

NeuroMatters

Connecting YOU to the Research

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Home Coming

Doing what it takes so that your child with ABI thrives

There's no place like home, but for kids returning from the hospital after a brain injury, there needs to be a lot more than the smell of baked cookies and a parent's warm lap to satisfy their needs. To make the transition successful, supports and services need to be in place. That's the conclusion of a recently funded Ontario Neurotrauma Foundation (ONF) study.

When children have a brain injury, it's likely that they will return home after a stay in the hospital. But every home is different. What makes a home a safe, nurturing, secure place for one child, but uncomfortable, lonely and even neglectful for another? ONF was interested in knowing, so it funded a study to look into this the issue.

Led by researchers Carol DeMatteo, Mary Law, Colin MacArthur, Angela Colantonio and Rachel Teplicky, the study collected data from 2001 to 2005 on 586 children with acquired brain injury (ABI) between the ages of 10 and 18. The data came from:

- previous ONF-funded studies
- Bloorview Kids Rehab (Toronto)
- Ontario Brain Injury Association (St. Catharines)
- Home for Independent Living and Learning Programme (Hamilton)
- Child Development Centre (Kingston)

Here's what the study found:

- Boys, especially those between the

ages of 10 and 14, were more likely than girls to receive an ABI.

- Most (over 90%) of the children were living at home.
- The community services used most often were physiotherapy, speech therapy, formal educational support, and especially in-school occupational therapy.
- There was little consistent documentation on attendance in ABI-specific and behaviour programmes, largely because there are so few of these programmes in Ontario.
- As they got older, the children were less likely to receive services and supports.

The researchers also interviewed 44 service providers for their views on what supports and services are needed for the best home environment for children with ABI. Says one service provider from Northern Ontario: "The ideal thing is to keep children with family. It will break down if they don't have the appropriate supports. Not just for the injured person, but also for the family."

Among the factors that families and discharge professionals need to consider when a child is medically ready to go home after a hospital stay are the following:

- the parents' ability to cope
- the family's acceptance of change
- financial stability
- the age, behaviour and character of the child
- the availability of community supports
- the availability of knowledgeable, safe and licensed programming for the age and skill level of the child
- the size of the wider community (there are generally more supports in larger population centres)



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- the availability of insurance money (to pay for specialized services)

These factors need to be considered before a child with ABI returns home from the hospital. As one service provider points out, “They go home. Sometimes once they are home, then they are frantically searching for services.” Planning for the child’s needs will make the transition easier on everyone.

The study also found that the service providers recommended the development of:

- services that are accessible (geographically, physically, technologically)
- more publicly-funded ABI specialty services (e.g. rehabilitation, respite,



“The ideal thing is to keep children with family. It will break down if they don’t have the appropriate supports. Not just for the injured person, but also for the family.”

system navigation, case management, psychological assessments and services, outreach, community integration)

- timely assessments and follow-up
- service integration by government, private sector and non-profit agencies (i.e., a more coordinated system of care and public education about ABI)
- a variety of government-funded living situations so that families have a choice about living arrangements for their child
- a province-wide, client/family-centred and ABI-focused model of care
- information and education for family members and service providers
- policy, legislation and follow-up with the Ministry of Education
- more research on ABI best practices
- a long-term study to look at changes to environment and service provision over time

Based on the review of the data and the interviews with the service providers, the study found that there were few community supports for children with ABI and their families because:

- general government-funded programmes usually don’t have staff who are knowledgeable about ABI
- there are few government-funded ABI-specific programmes
- there are no policies and legislation on ABI service delivery
- parents are often out of the loop on funding for ABI service delivery
- there is no formal relationship between different service agencies
- there are few community-based “one-stop shops” that can field specific questions about ABI and ABI resources
- as a child with ABI ages, families bump from one programme or ministry to another

The study’s findings highlight a suggested framework for children with ABI going home and integrating into the community. The recommendations can help with planning and coordination at the time of discharge. The study has categorized data that can be referenced in future research to better understand children with ABI, and the services and supports they need in their communities. As well, the study has given parents the information they need to ensure a nurturing home for their child and family. These findings empower them to push for the community services their child needs. A service provider from the Golden Horseshoe region says, “What’s interesting is watching parents...most are really, really strong. Not all of them, but most of them get to be significant advocates.”

The bottom line: home is an appropriate environment for children with ABI, but parents need to ensure that they have the necessary services and supports in place. Just as a child’s needs will continue to change, so too will his/her environment, programmes and services.

ONF's 10th Anniversary Celebration

On May 21, 2008 the Ontario Neurotrauma Foundation (ONF) celebrated its 10th anniversary - outdoors at Queen's Park. It was an elegant affair, and although the day was cool the celebration was well attended by consumers, politicians, medical practitioners, private insurance representatives, service providers, researchers, and public health officials. The celebration was a "thank you" to all those who support ONF.

The event was held on the lawn in front of the Ontario Legislature. The ONF celebration was a positive way to underline that ONF values all of our stakeholders and the partnerships we are engaged in with them.

For those involved in ONF's activities, the journey over the past ten years has been as fulfilling as it has been constructive. Consumer participation is an integral part of the organization. We were thrilled to have some of our consumer stakeholders and valued researchers there to celebrate with us. We were also joined by many association representatives, service providers, administrators, and policy makers. Many of our past board members were there to join us in celebrating our collective achievements, and they commented on how far ONF has come to achieve its mission.

The ONF's work becomes a powerful contribution to the neurotrauma community. By making the right connections and working with the right people, ONF has come a long way in



its ability to influence change and enhance the quality of life for those injured.

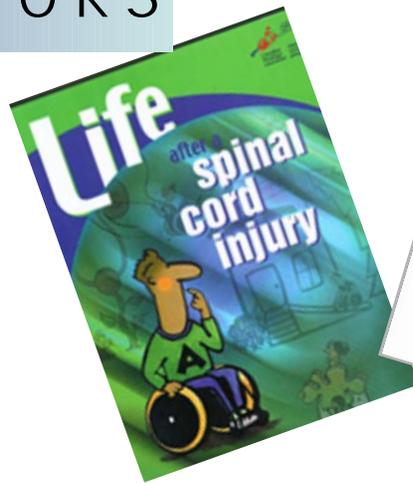


ONF Chief Executive Officer, Kent Bassett-Spiers with Dianne Cunningham, Chair, William Thorsteinson, Founding Chair and Daryl Rock, Past-Chair

ONF's 10th anniversary celebration was an occasion on which ONF encouraged stakeholders to come together - literally and figuratively - under the same tent. Given how hard ONF has worked over the past decade to bring these stakeholders together, the big tent was a highly appropriate symbol for stakeholders to mark and celebrate their unity of purpose with ONF.

The stakeholders have brought diverse thinking and collaboration to the table, and they have helped ONF to fulfill its mission of improving the quality of life for people with neurotrauma. On May 21, ONF was able to say, "today we are celebrating our past - but more importantly, we are looking towards our future."

BOOKS

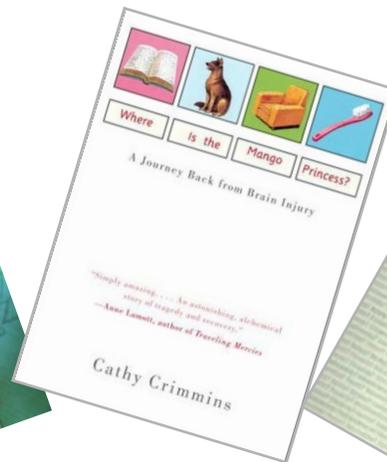


Life After A Spinal Cord Injury
Published by the Canadian Paraplegic Association

When a spinal cord injury occurs, it would be nice for those injured and their families to be able to refer to a general guide for explanations, answers and advice.

The Canadian Paraplegic Association may have just the thing. Originally produced by the Association des paraplégiques du Québec (APQ) for their members and clients, this 200-page resource guide, remains popular. It covers the “lingo” of SCI; the gamut of health care concerns; self-identity; and the need for recreational pursuits, exercise and healthy living. Throughout the publication are quotations from those who have “been there, done that.”

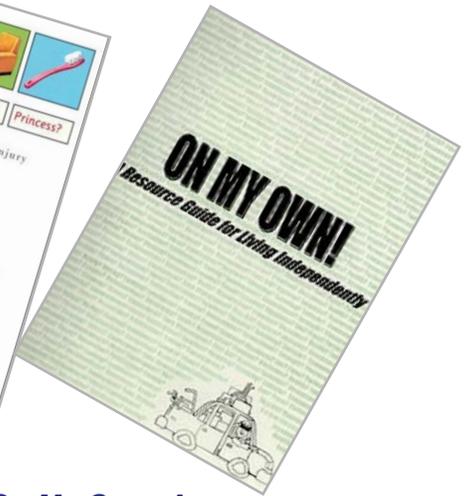
Available in English, French and Spanish.
Cost: \$30.00 (\$15.00 for CPA Members) + shipping and handling.
Contact: (613) 723-1033 or info@canparaplegic.org
ISBN: 0-9733658-0-3



Where is the Mango Princess?
by Cathy Crimmins

Cathy Crimmins was on holiday with her family when a boating accident resulted in a traumatic brain injury for her husband. *Where is the Mango Princess?* shares the very personal story of what she, her daughter and her husband experienced after he woke up from his coma. This is a good book for family and friends of a person with a brain injury. Crimmins captures the frustration, pain and humour one family went through as everyone involved readjusted to the new situation. The book also shows the good and bad things associated with the health care and insurance systems. For readers who have a connection to someone with a brain injury, this book is a must-read. The experiences are so real and raw. For those readers who have gone through similar situations, the book helps them feel like they are not alone.

Available in paperback and hardback
Cost: \$17.95
Publishers: Knopf Publishing Group
Contact: chapters.indigo.ca
ISBN - 10:0375704426
ISBN - 13:9780375704420



ON MY OWN!
Resource Guide for Living Independently
Published by the Canadian Abilities Foundation

On My Own is a resource guide designed to assist young people with disabilities in their transition to living independently. This handy little book covers everything from finding a place and setting it up, to dealing with possible loneliness, to looking for work and volunteer positions. *On My Own* offers the kinds of life tips and household hints you might get from a parent - but with this book, you won't have to!

Most of the book's valuable information was collected from answers to a comprehensive questionnaire on living independently. It was completed by an advisory committee of adults with disabilities - people with experiences to share. Their words of wisdom appear throughout the publication.

Cost: \$22 (+ \$3 shipping)
Contact: Canadian Abilities Foundation at (416) 923-1885 or able@abilities.ca
ISBN - 0-9737126-0-0

The Skinny on preparing your child with ABI for School

What do you discuss with the principal and vice principal?

- Contact the school prior to your child's first day.
- Ask for a meeting with the Principal, Vice Principal or Learning Resource Teacher.
- Make your contact aware that you are offering information to facilitate your child's success and to make their job easier. Offer to be an on-going resource to them.
- Give them copies of relevant medical and/or educational assessments or recommendations.
- Provide relevant information on your child's strengths, weaknesses, social and emotional needs.
- Give them background information about brain injury, and professional contacts that they can use to help prepare for your child. Remember: you are your child's advocate. Don't assume they will know.
- Know what you want for your child. Think about this before the meeting. Write your expectations down, if necessary.
- Find out what supports the school has available such as occupational therapy, speech therapy, and counselling. Recognize the limitations of the system's resources. Confrontation will be counter productive.
- Chances are that more than one teacher will be teaching your child. The school may have a music teacher, a gym teacher, and a librarian. Lunch monitors may have your child under their care. As well, your child may switch teachers next semester or next year. Expect to repeat discussions and explanations with each transition.
- Offer to have a brain injury professional, or someone from the Brain Injury Association, come in to speak to the staff.

What do you discuss with the teacher?

- Provide background information on your child's brain injury, and contact information for an ABI professional.
- Let the teacher know what you've learned about your child. Suggestions about how to prompt a change in behaviour, or how to see signs of frustration can be a huge help in the classroom.
- Work with the classroom teacher and the resource teacher to develop an educational plan for your child. Get a copy of the plan and review it with them every few months.
- Inform the teacher of any specific physical limitations that your child has and any accommodations that are required.
- Discuss with the teacher whether it would be possible for your child to rest in a quiet room during recess.

What do you discuss with your child?

- Transitions can be hard, so let your child know about the new school environment as early as possible. Try taking some trips to the school to show the playground, the entrances and the classroom windows. If your child is starting at the beginning of the school year, the school is usually open the last week of August, so go in with your child, take a tour, and try to meet the teacher.

What do you discuss with the other kids in the class?

- Before your child starts school, discuss the idea of having some friends over for a visit. These

friends may become great advocates for your child. They may know how to deflect awkward moments with other classmates. Make sure you have your child's agreement before you go ahead.

- You can talk to the kids in your child's class to let them know what to expect or what has changed. If possible, have your child give a short presentation to the class.
- Let kids know how they can help your child out.

What are some basic strategies for school success?

- Allow enough time in the morning to avoid everyone in the family feeling stressed before you leave the house.
- All kids can benefit from a snack being available right after school. This can help to avoid meltdowns because your child is hungry and tired.
- Try not to rush your child off to other lessons, appointments or play dates right after school. Take it slow and easy.
- When you feel your child is not being treated properly it is easy to get mad. Blowing up at the professional working with your child is not in your child's best interest. Call a meeting. Try writing your issues down beforehand. Bring a friend along for support. If things get heated, take a break and then come back to talk when you are feeling calmer.
- Keep talking - to your child, to your child's teacher, to friends, and to others in the school who are with your child. Open communication will reinforce to others what is important to you and your child, and you will have a good idea about how your child is learning.

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: Transitions: "Building Skills for Living in the Adult World"

When: May 21-23, 2008

Where: Toronto, ON

Overview: In its 4th year, this conference hosted 250 participants from Canada, the United States, Sweden, Australia, and the Netherlands. The first Transitions conference was held in 2002 with 100 participants in attendance. The next conference will be held in 2010. There was good representation from health care professionals, researchers, policy makers, and consumers.

Comments on Keynotes: Key note addresses were made by people with disabilities, including:

- Justin Hines, a songwriter whose debut album "Sides" has received major recognition and whose single "Wish You Well" has been in the top 20 national radio chart for nine months.
- Jeff Tiessen, founder and president of DT Publishing Group, whose focus is on fitness, sport and recreation demonstrated through his magazine *Active Living*. As a motivational speaker, he promotes healthy living and the portrayal of people with disabilities fully participating in their own recreational pursuits.
- Luca "Lazylegz" Patuelli is a breakdancer, and has been dancing for almost 8 years. He's competed in major international dance events and has had a positive influence in the breakdance community in Montreal, where he lives.

General Comments: The theme of the conference was "participation," defined by the World Health Organization as "the nature and extent of a person's involvement in life situations". Participation is

considered critical to the quality of life for consumers and their families. Needs change over time and it is imperative that researchers examine appropriate supports from infant to adult to senior years. Continuity of supports and services should be at the crux of chronic disease management.

It was nice to see that consumers were involved throughout the planning for and presentation of the conference process.

By Hedy Chandler

Conference: The Seventh World Congress on Brain Injury

When: April 9-12, 2008

Where: Lisbon, Portugal

Overview: The International Brain Injury Association (IBIA) was created in response to the growing demand from professionals and advocates throughout the world for collaboration and more information on all aspects of brain injury, from prevention to long-term care issues. Since 1993, the IBIA has hosted conferences which have become the largest gathering of international professionals and advocates working in the field of brain injury.

General Comments: For the first time there was a pre-conference symposium on mild brain injury "Advances and Controversies in Mild Traumatic Brain Injury". The symposium was co-sponsored by the International Brain Injury Association and the World Federation of Neurological Rehabilitation.

There were over 50 delegates from Canada and another 800 or so from around the world. Canadians had a strong representation in the scientific programme by making 26 presentations over the three days. Delegates included neurosurgeons, rehabilitation physicians, psychiatrists, speech

pathologists, occupational therapists, physiotherapists, social workers, nurses, case managers, paraprofessionals, families and survivors.

They all had one thing in common - a desire to share knowledge and ideas about how to make the world a better place for individuals living with the effects of a brain injury.

Things to Know

GET IN MOTION

"*Get in Motion*" is a free physical activity counselling service for Canadians living with a spinal cord injury. Operated from McMaster University's Department of Kinesiology, it is supported by the SCI Translational Research Network in partnership with the Rick Hansen Foundation.

"*Get in Motion*" is designed to provide you with information and ongoing telephone support to help you meet your physical activity goals. You will receive a free physical activity toolkit that includes two therabands and information on physical activity for people with spinal cord injury. You will also be invited to participate in a research study on the effectiveness of this new service.

Whether you are considering becoming physically active, have just begun

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a physical activity programme, or have been engaging in physical activity for a while, you can benefit from this service. Physical activity counselling sessions are created to meet your specific needs.

Topics of discussion may include, but are not limited to:

- Safety and benefits of physical activity for people with spinal cord injury
- Overcoming barriers to physical activity
- Locating accessible physical activities in your community
- Goal setting

To participate or receive more information from an exercise counsellor, please call: 1-866-678-1966 or e-mail motion@mcmaster.ca.

What in the World Wide Web is Going On

<http://www.onf.org>

Coming soon to a computer near you... ONF is nearing completion of a major update of its website. It will have a new look and feel, re-written content, improved site navigation, and easy access to information. Of particular interest will be the online eligibility guidelines and application forms for grants. Site visitors will be able to search the database to see the last 5 years of awards that have been granted. A brief synopsis of the projects includes researchers involved. Look for the new site near the end of June.

<http://www.cpaont.org>

CPA Ontario has recently updated its website with much easier online

access to information about programmes and services. Each regional office now has its own home page, so finding local events and news is just a click away. Check out the site and sign up for updates through the organization's e-zine, E-Spoken.

<http://www.accesstolearning.ca>

Access to Learning Canada is an online inventory that assists students with disabilities, parents and guidance counsellors in the research phase and assessment of the disability services of post-secondary schools. It has articles, links, news bulletins, and event listings about education and students with disabilities. Several Ontario universities and colleges have their disability services outlined.

The Ontario SCI Alliance

A partnership to improve quality of life for people with a SCI

For people with spinal cord injury (SCI), the journey to reach the point of optimal health and reintegration into the community in the aftermath of the injury is a continuous process that can pose significant challenges and barriers for them. These challenges and barriers can result in medical complications and delayed independence at a time when they are trying to put their lives back together.

The current system of community health supports for people with SCI is an inadequate patchwork of services that varies from one region to another. As a result, it is often difficult for people with SCI to access quality services in a timely fashion.

In 2007, ONF partnered with the Canadian Paraplegic Association Ontario (CPA Ontario) to establish the Ontario SCI Alliance in order to facilitate the timely provision of services for people with SCI. The Alliance has invited clinicians, researchers, service providers, consumers, and administrators to come together,

discuss the key issues, and develop strategies to effect changes to the health care system.

The Ontario SCI Alliance now has 40 participants who meet regularly. It has recently initiated an SCI Pilot Project in the Hamilton Region, providing support to people with SCI from the time of initial injury to community reintegration and beyond. The project is consumer-centred - meaning it customizes solutions to barriers for each individual.

In another recent initiative, the

Alliance has sought to increase access to high-quality medical care for those people with high-level SCI who use respiratory supports. They are the most fragile component of the SCI population: their medical attention has to be immediate, and they need appropriate strategies to support them in the community.

A team approach to providing health care in the community will better enable people with SCI to live active and healthy lives. For further information, stay tuned to future issues of *NeuroMatters*.

Events

July 11-13, 2008: Brain Injury Association of Canada, 5th annual AGM/Conference: "The Squeaky Wheel Gets the Grease: Getting What You Need", Villa St. Martin, Pierrefonds, QC. More info: <http://biac-aclc.ca/en/annual-conference/>

August 25-28, 2008: The 21st World Congress of Rehabilitation International: "Disability Rights and Social Participation: Ensuring a Society for All", Quebec City, QC. More info: <http://www.riqbec2008.org/>

October 23, 2008: The Brain Injury Association of Niagara and Friends Helping Friends Conference: "Pathways to Discovery: Resiliency, Empowerment and Innovation", Thorold, ON. More info: <http://www.obia.on.ca/bainconference.pdf>

November 3-4, 2008: Toronto ABI Network Conference. Exploring the latest in research and practice in the areas of acute care, rehabilitation and life-long living. More info: <http://www.abinetwork.ca/conference2008>

November 6-8, 2008: 3rd National Spinal Cord Injury Conference and the 16th Interurban Spinal Cord Injury Conference: "Innovation, Impact and Future Directions", Toronto, ON. More info: <http://www.torontorehab.com/education/scic08index.htm>

November 16-18, 2008: Ontario Injury Prevention Conference, Toronto, ON. Taking injury prevention from theory to practice and beyond. More info: <http://www.oninjuryresources.ca/OIPC/2008/>

National Spinal Cord Injury Conference Consumer Outreach Programme 2008

Toronto Rehab, CPA Ontario, Rick Hansen, National SCI Alliance, and ONF have partnered to support consumer involvement and attendance at the third National Spinal Cord Injury Conference to be held in Toronto, November 6, 7 and 8, 2008.

The following guidelines have been developed to assist consumers in understanding the purpose of the fund, eligibility and how to apply.

Guidelines

- The fund is for those who have no other means to obtain financial assistance to attend this conference.
- Financial assistance will be provided to attend the conference only, starting Thursday night to Saturday afternoon. Recipients are expected to attend the full conference, including a wrap-up lunch on Saturday and workshops that afternoon.
- Any costs beyond the conference, the recipient is expected to pay.
- Preference will be given to those consumers who have not been previously supported by this fund. However, those who have been previously funded may still apply.
- Recipients conference costs, including meals, will be covered. Reasonable travel costs and hotel costs for Thursday and Friday night will be covered. Individuals who need to stay an additional night will have the costs considered. Travel costs to take the train or to fly will be supported.

Mileage at 40 cents per kilometre will be provided to those driving to the conference as long as it is the most cost effective means of travel.

- Consumers attending the conference will be required to provide an overview in article format to the partner organizations, and to explain how they will engage consumers in their home communities about the outcomes of the conference.
- Consumers will be expected to make their travel, hotel and conference arrangements with the Toronto Rehab Conference Services department.
- Attendant services will be provided by CPA Ontario at the conference. Funding for extraordinary costs associated with attendant services (i.e. attendant travel costs) will be considered.
- Consumers accessing this fund will be required to complete an application form. These applications will be reviewed by representatives of the partner organizations and awards may be granted.
- Applications will be kept confidential and be available only to the partner representatives involved in the review.

Applications must be submitted by August 15, 2008. Successful applicants will be notified no later than September 10th, 2008.

For more information, please contact info@onf.org.



Ontario Neurotrauma Foundation

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