

Everyone Knows Someone . . .

Spotlight on Episodic Disabilities

Information Sheet #3 *



What is an episodic disability?

- With advances in medical technologies, **Canadians are increasingly living longer.**
- More and more Canadians are also **living with episodic disabilities.**
- Episodic disabilities are lifelong and chronic conditions like multiple sclerosis (MS), lupus, arthritis, diabetes, hepatitis C, HIV and some forms of cancer and mental illness.
- It is often difficult to predict when episodes of disability will occur, how severe they will be and how long they will last.

“Recurrent and episodic disabilities are becoming more prevalent in Canadian society.”¹

What makes an episodic disability different from a permanent disability?

A person can simultaneously live with both permanent and episodic disabilities; **however, there are clear distinctions.**

Unlike a permanent disability which is relatively consistent, an episodic disability is marked by fluctuating periods and degrees of illness and wellness.

For people living with episodic disabilities, this unpredictability can have a negative impact on meaningful community and employment participation, income security, social inclusion and access to care.

Did you know?

- Twenty percent of all Canadians will experience an episode of mental illness in their lifetime²
- Two million Canadians have diabetes³
- 65,000 Canadians are living with HIV⁴
- Between 55,000 and 75,000 Canadians have MS⁵
- Over four million Canadians are affected by arthritis, with numbers expected to double by 2020⁶

The combined impact is staggering.

What are some of the challenges of living with an episodic disability?

- **Definitions:** Definitions – used in legislation, by health care and insurance providers and government benefit programs – can differ, creating barriers to accessing and coordinating supports.
- **Care, Treatment and Support:** Due to the unpredictable and changing needs associated with an episodic disability, treatment and personal goals can be difficult to plan. Systemic and practical barriers can prevent timely access to crucial health and social services, including rehabilitation.
- **Legislation and Policy:** Legislation needs to be barrier-free for people with episodic disabilities. Trial periods for employment, automatic reinstatement of disability benefits and extended health benefit coverage while earning an income are all critical components of a flexible and comprehensive set of policies.
- **Education:** Greater awareness is needed among policy makers, employers, insurers, funders, health care providers and the public about the challenges people living with episodic disabilities face, as well as their caregivers.

Episodic Disabilities & Employment

- People living with episodic disabilities may move in and out of the labour force in an unpredictable manner. Some must leave the job without warning for indeterminate lengths of time.
- With varying capacities to contribute to the economy, **many Canadians with episodic disabilities wish to work to their full potential** to complement disability income support when unable to work.
- **Flexibility is essential.** Employers, insurance industry representatives, governments, unions and disability communities need to collaborate on implementing flexible personnel policies that provide practical, creative and inclusive accommodations, such as part time, flextime, job share and work-at-home options.

“There are issues like how to live on a fixed income, how to find suitable accommodation and, worst of all, how to fit yourself into society. I think it can be a very lonely life”

- Person living with MS

Episodic Disabilities & Income Support

If a person's main source of income is a disability pension and his/her health fluctuates, disability benefits may be eliminated during periods of improved health. Complicated claim procedures may need to be repeated. Benefits may be difficult to reinstate when required again during periods of illness. **This 'all or nothing' approach can act as a disincentive to return to work.**

The experience of many people with disabilities is that these policies trap them in poverty by creating barriers that prevent them from staying on the job or returning to work.

“My patient is feeling better right now and would like to return to work. But if he returns, he will be cut off from his long-term disability benefits. He has decided not to return to work because the fear is too great.

I think return to work would help his self-esteem. He has suffered from depression. If going back to work doesn't work out, there's a real sense of failure.”⁷

Advancing Innovative Solutions

- More flexible disability income support programs would facilitate labour force participation of Canadians with episodic disabilities consistent with their capabilities.
- Access to partial disability benefits when unable to work would enable people to work to their capacity when their health permits. This would facilitate greater financial independence through earned income, and contribute to the economy through income tax and Employment Insurance premiums; it would also offer cost savings to government disability programs.

This leads to a win-win situation for all involved.

For more information, please contact:

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¹ From the Government of Canada's response to the 2003 report "Listening to Canadians: A First View of the Canada Pension Plan Disability Program."

² http://www.phac-aspc.gc.ca/cd-mc/mi-mm/mi_figures-mm_figures-eng.php

³ <http://www.phac-aspc.gc.ca/cd-mc/diabetes-diabete/face-eng.php>

⁴ <http://www.phac-aspc.gc.ca/aids-sida/publication/survreport/estim08-eng.php>

⁵ http://www.mssociety.ca/en/involved/advocacy/socact_brief_fin2010PreBudgetConsult_Aug09.htm

⁶ <http://www.phac-aspc.gc.ca/cd-mc/musculo/arthritis-arthritis-eng.php>

⁷ Dr. David Grossman, College of Family Physicians of Canada, From "Looking Beyond the Silo," CWGHR, 2002.

* This initiative is supported by a financial contribution from the Ontario Trillium Foundation, an agency of the Government of Ontario. This information sheet is the third in a series of four on episodic disabilities [MAY 2010].