


Unsteady employment

With improved health comes the often stressful and unsettling prospect of returning to the workforce

by Glyn Townson

We've come a long way in Canada in the past 20 years with the AIDS pandemic. What began as a fatal incurable disease in the 1980s and early 1990s has shifted to—in many cases—a chronic infection with episodic periods of wellness and unwellness for PWAs accessing antiretroviral treatment. (See the Nov/Dec 2005 issue of *living*  for a discussion of HIV as an episodic disability.) Longer life expectancy and managed side effects have a number of implications for people living with HIV/AIDS, including continuing stigma and discrimination, and the ever-increasing costs of new and powerful medications entering the marketplace.

A key issue is the idea of returning to, or entering the workforce in some capacity. What are the barriers for those who were once considered near the end of their lives and now living longer than they thought possible? There are also PWAs who never entered the workforce and may now want to explore employment possibilities.

We need a better understanding of what changes can be made to encourage those PWAs who want to return to work and how to provide them adequate supports. Our society places a lot of value on our occupations and on paid employment in general.

As an episodic condition, however, the unpredictable nature of HIV raises a lot of questions. Each person's case is unique. The challenge is to manage the side effects of often-complex drug regimens, fatigue, diarrhea, and neuropathy, as well as the time constraints of doctors and specialist appointments.

Cut off from disability benefits

Some individual stories illustrate how the climate is changing. In early 1996, a close friend—who had been living with AIDS for a number of years and was receiving private long-term disability insurance—started taking the newly-available highly active antiretroviral therapy (HAART). His health improved. “At this rate I may have to consider going back to work,” he said at the time. “How horrible—my old job no longer exists and I would hate to have to start all over.”

Later that year, he passed away from Non-Hodgkin's lymphoma, but his concern hit a chord: What do you do when

confronted with the possibility of having to go back to work after many years of not working and relying on private or public benefits?

More recently, another friend talked about a general turn-around in his health, currently managed with antiretrovirals. He was weighing the pros and cons of re-entering the workforce after an absence of many years. A paid position came available at an organization where he volunteered. There were a lot of issues to consider, such as being cut off of his housing subsidy. Would the new employer offer extended benefits? What if the situation didn't work out and the stress of working was too much? Would he be able to get back any of the current benefits he now depended upon?

In the end, with no guarantee of benefits or security, he decided to decline the position, even though he was still interested in some kind of employment.

And in another recent incident, a PWA was employed but didn't have access to the same extended benefits packages other HIV-negative employees enjoyed. He questioned his employer about this discrepancy and soon found himself out of a job.

Researching the issues

Despite these troublesome cases, there are many success stories where people returned to the workforce and continue to enjoy full benefits and a safe work environment. Still, there are a lot of issues to consider when you're HIV-positive and contemplating joining, or re-joining, the workforce. Fortunately, there are groups working to address the employment issues of people living with disabilities—including part-time work and flextime—to ensure that returning to work is possible and not loaded with disincentives.

The Canadian Working Group on HIV/AIDS and Rehabilitation (CWGHR) has been researching these issues and has already had a positive impact on how people view HIV/AIDS as an episodic illness. For example, the Canadian Pension Plan (CPP) recently announced a rapid reinstatement program for those who relinquished their disability benefits but need them restored. It's a major first step in identifying some of the barriers to returning to work for periods of time.

continued on next page

Unfortunately, CPP disability is not enough for most to survive on, and provincial income assistance programs and private insurance schemes are inflexible in dealing with issues around income supports and episodic illness.

What do you do when confronted with the possibility of having to go back to work after many years of not working and relying on private or public benefits?

Two major projects

CWGHR has two major projects in progress. The first project addresses issues surrounding episodic disabilities, labour force participation, and social inclusion. The key areas of this multi-staged project include researching existing private and public disability income supports and workplace policies, programs, and practices—both nationally and internationally—to determine gaps, strengths, and barriers to full social inclusion. The research will identify and recommend:

- ▶ new models and enhancements to existing disability income support plans, and
- ▶ workplace policies that will contribute to labour force participation for people living with HIV and other episodic disabilities.

The final stages of the research will establish the cost-benefit analysis of these recommendations, and then develop pilot projects to test and evaluate them.

CWGHR's second project is called "Interprofessional Learning in Rehabilitation in the Context of HIV: Stakeholder Capacity Building through Development of New Knowledge, Curriculum

Resources, and Partnerships." This project will build on current interprofessional education initiatives to increase rehabilitation professionals' ability to respond to the rehabilitation needs of PWAs. It will draw on the expertise of clinicians, educators, and researchers to develop interprofessional curriculum resources on HIV for rehabilitation professionals.

In that regard, in June 2005, the University of Toronto's HIV Social Behavioural and Epidemiological Studies Unit completed a study entitled "HIV and Rehabilitation: The Canadian Providers' Survey." Rehabilitation specialists were asked about their knowledge of HIV/AIDS and how they felt they could support PWAs in managing side effects and barriers to employment. The results showed a real disconnect: providers were unaware of the types of services available and were generally unfamiliar with the issues facing people living with episodic conditions. Clearly more education and attention is needed in this area.

Identifying and implementing changes to help PWAs remain at work as long as possible, and assisting those who wish to return to the work force in some capacity, are important initiatives to improve our lives and our self-images. ☺



Glyn Townson

is the vice-chair of the BCPWA Society.

For more information on these projects, visit the Canadian Working Group on HIV/AIDS Web site at www.backtolife.ca

We need people like you. BCPWA has volunteer opportunities in the following areas:

Web site maintenance > Communications

Administration > Internet research, filing, database management, reception, etc.

Special events > AccolAIDS Awards Gala and WALK for LIFE

Writers > *living* ☺ magazine, Communications

Workshop development and delivery > Communications and *living* ☺ magazine

Benefits of becoming a volunteer:

- ◆ *Make a difference in the Society and someone's life*
- ◆ *Gain work experience and upgrade job skills*
- ◆ *Find out more about HIV disease*

If you are interested in becoming a volunteer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

volunteer @ BCPWA