



People Living with HIV and other Episodic Disabilities, and Employment: Critical Roles for Nurses

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Objectives



This session will:

- Provide background on HIV and other episodic disabilities as related to income support and labour force participation
- Describe CWGHR's Episodic Disabilities Initiatives
- Encourage dialogue on responding to 'episodic-specific' employment needs of people living with HIV and other illnesses
- Encourage discussion of the roles of nurses

Issue



Disabilities such as HIV, multiple sclerosis, hepatitis C, lupus, & some forms of mental illnesses, arthritis & cancers, can be lifelong & episodic in nature. As fluctuations occur in a person's functioning & health, the unpredictable & episodic nature of some disabilities presents challenges to active labour force participation, stable income & social inclusion.

Contrast with Traditional Understanding of Disability



- **‘Disability’** as it is generally understood: lifelong & relatively consistent
- **‘Episodic disability’**: unpredictable, intermittent periods of good & not so good health; implications for working, insurance benefits, vocational rehab & other care

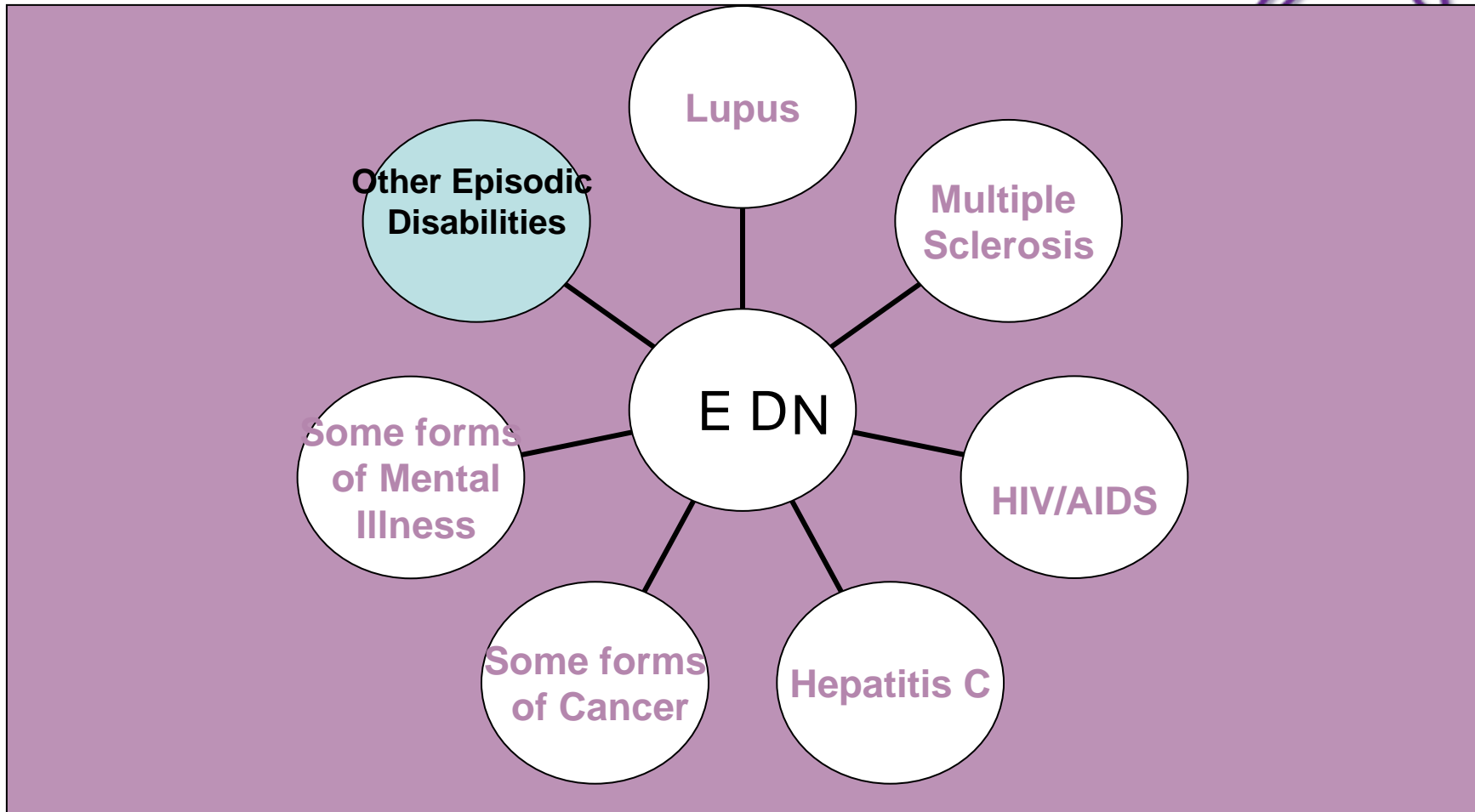
What is the Episodic Disabilities Network (EDN)?



The *EDN* includes participation of the, *Canadian Mental Health Association, Canadian Working Group on HIV and Rehabilitation, Lupus Canada, Multiple Sclerosis Society of Canada, Canadian AIDS Society, Arthritis Canada* & other national disability organizations.

The EDN encourages policies & programs to improve quality of life & promote inclusion for people with episodic disabilities.

The Episodic Disabilities Network



Episodic Disabilities Project



The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national multi-sector working group, that, through research & education:

- co-ordinates a national response to rehab issues
- facilitates and supports program development
- provides recommendations on rehab and HIV

CWGHR sponsored the project, funded by *Human Resources and Social Development Canada* until March 2007. CWGHR is continuing to lead in discussions of episodic disabilities

Episodic Disabilities Research



Using multi-sector and cross-disability perspectives:

- Undertook an international policy review
- Developed recommendations for optimal labour force engagement, income and benefit supports for people with episodic disabilities
- Undertook a cost-benefit analysis
- Analyzed responses of HR professionals about episodic disabilities

Lessons Learned

From model programs / policies



- Multi-sector coordination among all relevant private & public sector stakeholders (The Netherlands, Germany, Sweden)
- Flexibility in policies & programs to accommodate episodic participation in the labour force with sustainable income and benefit support regardless of employment status (*'flexicurity'*)
- Partial disability income support integrated with employment earnings when a person with an episodic disability works part time
 - significant cost savings to the insurance carrier
 - more labour force participation options for people with episodic disabilities.

Lessons Learned

continued



- Need for a core body of knowledge and training on episodic disabilities for human resources professionals.
- Need for more insurance options that remove the disincentives to participate in the labour force to one's potential.

Research Conclusions



There are current policy / program disincentives to labour force participation and income support for PHAs

- Inconsistent definitions & eligibility requirements
- Health care benefits may be income-dependent – when income rises, benefits are lost
- Time required for processing claims under different jurisdictions x time needed to apply (because of episodic nature)
- Lack of portability
- Support programs (housing, income, health benefits, employment) are often designed in isolation and in different departments, jurisdictions and sectors.



- Current disincentives to employment must be replaced by flexible policies for people living with episodic disabilities to participate effectively in the workforce.
- Policies must promote income security regardless of employment status.

Next Steps



With all relevant stakeholders

- Identify & implement (initially with demonstration projects) the policy changes that are needed
- Design demonstration projects in workplaces to implement the changes that reduce risk for people with episodic disabilities to engage in the workforce
- Evaluate the implications of the policy & program changes on workforce participation, health, quality of life, economic & social variables
- Educate & inform about episodic disabilities

Discussion



Lou has been HIV + for 20 years, receiving CPP-D and LTD. Lou states that he could have & wanted to work much of that time, but believes he risks losing his CPP-D and private LTD benefits if he indicates he could work, because his next episode is unpredictable. He is dependent on income support when not able to work, & needs the health benefits whether or not he is working. What role can you play in order to assist him to explore his employment options?



What are the benefits for

- An employment site
- The person
- The larger community

when people with (episodic) disabilities have increased access to the labour market?

Role of Nurses



- Provide assessment for disability income support and / or rehabilitation
- Refer to rehabilitation services
- Counsel
- Advocate for supports
- Participate in Insurance Appeals Boards
- Participate in newly established national network of PHAs interested in employment
- Participate in possible mentorship models
- Increase knowledge of incentives for employers through Opportunities Fund and other programs

For more information



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