Everyone Knows Someone Living and Working with an Episodic Disability

"Handi-Transit must now accommodate people with episodic disabilities", that was the attention grabbing headline of a newspaper article in the Winnipeg Free Press on August 25th, 2014. It briefly covered the journey of Diane Driedger, former director of the Manitoba League of Persons with Disabilities, who filed a complaint with the Manitoba Human Rights Commission against Handi-Transit after her Handi-Transit service was cut off. Diane lives with fibromyalgia, but it was in 2009, after she recovered from breast cancer, that her Handi-Transit service was cut off even though her chronic fibromyalgia still caused her frequent pain and fatigue that, according to the article, "made travelling by conventional transit impossible some days."

This ruling is not only a major victory for Diane, but it is also a major one for everyone living with an episodic disability. Often, when people refer to disabilities, the first thoughts that come to mind are permanent disabilities that are relatively static in nature. The concept of "episodic disability" is a new way of understanding the lived experience of the many Canadians whose health fluctuates unpredictably from well to disabled, sometimes on a daily basis. Scientific, medical and rehabilitation gains are increasingly changing what might have been fatal conditions to chronic life-long illnesses. The term episodic disability currently encompasses at least 27 different chronic illness conditions². For example, HIV/AIDS, multiple sclerosis (MS), arthritis, lupus and some forms of cancer may be seen as chronic and manageable but episodically disabling conditions for many people.

Other examples of episodic disabilities include chronic fatigue syndrome, diabetes, Crohn's disease and mental illness. Chronic and episodic illnesses are unpredictable. People living with episodic disabilities have periods of wellness that are followed by periods of illness, during which times they experience great difficulty with undertaking their usual activities of daily living. For example, people with episodic disabilities may find it very difficult to continue working at the same intensity while experiencing an illness episode. According to Wendy Porch, Disability Specialist and Education Coordinator at the Canadian Working Group on HIV and Rehabilitation (CWGHR), "these periods may vary in severity, length and predictability from one person to another, so the term "episodic disabilities" has been used to capture the episodic nature of these life-long chronic diseases." Episodic disabilities are becoming more prevalent in Canada³ due in part to advances in treatment and the aging of our population. The 2006 Participation and Activity Limitations Survey (PALS) identified that 1.1 million Canadians, 46% of Canadians with an identified disability, have an *episodic health condition*.

Since 2001, CWGHR has been working at the national level on issues specific to episodic disabilities, with a focus on research, policies and programs that impact health and quality of life, social inclusion, employment and income security for people living with episodic disabilities. CWGHR is also one of the

¹ "Handi-Transit Must Now Accommodate People with Episodic Disaiblities", Winnipeg Free Press, August 25th, 2014.

Available at: http://www.winnipegfreepress.com/local/Handi-Transit-must-now-accommodate-people-with-episodic-disabilities-272585641.html?cx nav8ource=d-tiles-3 [Accessed October 1st, 2014]

The term "episodic disability" currently includes 27 different types of illnesses identified in the literature and research (see Furrie, 2010)

³ Government of Canada response to "Listening to Canadians: A First View of the Future of the Canada Pension Plan Disability Program". The Fifth Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities. November 2003, p 22.

⁴ Furrie 2010

founding members of the Episodic Disabilities Network (national in scope) and the Ontario Episodic Disabilities Network.

If we bear the stats mentioned above in mind, it is clear that everyone knows someone living with an episodic disability. How many people are there with episodic disabilities where you work? As a human resources (HR) professional, **you play a pivotal role** in maximizing the work potential of employees with episodic disabilities. **And,** if you're like most HR professionals in Canada, you want to know more about episodic disabilities.

A 2006 survey of Canadian Council of Human Resources Association members done by CWGHR found that:

- ➤ Over 70% could not identify cases of employees with episodic disabilities
- ➤ Over 60% needed more knowledge on managing cases involving episodic disabilities
- ➤ The majority said training is needed in dealing with cases of employees with episodic disabilities

To meet this need, for the past six years, CWGHR has been offering two interactive self-directed on-line courses. Managing Episodic Disabilities: An Introduction and Managing Episodic Disabilities: Accommodation Best Practices help HR professionals understand and help employees by providing the necessary tools to begin a dialogue about the work needs of people living with episodic disabilities. The courses cover topics including, recruiting people with episodic disabilities and retaining existing employees by implementing workplace accommodation best practices. CWGHR in partnership with HRMAM is pleased to offer these online courses to HRMAM members. We recognize that you play a pivotal role in maximizing the work potential of all employees, including those living with episodic disabilities.

Diane Driedger's case has opened up possibilities in the transit system in Winnipeg for accommodating other people living with episodic disabilities. Will your company do the same in the workplace setting?

To find out more about the on-line courses contact CWGHR at cwghrcampus@hivandrehab.ca or visit cwghrcampus.hivandrehab.ca