

NeuroMatters

Connecting YOU to the Research

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Mentorship has its Privileges

Peer support for people with ABI and their family members

We humans are a yacky bunch. Talking somehow makes us feel better. Even the shyest among us talk to friends - especially when we have a problem. And the best person to talk to when we have a problem is someone who has gone through the same hard times.

Yes - "misery loves company", but there's more to that saying than just listening to each other complain. When we talk to others who have gone through what we are going through, we get ideas from them. We learn from what they did, and through our sharing we decide what is best for ourselves and move on in our lives. Sometimes it is hard to find a person to talk to who has gone through what we are going through and so it is nice to have a programme that will find matches for people.

A peer mentorship programme brings together two types of people: those who want help and those who give it. Peer mentorship programmes have worked in the past for business people, university students, alcoholics, and people with various disabilities such as diabetes, mental health and cancer. The best part about a peer mentorship programme is that the person offering support (the mentor) is someone who has "been there, done that." More so, the mentor has understanding, empathy, and advice. The mentor has life experiences that can help the person who needs guidance (the partner). It is this piece that makes a peer support programme so special, because even a trained profes-

sional does not always have those life experiences.

Back in 2004, the Ontario Brain Injury Association (OBIA) began a Community Support Network. At the very first meeting it was agreed that a peer mentorship programme should start across Ontario. According to OBIA, there are approximately 18,000 brain injuries in Ontario every year, and over 1,200,000 individuals are living with the effects of acquired brain injury (ABI). The members of the Network knew that when people with ABI got out of hospital, they often had a hard time getting their life back on track. Returning to their community was not always easy. These people needed to be connecting with others who knew how they were feeling and who could help them out. The same was true for family members of people with ABI. They, too, often needed to connect with people who knew what this new family role was like. Given the size of Ontario, OBIA felt that to be available to all who would want to take advantage of the programme, it would have to be delivered individually by phone or email rather than face-to-face.


Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

The first peer mentorships began in April 2006, and will continue until March, 2009. During this time, researchers funded by the Ontario Neurotrauma Foundation (ONF) will review the peer mentoring programme to see if it proves successful, both for the partners who seek support (including family members) and for the mentors who provide it (also including family members). The researchers will look at the outcomes of the peer/mentor support. They are interested in what has changed for the people involved in the programme. So, they will ask questions about:

- What have they learned about brain injury?
- Do they know about brain injury resources in their communities?
- Are they better able to communicate

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with health care providers?

- Are they better able to ask for support from family and friends?
- Do they feel better than they did before they had a mentor?
- Do they feel that their lives have improved?

The researchers will also want to find out about how happy people were with the programme. They want to know:

- Did they enjoy being part of the peer/mentor partnership?
- Were they satisfied with the length of the partnership?
- Were they satisfied with how involved they were with their peers/mentors?
- Did they like their peer/mentors?
- Did they feel that they were doing more useful things daily?
- Did they feel that they were going out and doing more things in the community?
- Did they go less often to their family doctors?

- Did they get more out of peer/mentor sharing than other services in the community?

The researchers plan to look at how people with ABI felt before and at the end of their peer/mentor partnership. If possible, the researchers will also compare people who are waiting to be part of the programme with people who have completed it.

The findings will help to determine the usefulness of the peer/mentorship programme, whether it should be continued, and whether the programme can be improved. As Kathy Boschen, Director of the evaluation study, states: "This innovative programme has the exciting potential to help individuals and families affected by brain injury right in their own homes. We would hope that it could become available right across the province if our research results show that the outcomes for our first group of mentors and partners are positive."

Conference Notes

by Tara Jeji and John Shepherd

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

Conference: 15th Inter-Urban Spinal Cord Injury Conference

When: October 25 & 26, 2007

Where: Hamilton, ON

Overview: It was a well-attended conference with a wide range of topics in SCI presented at concurrent workshops and poster sessions. There were three presenters with SCI at the conference.

Tara Jeji presented "Challenges Faced by women with Spinal Cord Injury," which had a special focus on inner-city, minority women living in Detroit, Michigan, USA.

Ed Smith, from Newfoundland, was the keynote speaker. He spoke about his experiences from his book "From the Ashes of My Dreams." Ed covered his experiences immediately post injury, hospitalization with special attention to his interaction with healthcare professionals and policy.

Chaplain Adrian Dileman presented "Significance of Anniversary Date of Spinal Cord Injury." He presented on his research findings with a small number of participants.

For information on the 16th Interurban Spinal Cord Conference, to be held in Toronto, Ontario, please go to the website of Toronto Rehab, <http://www.torontorehab.on.ca/> where details will appear as the conference is developed.

Events

November 1 to 30, and December 1 to 31, 2007:

"Weaving the Ties That Bind: Online Training Course for Facilitating Social Support Networks" This course provides participants with the knowledge and skills necessary to become a social network facilitator. More info: http://www.planinstitute.ca/events_index.cfm, hflaming@plan.ca, 604-439-9566

December 3, 2007: "International Day of People with Disabilities" Showcase of Toronto success stories, featuring the "Invitation to Poetry" event. Toronto, ON. Attendant services and captioning provided. Wheelchair accessible. Space is limited. More info: cwong5@toronto.ca, 416-338-4756, <http://www.toronto.ca/diversity>.

January 18 to 19, 2008: "Women's Health Matters Forum & Expo 2008: Linking Environmental Impacts and Women's Health" - helping women of all ages become better informed about the impact of the environment on their health and the health of their family members. More info: <http://www.womenshealthmatters.ca/forum/index.html>.

January 31, 2008: 6:30 - 8 p.m. Peer Connections: "Travel and Touring with a Disability" - The Canadian Paraplegic Association Ontario looks at everything you ever wanted to know about travel and touring with a disability at Lyndhurst Centre, Toronto. More info: peersupport@cpaont.org, 416-422-5644 ext. 242.

If you have events you would like included in this newsletter, please send them to info@onf.org for consideration. Unfortunately, due to space considerations, not all events will be able to be published.

BOOKS



***Educating Educators about
ABI Resource Book -
Published by the Ontario
Brain Injury Association***

Your child is at the end of her first term in school and you find yourself scratching your head, wondering how you are going to get her teacher to understand her brain injury. This scenario is so familiar to parents with kids with ABI that researchers from Brock University and the Ontario Brain Injury Association wrote the Educating Educators about ABI Resource Book. Because there are approximately 27,000 students in the classrooms of Ontario who have experienced a brain injury, ONF agreed to fund the development of this guide to provide hands-on, practical information to educators. Topics covered include: understanding ABI from a development perspective; working with kids with ABI in the school setting; general techniques that work, assessment and planning. Available through the Ontario Brain Injury Association in English and French. Cost: \$25 + shipping and handling. Contact: 905.641.8877 obia@obia.on.ca ISBN: 0-9733658-0-3 (English) 0-9733658-1-1 (French)

***The Parenting Book for
Persons with a Disability:
From planning your family to
raising adolescents -
Published by the Centre for
Independent Living in Toronto***

The first of its kind in Canada! Written from the perspective of the Independent Living philosophy, this unique resource celebrates parenting as a viable and rewarding option for people with disabilities. A reference for parents and prospective parents with a disability, health care providers, social workers, midwives, and other professionals. Covers topics such as: new devices; peer support and advice, and guidelines for discussing disability with your children. The book offers practical information for parents as they anticipate the steps and stages in their child's life. It includes personal accounts by parents with disabilities and resources and strategies for securing needed services. Cost: \$20 in Canada. Contact: pdn@cilt.ca. ISBN: 1-895676-32-0

***The Organ of Intelligence:
The quirky and perverse jour-
ney of a head injury survivor -
by Gregory Goldberg***

This novel is the first by Gregory Goldberg. The main character, Reuben Cohen, struggles through an awkward adolescence to find some skill on the ice, playing hockey with the guys. He dabbles at jobs and at last finds one that suits his spirit. He falls in love and life is joyously full - he has a beautiful wife, a freshly-painted, starter home, and plans for a family. Ah bliss! Life is perfect and the future is bright. And then it happens. A knock on the noggin changes Reuben's life. Thanks to fate, Reuben Cohen - teammate, fry cook and husband - is suddenly a man without boundaries, cut adrift from society. Understanding is forever altered. A portion of the proceeds from sales will be donated to the Lower Mainland Brain Injury Association in Vancouver, B.C. Cost: \$24.84 in Canada. Contact: <http://www.trafford.com/06-1268>. ISBN 1-4120-9513-1

To Our Future, Health and Happiness

Women with spinal cord injuries share their stories

We all have questions about getting old. What will it be like? What will I be like as an old person? For someone with a spinal cord injury (SCI), these are big concerns because aging with a SCI brings on other problems, such as a greater risk for pressure sores, loss of feeling and strength, joint pain, and bathroom difficulties. But for women with SCI, there are also other worries.

Before 1999, there was little research into the impact of aging on women with SCI. Out of every 100 people who experienced a SCI, 80 of them were men. (This is still the case today.) Research tended to focus on either male issues or on issues that crossed gender lines. So when the Ontario Neurotrauma Foundation (ONF) funded studies into this area of research starting in 1999, it was breaking relatively new ground.

Some women have offered their views and experiences to three different research studies focused on aging. Please read on to find out about fears, expectations and hope.

IN THE BEGINNING...

In the first study, led by Wendy Pentland at Queens University, the research team focused on how 29 Ontario women living with SCI, between the ages of 35 and 70, felt about their disability as they aged; how they coped as they aged, and what they felt they needed as they got older to be able to feel included in society. The women in the study had concerns about:

- being alone in their senior years (women live longer than men, and women with SCI have a higher divorce rate that men or women without disabilities)
- their own disability getting worse
- physical and health changes (such as fatigue, gynecological and sexuality issues, bowel and bladder management, appearance, pain and muscle weakness)
- money worries
- fewer friends (because of not being able to get out and see people)
- less care giving available from those close to them (because of family

- members moving away from home, or partners developing a disability)
- changing roles within their families
- losing independence
- changing relationships with professionals and service providers
- not enough woman-specific information and resources on SCI for them - and for professionals

The study's research team asked the women how they dealt with these concerns. Some of them said that attitude and behaviour played an important role in coping with aging. They adjusted to ongoing challenges and engaged in activities that were personally meaningful. Being actively involved in decision making was important. As one woman said, "You may have coped in different ways when you were able-bodied, and you may have more limited numbers of ways to cope when you have a disability - fewer choices. It doesn't mean you don't have choices. For me it doesn't mean you have to feel powerless."

For some of the women, coping strategies did not come easily. As one woman expressed, "I'll look at things on my schedule for the day and know I'm not going to be able to accomplish them... but I really need to. I find that mentally and emotionally very hard because I used to be able to do all that, but now physically and emotionally I just can't pull myself together." Not knowing where to turn or what to expect or even who to ask made it more difficult for the women to face the prospect of aging.

As a group, the women indicated that the following ways of coping were important:

- Talking to a friend, a spouse or a family member who could share experiences, challenges and information.
- Learning how to talk to family doctors and other professionals to improve health care.
- Using technology and other devices to make life easier (for example: computers, specially designed bras, power chairs, accessible vans).
- Hiring flexible, educated attendants who could: identify health problems early on, help prevent health issues from developing, and assist in household activities.
- Seeking out recreational opportunities in order keep fit and to socialize.

At the end of the study the women came up with a list of ideas that they thought would help women with SCI.

- peer support groups
- tele-health programmes staffed by experts with information relevant to women with SCI
- tele-consult programmes, so that family doctors could talk directly with SCI specialists.

A SECOND STUDY BEGINS...

After the completion of the Impact of Aging study, the ONF funded another one, again led by Wendy Pentland from Queen's University with a team including Maria Gould and Djenana Jalovcic, on telephone-based peer support for women with SCI living in rural Ontario. Telephone-based peer support groups have benefited breast cancer survivors, people with multiple sclerosis, and people living with HIV/AIDS. The ONF wanted to know whether this type of support group could help women with SCI living in remote communities.

Seven women from rural Ontario agreed to become members of a support group. A special part of this project was that it followed a participatory development format meaning the women, with the help of a facilitator, developed, designed, and planned how they wanted the telephone peer

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support to run. From December 2002 to August 2004, they talked to each other in 35 teleconferences and had one face-to-face meeting. The women took part in the planning, implementation, and evaluation of the study. Some of the teleconferences focused on peer support, and covered topics such as home renovations, attendants, relationships, dealing with health care professionals, and other personal experiences. Guest speakers attended other teleconferences, and these speakers covered topics such as the effects of long term SCI on joints, new research, managing pain, menopause, nutrition, and fitness - all from the point of view of women with SCI. As one woman commented after a neurologist spoke to the group: "Even if you do have a chance to meet a neurologist, you would



never get them to sit and talk to you for an hour."

At the end of the study, the women were mostly satisfied with the support and knowledge they gained. Some women said they got a lot out of the group sharing and others stated that their experience was satisfactory although they felt their connections were not as strong as some of the other women's. One woman said: "It makes you want to reach out and

touch right across the provinces and get everybody connected and feeling this way, feeling positive and good and uplifted and happy and non-lonely. It does something positive for you." Another woman shared: "I really felt good when I came off the teleconference. And, there has never been anything like that in 13 years that I could say did that for me."

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Kim Ritchie, one of the telephone peer support group members, had such a great experience from the connections she made and learning she gained, that in 2005 she developed the website www.proactivespinalnetwork.com. Ritchie experienced technical and resource challenges in developing and expanding the site to meet the needs of women

with SCI in the way she had hoped. The timing of the One Knowledge Mobilization Funding Competition was perfect. The research team from the previous telephone peer support study and Ritchie put their heads together and applied to the ONF for funding to assist Ritchie to improve the website. The team figured out what information was needed for the site, how people would find their way around the site, and how to let people know about it. Ritchie's role evolved into the Founder/Publisher. The content on the site covers topics such as health issues, relationships, pain, and personal stories.

Unfortunately, the website's message boards are closed temporarily because of spamming issues, but website administrators are working on a way to fix the problem. Until that happens, women can submit their stories about their personal experiences, and give feedback and suggestions for improvement on the site.

ALONG CAME THE WEB...

The teleconference study was successful and meaningful to the people who took part in it - but there were only 7 women involved. There was a need to share information with more people and the ONF agreed to fund a new idea. The goal of the next project was find, organize and share information about aging that would be interesting to women with SCI and post it on a website.

From a pilot study to teleconferences to the Web, the ONF has funded studies and initiatives that help women with SCI. Through shared information with others - collective experiences - aging will hopefully not be something unknown and feared.



Support for women with disabilities

<http://www.nurturingbelonging.ca>

The Belonging Initiative is a national collaboration that seeks to nurture belonging and end isolation for people with disabilities. It accepts and posts stories to its website from peo-

ple who feel that they have overcome their own isolation, and who have found acceptance and inclusion. (These stories can be viewed by those still searching for their own belonging.)

<http://cilt.ca/nurturing.aspx>

Nurturing Assistance is a consumer-oriented service that provides physical assistance to those parents with disabilities who have young children. Nurturing Assistants are paid employees who work under the direction and in the presence of the parent. They assist a parent with parenting activities, such as bathing and changing the child; preparing meals; lifting, carrying, nursing and cuddling the child; playing; and parent-child interaction. Funding is not available in all parts of the province, but the website provides a good overview of the service and how to find funding.

<http://www.bcm.edu/crowd/>

The Centre for Research on Women with Disabilities (CROWD) is located at Baylor College of Medicine in Houston, Texas. Its mission is to promote, develop and distribute information to improve the health and expand the life choices of women with disabilities. Its website has a wide array of resources for women with disabilities.

<http://health.groups.yahoo.com/group/womenwithsci/>

This Yahoo! message board has been created specifically for women with SCI. There is consistent activity, so users will likely be able to connect with others.

www.thescizone.com

The mission of this non-profit website is to provide reliable information on spinal cord injury related issues. Members of the site can post information of importance.

<http://lookingglass.org/parents/>

Through the Looking Glass, an American disability organization, runs the programme: The National Resource Centre for Parents with Disabilities. This programme services specific to parenting with a disability. They are particularly focused on custody, adoption, adaptive baby-care equipment, pregnancy & birthing, as well as general parenting issues.

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consumer items for people with a spinal cord injury and
an acquired brain injury as well as family and caregivers


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

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www.onf/newsletter/
or if you are a consumer
living in Ontario,
contact ONF at:
(416) 422-2228
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<http://cilt.ca/parenting.aspx>

The Parenting with a Disability Network is a peer network for parents - and prospective parents - with a disability. It seeks to develop consumer-friendly approaches to parenting with a disability by providing opportunities for peer support, information-sharing, and education.

Things to Know

CAREGIVER PORTAL

A new web portal is being created to help the three million Canadians who provide two billion hours of care to loved ones. The bilingual site will have information on:

- Providing care
- Respite supports
- Financial advice
- Networking with other caregivers
- “Caregiver Electronic Records” to connect caregivers with home and community care sectors

“The caregiver portal is one of many examples of emerging technologies that are managing the vast flow of information that is critical to delivering quality care,” said Richard Alvarez, President and CEO of Canada Health Infoway. The portal is expected to be launched in June, 2008.

iDAPT

The Toronto Rehabilitation Institute has announced its \$36 million research initiative -iDAPT (Intelligent Design for Adaptation, Participation and Technology.) iDAPT will be a place where new therapies and assistive technologies will be developed for people recovering from, and living with, disabling injury or illness.

“iDAPT offers new hope,” says Dr. Geoff Fernie, Toronto Rehab's Vice President, Research. “iDAPT will help people with disabilities and older people to adapt to new challenges and equip them with innovative and well-designed products that they will actually use and benefit from.”

iDAPT will be located at - University Centre (550 University Avenue, Toronto) and Lyndhurst Centre (520 Sutherland Drive, Toronto). The facilities will include:

- The Challenging Environment Assessment Laboratory (CEAL) that will be far below the hospital's will be far below the hospital's University Centre. CEAL will be equipped to create winter-like conditions including ice, winds, and snow so that researchers can safely test people's balance and mobility devices in real-life situations.
- A typical hospital room where researchers can develop and test new technologies to help nurses and reduce caregiver injuries.
- A laboratory with a single-storey house where researchers can develop technologies to help people live as independently as possible.
- A “movement evaluation” lab that will advance research on treatments for paralysis caused by stroke and spinal cord injury.

Several iDAPT laboratories and work

shops are already open and the remaining labs - including CEAL - are expected to open in 2011.

THE MEDS CHECK PROGRAMME

“Meds Check” is a free government service that provides Ontarians with an opportunity to consult with their pharmacist one-on-one for up to 30 minutes once a year to review the medications they are taking.

“This is the first programme of its kind in Canada and it will ensure that people are getting the most from their medications by taking them properly and safely,” said George Smitherman, Minister of Health and Long-Term Care. “We recognize pharmacists for the valuable role they play in patient care - that is why we have created the Meds Check programme.”

Talk to your pharmacist to book your appointment.

A Snowman's Conundrum

I have such a love-hate relationship with freshly fallen snow.



The Skinny on Pressure Sores

What is it?

- It is an area of the skin that is not getting enough blood flow -- it doesn't turn white when you push on it, and it may be warm or swollen.
- It starts as a red/dark patch.

What causes it?

- It is caused by continuous pressure on an area of skin, such that blood can't provide oxygen to that area; this can happen in a matter of hours!
- It is more likely to occur near bony areas (e.g. bum, hips, ankles).
- Moisture, friction, and clothing rubbing against your body can lead to pressure sores.
- Urine and bowel movements have acid and germs that can break down the skin.
- Poor nutrition and poor general health may make it more likely for you to develop a pressure sore.
- Certain medications (e.g. sedatives) can make you less aware of the skin starting to break down.

What do you need to know?

- The faster you deal with it, the

faster it will heal.

- If not treated, the skin can break down, causing blisters, an open wound and ultimately infection in the skin, bones and joints. Nasty!
- It can be dangerous, even life-threatening if you ignore it; a neglected pressure sore may require surgery.

How do you prevent it?

- Use cushions, mattresses and pads to take pressure off your skin.
- With or without help, move around to take pressure off your skin.
- Eat well.
- Get lots of rest.
- Exercise, because exercise improves blood circulation.
- Keep your skin clean.
- If your skin is dry and prone to cracking, use moisturizing lotion.
- Do daily skin checks - use a mirror for hard-to-see areas or get someone to help you.

What do you do about it?

- See your doctor, especially if it does not clear up in a day.
- Reduce the pressure.
- Determine what triggered it, and then resolve that problem.
- Rest and relax.

What in the World Wide Web is Going On

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

The Substance Use and Brain Injury (SUBI) Bridging Project was initiated to study the problem of substance use/abuse and the effects on people with brain injuries. This website provides information for healthcare providers, people with an acquired brain injury, and other interested stakeholders.

http://www.canparaplegic.org/en/SCI_Facts_67.html

Visit this page for all your SCI Facts. A great overview of what is important to know if you, or someone you know, has a spinal cord injury.



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: info@onf.org

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