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Promoting quality of life through research, education and cross-sector partnerships

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Welcome to the first issue of *backtolife.ca*, the newsletter of the Canadian Working Group on HIV and Rehabilitation (CWGHR). This introductory issue will provide an overview of CWGHR and some of our activities. Our hope is to use this newsletter to provide information and updates on current issues and activities on rehabilitation in the context of HIV.

Who is CWGHR?

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national organization dedicated to the needs of people living with HIV disease. In 1998, *Rehabilitation Services: A Comprehensive Guide for the Care of Persons with HIV Disease* was published by Health Canada and Wellesley Central Hospital. During the development of this resource, a need emerged for national vision and coordination in the area of rehabilitation in the context of HIV disease. CWGHR was founded to respond to this need.

The "multi-sector approach" is one of the main strengths of CWGHR, providing the basis for learning from, reaching out to and collaborating with all relevant stakeholders in rehabilitation in the context of HIV disease. CWGHR members include:

- People living with HIV disease.
- Representatives of:
 - ▶ community-based HIV and other disability organizations
 - ▶ national associations of health professionals
 - ▶ government departments,
 - ▶ private businesses
 - ▶ employment related agencies

Background – HIV, Disability and Rehabilitation

The profile of HIV disease is changing. At one time, HIV infection caused predictable decline in health, and death. While there is still no cure for HIV disease, today new drugs can slow disease progression and help people to live longer with improved quality of life.

However, living longer with HIV often means living with impairments, disabilities and

handicaps. These include pain, weakness and coordination impairments, fatigue, weight loss and problems with vision. HIV can cause cardiac and respiratory impairments, and neurological, psychological and social problems may also arise. While new drug therapies can improve immune status, they are often very complicated and can cause side effects, which can be moderate and inconvenient, or severe and debilitating.

"Advancement of rehabilitation services for HIV-related disabilities; research and project funding; education and information; multi-sector partnerships."

Rehabilitation is important because people living with HIV disease experience all of these conditions. The goal of rehabilitation is to help people to improve their lives. In the context of HIV, CWGHR believes the goal of rehabilitation is to optimize the individual's participation in active living.

Centred on the needs of people living with HIV, CWGHR has two primary mandates:

- Coordinate a national response to, facilitate and support the development of, and provide advice on rehabilitation issues in the context of HIV disease
- Raise and distribute funds for rehabilitation projects in the context of HIV disease



La Stratégie canadienne sur le VIH/sida
Canadian Strategy on HIV/AIDS



Human Resources Development Canada

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During the upcoming year, research and education on rehabilitation in the context of HIV are two of CWGHR's priorities. This newsletter will be a vehicle for providing updates on new information and the innovative work that organizations and individuals across Canada are undertaking in these important areas.

Looking Beyond the Silos: Disability Issues in HIV and Other Lifelong Episodic Conditions

This summary provides a brief overview of the recently completed CWGHR "Cross Disability" project. A full report of the project is available from the National AIDS Clearinghouse and the CWGHR web site www.hivandrehab.ca

"Looking Beyond the Silos" was developed to define some common 'disability' and 'rehabilitation' issues among people living with HIV and people with other lifelong episodic conditions. There was a strong desire to initiate dialogue among various Canadian disability groups regarding those unique issues pertaining to lifelong episodic illness, and to explore possibilities for future partnerships between/among organizations.

The research question emerged from an environmental scan to determine emerging issues/gaps in knowledge related to rehabilitation in the context of HIV.

- Phase one of the research involved interviews with non-HIV groups dealing with lifelong episodic illness/disability to identify areas of mutual concern.
- Phase two involved a national consultation with key organizations to explore shared program/policy issues and potential collaborations
- Phase three involved a meeting with Dr. Carolyn Bennett, MP, and Chair of the Sub-committee on the Status of Persons with Disabilities (Government of Canada) regarding cross disability concerns and issues of lifelong episodic conditions

EMERGING THEMES: Many issues emerged through this project, particularly: public and private insurance provision; income support; workplace accommodation and employment issues; service provision and support for individuals; and a need for work on definitions regarding types of disability. These themes were shared in the meeting with Dr. Bennett.

FUTURE DIRECTIONS: The issues identified through this project have sparked challenging and exciting discussions. CWGHR members have determined that issues of lifelong episodic disability are a priority for our work in the coming year. Continued research and education will be undertaken to develop further knowledge and understanding of the complexities of these issues. There was also expressed commitment from a number of organizations to continued collaboration with CWGHR on cross disability issues. CWGHR is committed to continuing the momentum developed through this project. We will provide updates as new activities are undertaken.

Peggy Proctor

Peggy is a physiotherapist working at the School of Physical Therapy at the University of Saskatchewan and was the Coordinator of the Cross Disability project "Looking beyond the Silos".

"There was also expressed commitment from a number of organizations to continued collaboration with CWGHR on cross disability issues."
- Looking Beyond the Silos

Highlighting a model for HIV and rehabilitation: St. Michael's Hospital

The HIV program at St. Michael's Hospital, in downtown Toronto, is striving to meet the many challenges of offering comprehensive and holistic care for people living with HIV and AIDS. A central factor in the program's success is the inclusion of a wide variety of health care

disciplines within the HIV team. As HIV disease evolves and takes on the characteristics of an episodic, chronic disease, one of the important aims of the team is to address the unique rehabilitation needs of its clients. The team's physical therapist, occupational therapist, and massage therapist address physical rehabilitation; and a holistic rehabilitation approach is achieved in collaboration with the team's social worker, registered dietician, psychiatrist, psychologist, doctors, nurses and pharmacists to maximize clients' abilities while effectively managing their HIV disease.

When a person is admitted to hospital with an opportunistic infection or other condition related to HIV, their medical care includes an assessment by the physical therapist, who will assess the acute rehabilitation needs associated with a hospital admission. Common rehabilitation issues include deconditioning, mobility and respiratory problems, and

the establishment of services for people to return home. In order to provide a good continuum of care, the same physical therapist can follow a patient when they return home, continuing to address their rehabilitation needs as they get stronger and return to normal activities. As well, the physical therapist, occupational therapist and massage therapist work together with clients who are at home but have some rehabilitation needs in order to maintain independence, improve quality of life and/or increase their physical fitness to maintain a healthy lifestyle. Problems encountered by these types of clients can range from low physical strength and stamina, to neurological impairments, or pain management.

The expanding focus by St. Michael's on HIV and rehabilitation is an effort to address quality of life issues in conjunction with the complex medical issues. This collaborative strategy towards rehabilitation has allowed St. Michael's HIV team to expand its understanding of HIV care. As HIV continues to change and evolve we believe that rehabilitation will play an important part in delivering top quality client-centred care.

**Chris Sulway, Physiotherapist
Inner City Health Programme - HIV team
St. Michael's Hospital, Toronto**

Chris is also a member of CWGHR's Education/Practice Advisory Committee (EPAC).

Innovative research on rehabilitation in the context of HIV – moving the field forward

A project at McMaster University has found the participation of a person living with HIV (PWH) in the education of physiotherapy, occupational therapy, medical, nursing and social work students to be highly rated. Funded by CWGHR, Patty Solomon, Dale Guenter and Penny Salvatori of McMaster developed an 8 week course with a focus on rehabilitation and HIV. Students participated in small group, problem-based discussions with a faculty tutor and a PWH as a co-facilitator. Analysis revealed that students highly valued the role and input of the PWH as "resource tutor". The resource tutor was able to bring life and reality to the scenarios under study and encourage reflection to a degree unlikely to occur in a

more traditional course. The presence of the resource tutor also challenged the students to address their own assumptions and values. A quote from the journal of a participant illustrates the valuable nature of the learning:

"At the end of tutorial as I walked home I began to feel more comfortable with the idea of interacting with an HIV/AIDS person. I cannot say what helped exactly. The one thing that I can see being different from when we learned about it in class was the presence of (the resource tutor) in our group. It was my first time speaking with someone with HIV. As he shares his personal experiences, I gain more understanding around the topic, beyond what the literature tells us."

Another innovative aspect of the program was the interdisciplinary format. Students felt that they were able to learn and achieve more by working together as is highlighted in a quote from another participant:

"I think - especially with the rehabilitation end of HIV - the interdisciplinary aspect was really beneficial because I think nurses do have a role in it but there is a huge role for all the other professions too. And if I just tried to learn about HIV rehabilitation with nursing I would have missed a lot of the picture".

Building on the project's success, Solomon and Guenter have developed a training program for PWHs and are evaluating its impact from both the learners' and the PWHs' perspectives.

Patty Solomon, PhD, PT

Patty Solomon is Associate Professor and Chair of Physical Therapy at the Rehabilitation School, McMaster University, and one of the principal researchers in this project.

"I think - especially with the rehabilitation end of HIV - the interdisciplinary aspect was really beneficial because I think nurses do have a role in it but there is a huge role for all the other professions too. And if I just tried to learn about HIV rehabilitation with nursing I would have missed a lot of the picture".

- Participant in McMaster University Project

Order from Chaos

CWGHR: an acronym for Canadian Working Group on HIV and Rehabilitation. Quite a mouthful. But what is it?

The two workshops I have attended with a mixture of PHA's, professionals and HIV naïve individuals allowed an interplay of view points as to what kind of support network is needed and available. I was immediately aware that someone other than me had an understanding of the present and future issues.

Present are the immediate survival issues and the necessity for more than just an HIV specialist to oversee your condition, but a team of professionals: counsellors, nutritionists, social workers, pharmacists to name a few. Each of these professionals are then able to contribute their expertise in battling social issues and secondary yet life threatening illnesses attributed to HIV.

Future issues are educating these associated professions of the HIV health trends imposed upon long-term survivors: diabetes, cancers, heart disease, and arthritis. Such preparedness minimizes the multi-tasking each health crisis brings upon both the professional and the patient. It prepares these associated professions for the HIV reality and the continuing threat it imposes on a PHA.

"The two workshops I have attended with a mixture of PHA's, professionals and HIV naïve individuals allowed an interplay of view points as to what kind of support network is needed and available. I was immediately aware that someone other than me had an understanding of the present and future issues."

- Order from Chaos

While this advocacy and lobbying is preventative it allows a PHA a course of action to minimize the crisis of a continual health threat. Then the PHA has some power, some control to gain order out of chaos. Such a course enhances a positive direction for the PHA in their quality of life and health promotion.

Robert Vanidour

Robert Vanidour lives in southwestern Ontario and played a lead role in arranging for CWGHR's workshop to be presented at the Opening Doors conference in London, Ontario.

The World According to CWGHR: Workshops on HIV and Rehabilitation

'The World According to CWGHR' is the name of a workshop I have come to think of as "The CWGHR Roadshow". Originally developed from a collaboration between CWGHR and the Ontario AIDS Network for a PHA (person/s with HIV/AIDS) conference in 2001, it was then adapted for the 2001 Canadian HIV/AIDS Skills Building Symposium in Montreal. It has since appeared in London, ON, Vancouver and St John's. CWGHR workshops are co-hosted by local organizations across Canada in order to better meet specific community needs.

The workshop is designed to reflect CWGHR's national, collaborative, multi-sectoral, interdisciplinary approach to rehabilitation in the context of HIV. Facilitated by staff and members of CWGHR, the workshop also includes experts from various sectors in the local community, including rehabilitation health care providers, Government (policy and funding), Social Services, Private Sector, and disability / benefits programs. Common terms and definitions are introduced such as "Impairments, Disabilities and Handicaps", helping provide some shared language. A snapshot of the local/ regional rehabilitation landscape is given from the perspective of the various presenters, and participants then discuss ways to improve access to and delivery of rehabilitation in the context of HIV.

“One of the most commonly identified “best thing about the workshop” is the opportunity to network and brainstorm with such a diverse group. As we plan future workshops, we look forward to molding the workshop for different groups and different regions across Canada and beyond.”

- The World According to CWGHR

While the workshop can be tailored to specific audiences such as people living with HIV/AIDS, nurses, physiotherapists, or physicians, participant groups have largely been multidisciplinary and multi-sectoral, reflecting the diversity of rehabilitation and HIV. One of the most commonly identified “best thing about the workshop” is the opportunity to network and brainstorm with such a diverse group. As we plan future workshops, we look forward to molding the workshop for different groups and different regions across Canada and beyond.

It is good to know from people that they are getting so much out of the workshops, because so is CWGHR. Each workshop allows us to learn more about rehabilitation issues, develop new partnerships across the country and ensure CWGHR’s priorities are hitting the mark at the front line. Participant feedback provides the opportunity to refine and improve the workshop.

We try to make the workshops enjoyable as well as informative, so give us a call at (416) 324-4182 or email: cwghr@hivandrehab.ca and arrange to have ‘The World According to CWGHR’ come to your backyard.

Peter Williams

Peter has been working with CWGHR to plan and coordinate our workshops across Canada.

While the content of these articles is, to the best of our knowledge current and reliable, information is not a substitute for actual health care and treatment. Articles do not necessarily reflect the official policy of CWGHR or any sponsoring organizations.

Our Sponsors

Bristol-Myers Squibb Company is committed to extending and enhancing the lives of all people living with HIV/AIDS and to bringing its medicines to people everywhere. As a leader in the HIV/AIDS field, Bristol-Myers Squibb is involved in clinical research; patient education; training for health care providers; partnerships with government, academic and non-governmental organizations; community outreach and support; and philanthropy.

Our dedication to assisting all people living with HIV/AIDS is most evident in our continued search for and development of new and effective drug treatments that respond to the needs of people living with HIV and AIDS.

Bristol-Myers Squibb recognizes the importance of being well informed about HIV/AIDS. To this end, Bristol-Myers Squibb is proud to support the work carried out by the **Canadian Working Group on HIV and Rehabilitation (CWGHR)** in assisting people living with HIV/AIDS. We recognize the many challenges faced by people living with HIV/AIDS and congratulate CWGHR on the work it does on behalf of the Canadian HIV/AIDS community.

Bristol-Myers Squibb would like to acknowledge the efforts of all people who dedicate themselves to improving our understanding of this disease and who join in the fight against AIDS.



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