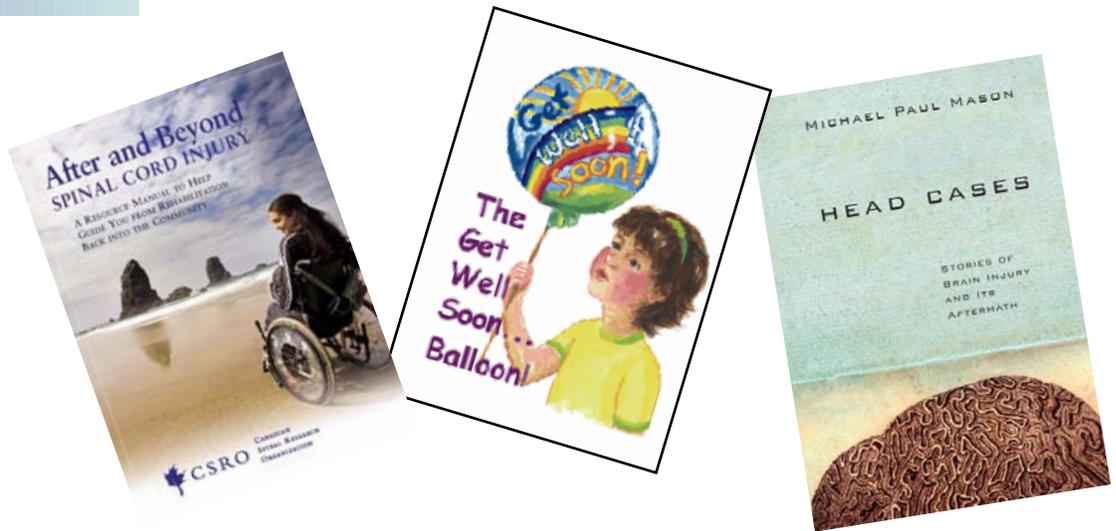
May 1-2, 2008: "Relax and Learn, 2008" - presented by Community Solutions, specialists in ABI will consult with you in a small-group, case-study format related to their area of expertise including: paediatrics, behavioural difficulties, neuropsychiatric disorders, substance abuse and sexuality. More info: commsol@sympatico.ca

June 4-8 2008: "3rd Congress of the World Union of Wound Healing Societies" hosted by the University of Toronto, Faculty of Medicine and Departments of Medicine and Public Health at Metro Toronto Convention Centre. The conference theme is Wound Care Efficacy, Effectiveness & Efficiency. More info: <http://www.wuwhs2008.ca>

June 6-7 2008: "People in Motion" - Canada's premier event for people with disabilities, seniors with special needs and professionals working in related areas. Free admission. More info: <http://www.people-in-motion.com/>

July 25-26, 2008: "Ontario ParaSport Summer Games" - Held at Variety Village, this set of Games, including track and field, boccia, wheelchair tennis, goalball, para equestrian, and powerlifting, is the Ontario championships for athletes with physical disabilities. More info: <http://www.varietystudio.ca>

BOOKS



After and Beyond Spinal Cord Injury

Published by the Canadian Spinal Research Organization

In its third edition, this resource manual is thorough in its coverage of issues pertaining to spinal cord injury that may occur after the rehabilitation process. It's a "go to" guide for those making the transition from a rehabilitation institute to the community.

The manual provides:

- personal stories
- a section on pain management
- healthcare information on topics such as bowel /bladder management and skin care
- information about independent living, such as managing attendants and home modifications.

Cost: FREE to people with spinal cord injuries and their families (However shipping and handling can range between \$10-\$20)

Professionals: \$56 + shipping and handling

Contact: (800) 361-4004 or

info@csro.com

The Get Well Soon... Balloon

by Vicki Sue Parker

When Ms. Parker was first diagnosed with a brain injury, she wanted a way to explain it to her children. She knew they had confusion, a sense of loss and frustration. She needed a tool that would pull them together and offer some explanation.

She had spent lots of time reading to them and knew they often understood and could relate to real-life situations when they had read a similar story in a book.

For this reason, she decided to write *The Get Well Soon... Balloon*. Not only does the book explain brain injury to children, but it also addresses the feelings they experience because of a family member's injury. The book is suitable for pre-school and primary school children.

Cost: \$15

Publishers: Lash & Associates Publishing.

Contact: (919) 562-0015

ISBN 10: 1931117357

Head Cases: Stories of Brain Injury and Its Aftermath

by Michael Paul Mason

Written by a brain injury case manager, this book looks at the lives of people who have faced neurotrauma and how it changed their worlds.

Publisher's Weekly says, "Mason writes with passion and urgency about the unheralded but compelling stories of Americans injured in car accidents or through a miscalculation while snowboarding... He also tells stories of tremendous courage and perseverance as survivors and their families work to re-establish the everyday skills they had before their injury. The strange effects of neurological damage will draw fans of Oliver Sacks, but Mason's poignant and caring accounts of his clients' lives are sure to touch the hearts of a wide range of readers."

This title will be released on April 1, 2008. Pre-order now! Sold by Amazon.com, Barnes and Noble, or Powell's Books.

Cost: \$25.00 Publishers: Farrar, Straus and Giroux

ISBN 13: 9780374134525

Caring About Health Care

A team approach for change

When bad news strikes a friend, people often say “Well, at least he has his health.” He could lose his job, break up with a loved one, or flunk out of school - but as long as he has his health, all is not lost. These well-intentioned words can annoy people with disabilities because many do not actually have their health under control. And that often happens because the health care system places barriers on their ability to control their health. In the end, their quality of life is compromised.



In 2003, the Ontario Neurotrauma Foundation (ONF) decided to fund research into the issues that people with spinal cord injuries (SCI) faced in the primary health care system. The research team reviewed the literature and then held focus groups with people with SCI and service providers. The research resulted in some interesting findings and recommendations. More on that later!

People with SCI are a relatively small group - three in 100,000 Ontarians have an SCI - and not many people have the training to properly care for them. And yet, people with SCI generally access the health care system more often than the general population because of secondary complica-

tions from their SCI, such as urinary tract infections, pressure sores, bladder cancer, kidney disease, osteoporosis, colon cancer, and breathing concerns.

People with SCI have difficulty getting health care for different reasons - for example:

- physical barriers in a hospital or medical office
- cumbersome or expensive transportation arrangements
- negative attitudes or assumptions on the part of medical staff
- few professionals are trained to deal with SCI issues
- trained professionals generally practise in larger cities
- long wait times

- inadequate or non-existent attendant or interpretation services
- costly mobility devices and other services

Interestingly, a 2004 telephone poll of 1,843 Canadian adults suggests that “Canadians believe that people with disabilities should have the chance to participate in life to their fullest potential, that this is part of the ‘Canadian way’ of doing things... [m]ore than 80% of Canadians strongly or somewhat agree that public funds should support individuals, even with the most challenging disabilities, to live in the community rather than in institutional settings.” To do so, means that there needs to be accessible health care provided in the community.

The members of the focus group had some ideas on how people with SCI could be better served. They recommended the creation of an online site - through TeleHealth or an Internet site maintained by a reputable organization - where doctors and people with SCI could access information about SCI and find solutions to health-related problems.

They also recommended the creation of community “one stop” healthcare centres with access to wound care nurses, attendants, social workers, case managers, urologists, physiatrists, advocacy workers, recreational

...continued on page 5

...continued from page 4

therapists, vocational counsellors, physiotherapists, massage therapists, rehabilitation specialists, neurologists, family physicians, and chiroprodists. Specialized SCI centres could develop best practices and resources, and share them with other centres and individual doctors.

After reviewing these recommendations, the ONF decided in December, 2007 to fund the development of three demonstration projects to deliver primary care services to people with physical disabilities. A task force of professionals from medical, academic and service backgrounds will:

- develop guidelines and staff roles for team-based care
- create educational materials and distribute them to other service providers
- outline management procedures based (a) on best practices that are presently being used in other health care settings and (b) recommendations by key stakeholders
- partner with like-minded service

providers to develop a referral network for people with physical disabilities.

Bridgepoint Family Health in Toronto will be one of the sites for the project. Bridgepoint already serves people with disabilities and their families, and their team will take the guidelines developed by the task force and begin working them into every day activities. Two other sites will soon be chosen.

At the conclusion of this project, an evaluation will be conducted to see how well the pilots are working on a functional level, and at serving people with physical disabilities. There is also the need to evaluate where the providers identify need for improvements. The project is expected to be complete by the end of 2008.

Hopefully, these sites focused on health care for people with disabilities will become the new hubs in Ontario of relevant information and service. No longer will people have to scramble to find resources and services. Finally these resources will be accessible.

Back in the 'Hood

Research that focuses on community integration for people with ABI

We all like to be independent, have connections to others, and engage in meaningful activity. For survivors of acquired brain injury (ABI), finding ways to get back into the community after an injury can be very challenging and even scary. Life is different after ABI, and people often find that their roles have changed, and that they have different needs. This can affect how a person gets involved in the community.

The Ontario Neurotrauma Foundation (ONF) wants to do more to increase community integration for survivors of ABI, by researching:

- ways to help survivors become involved in the community
- the availability of supports that encourage community involvement
- when people need these supports
- successful integration ideas ("best practices") in order to help people rebuild their lives in meaningful ways.

ONF plans to develop a research programme focusing on community integration, and wants to approach this in a way that can lead to change. A meeting was held in February with survivors, service providers, researchers, and policy and association representatives. The goal of the meeting was to determine some of the key issues regarding community integration for adults with ABI. The findings will assist ONF and its partners to move forward. Stay tuned for more information about this in future issues of NeuroMatters!

TELL
a
FRIEND

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is free

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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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Sign up online for your copy of
the NeuroMatters e-zine at:
www.onf/newsletter/
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(416) 422-2228
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Take Charge, Take Care

The building blocks of healthy living

"I learned I can do anything if I start out with small steps" - programme participant

Living a healthy life is something everyone aspires to. But for many people, it can be hard to achieve the level of health they desire.

It's not so much that they don't know what to do. The challenge is making it happen. People lead busy lives and sometimes feel overwhelmed by the challenges they face.

For people who live with a chronic health condition, it can be hard to figure out how to manage the extra demands on their time and attention. Throw in a physical disability or functional limitation, and you have a recipe for frustration.

TAKING CHARGE OF YOUR HEALTH, TAKING CARE OF YOURSELF

The Take Charge, Take Care workshop has been designed to help people develop the skills they need to take care of themselves and manage the daily challenges of living with a chronic health condition. During a series of 6 weekly sessions, the workshop covers topics including:

- Goal setting and problem solving
- Managing pain and fatigue
- Handling difficult emotions like frustration and fear
- Fitness and healthy eating
- Tools for reducing stress and anxiety
- Working with your health care team

The workshop follows a process developed at Stanford University, originally aimed at people with chronic diseases like diabetes and asthma. It has been used successfully around the world for people facing many different kinds of health challenges.

Now, for the first time, it is being offered here in Ontario, to people with spinal cord injuries, although anyone living with a chronic health condition can benefit from the workshop. Friends, family members and caregivers of people living with chronic health conditions are also welcome.

Sponsored by ONF and the Institute for Optimizing Health Outcomes, Take Charge, Take Care is free of charge to participants.

LEARNING FROM PEERS

An essential part of the workshop's effectiveness is the group interaction that takes place. Participants learn from each other and together practise the skills they are developing. The workshop is also led by peers (people facing similar health challenges).

The first series of Take Charge, Take Care workshops will be led by Tara Jeji (Program Director, SCI at ONF) and John Shepherd. Both Tara and John have experience living with quadriplegia and have been trained by Stanford-approved trainers.

This pilot workshop will be offered initially at two locations in midtown Toronto: the Anne Johnston Health Station and Toronto Rehab's Lyndhurst Centre. The first sessions will take place on Thursdays beginning April 24th. Once completed, the pilot will be evaluated and adapted as required. The workshop will be offered again in the fall and rolled out across Ontario in 2009. Training will be provided for volunteer leaders.

For more information, or to register, go to www.takechargetakecare.ca.

Conference Notes

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

Conference: Sex, Wheels and Relationships III presented by CPA Ontario

When: February 14, 2008

Where: Toronto, ON

Overview: This conference was held for the Canadian Paraplegic Association Ontario's membership and healthcare practitioners. Attendees were provided with an array of topics of interest.

Esther Ignagni and Jennifer Paterson, from the School of Disability Studies at Ryerson University presented "Psychological Effects of Disability on Relationships," which looked at various different relationships from family to romantic.

Dr. Johannes Keunen from Mount Sinai Maternal Fetal Medicine Unit spoke about "Pregnancy and Disability," and offered a comprehensive, practical, audience-friendly presentation.

Dr. Magdy Hassouna, an Associate Professor of Urology at the University of Toronto, presented the topic of "Erectile Dysfunction" covering all affects from varying injury levels.

The key-note speaker was disability expert and author, Lisa Bendall. Pulling from her books and family life, Lisa gave a practical and sometimes humorous talk about relationships and disability.

The afternoon sessions involved discussion groups about: dating with a disability; supporting your partner; power imbalances; parenting with a disability; pregnancy and erectile dysfunction.

Things to Know

SPINAL CORD INJURY TRANSLATIONAL RESEARCH NETWORK

The Government of Ontario has announced a \$10 million commitment to supporting Ontario's involvement in a national [Spinal Cord Injury Translational Research Network \(SCI-TRN\)](#), to benefit those living with SCI in the Province.

The Ontario Neurotrauma Foundation (ONF) and the Rick Hansen Foundation (RHF) have partnered together to maximize the province's investment.

Ontario's five-year, \$10-million investment will:

- Give patients new treatment options by putting discoveries into action faster
- Help researchers collect better information on spinal cord injuries
- Attract talented researchers and link them with colleagues around the world.

"Together, we can make life easier for Ontarians living with a spinal cord injury by bringing exciting discoveries from the lab to the clinic faster," said Premier Dalton McGuinty.

An estimated 42,000 Canadians are currently living with SCI at a cost to the health care system of between \$1.25 million and \$25 million during the lifetime of each injured person. Ontario accounts for 39% of the national population which makes the government's investment in this national initiative a significant step forward.

\$20,000 SCHOLARSHIPS AVAILABLE

Toronto Rehab is pleased to announce it is now accepting applications for its innovative Scholarship in Rehabilitation-related Research for Graduate Students with Disabilities. Many fields of study may be eligible, from Computer Science, Statistics, and Engineering to Chemistry, Medicine, Health Policy, and Psychology.

Believed to be the first-of-its-kind in Canada, the scholarship provides an award of \$20,000 and funding for educational disability expenses such as assistive software and devices. The scholarship committee actively works with the scholars to support their academic and research success and their future career goals. The programme is made possible by the financial generosity of the TD Bank Financial Group.

The scholarship is open to students planning to attend McMaster, Ryerson, University of Toronto, Waterloo, Wilfred Laurier, and York. The application is due May 1, 2008.

For more information and to read about current recipients visit, <http://www.torontorehab.com/research/disabilityscholarship.htm>

ACCESS TO ENTERTAINMENT CARD

If you haven't got one yet, you are missing out! The Access to Entertainment Card is honoured by Famous Players and Cineplex Galaxy. The card provides either free or discounted admission (to a maximum of \$3) to caregivers/support people accompanying people with disabilities to participating theatres across Canada. To apply for a card, link to: http://www.access2.ca/english_default.html

What in the World Wide Web is Going On

<http://www.obia-csn-rsc.org/>

A Community Support Network for people living with ABI. The site includes information on the Peer Support Mentoring Programme, and a searchable directory of companies and associations that are active in the field of ABI in Ontario.

<http://www.ala.ca>

Do you want to get active but you don't know where to start? The website of the Active Living Alliance for Canadians with a Disability is the place to visit! Use the Profiled Activity Search to find activities that

suit you and are located near to you. Also included on this site are activity fact sheets as well as information on accessible play spaces, and the latest research about active living.

<http://www.bridgpointhealth.ca/>

Link here to find out about Bridgepoint Health and its integrated network of programmes and services for people with disabilities needing health care services.

The Skinny on the Bowel

Here's how a bowel movement works:

- You eat
- Your stomach digests the food and pushes the waste into the small intestine
- The small intestine pushes the waste into the large intestine
- The large intestine is also known as the colon
- The small and large intestines are the "bowel"
- At the end of the bowel is the rectum
- The rectum is kept closed by the anus - which has a sphincter (or valve) that opens as the stool moves out of the body, and then closes

Spastic/reflexic bowel:

- Caused if the SCI is at the neck (cervical) or chest (thoracic) level
- Your body can still move the waste through the bowel
- Your bowel fills up and will empty when full (maybe not at a convenient time)
- You may not feel you are close to having a bowel movement
- Between bowel movements, your anus sphincter is closed

Flaccid/areflexic bowel:

- Caused if the SCI is at the lower back (lumbar) or sacral (tail bone) level
- Your body is not able to move the waste through the body
- You do not feel you are close to having a bowel movement
- The anus sphincter does not close tightly and therefore can leak

Bowel programme:

The idea of a bowel programme is to get your bowel movements into a routine.

Things you can do to have a healthy bowel movement:

- Aim to have your bowel movement at the same time of day every day or every other day
- Prune juice is nature's laxative and there are other ones your doctor can tell you about
- Drink water to avoid constipation
- Eat your fruits, veggies and whole grains
- Avoid spicy or greasy food, caf-

feine, onions, green peppers or other foods that may cause diarrhea

- Use a good gel or air cushion to alleviate hemorrhoids
- If you have a spastic/reflexic bowel, use digital stimulation to remove the stool in the rectum and then use suppositories to finish the bowel movement
- If you have a flaccid/areflexic bowel, suppositories will not be useful - you will have to clean the rectum manually every day
- Use lubricant gel and make sure you nails are clean and short when doing finger stimulation
- Stick to your programme to avoid accidents and getting constipated

Compact bowel:

If you know you haven't had a bowel movement in a while, you are susceptible to an abnormal reaction to the stimulus in your body that will cause autonomic dysreflexia, or dangerously high blood pressure. Symptoms come on quickly and include: a headache, feeling sick, sweating and feeling flushed. Get immediate, emergency medical attention.



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