

Working it out

Being HIV-positive and holding down a full-time job can be challenging—as well as rewarding for all involved

by Moffatt Clarke



So, what's it like if you're HIV-positive and you work full-time? It's a great question—one that doesn't seem to get asked very much, let alone answered. Here are some of the key issues and concerns, along with a few ideas to make your life, on and off the job, fuller and more manageable.

A healthy workplace

First of all, there's a need to create healthy workplaces for PWAs. Many organizations, including my own, are concerned with poor employee retention and with employees taking stress leave. Employers are looking to address these issues by implementing a variety of initiatives to address work-life balance, including health promotion and healthy living programs, for all staff. Employees living with HIV and other episodic conditions can benefit from these initiatives. Some examples include:

Supporting disclosure of HIV status when appropriate. At the top of the list of concerns is the question: Do you disclose your HIV status to your manager, your co-workers, your clients, and customers? The answer is always situation-specific. Being open is prudent in some cases. For me, however, if I'm feeling well and productive, it doesn't need to be an issue in the workplace.

Promoting flexible work arrangements. Modernized human resource policies that make working arrangements more flexible often benefit HIV-positive staff. Flexible arrangements include compressed workweeks, variable workday hours, self-funded leave, leave with income averaging, and working from home.

Responding to the duty to accommodate. Increasing focus is being paid to "duty to accommodate" policies for employees with disabilities, with a view to removing barriers that prevent your full participation in the workplace. Examples include identifying and removing barriers to employment, career development, and promotion.

Making sure other supports are in place

Many group disability insurance plans were designed decades ago when many diseases or conditions either didn't exist or weren't disclosed. Disability insurance plans need to be revised so they're more compatible with the needs of people with episodic conditions like HIV. Flexible coverage would enable people to work when well enough, and know they'll have coverage when they're not. (See the sidebar for the stories of two PWAs and their experiences with part-time disability insurance.)

The ups and downs of dealing with disability insurance: two first-hand stories

Bruce's story

"In 1995, I spoke with my doctor who had expressed concerns regarding the amount of stress my job entailed. I asked pointblank if he would support me in a request to either take time off or to work less. He agreed immediately, so I sat down and drafted a letter to my employer. For financial reasons as well as a personal belief that the regular routine of work was a good thing for me, I didn't want to go on full-time disability. Since my particular disability plan wasn't tax free, I would have ended up in financial difficulty had I pursued that avenue.

"Instead, I asked that I work a nine-day fortnight, with my disability plan covering the remaining one day every two weeks. My doctor provided a supporting letter and very soon thereafter the plan was accepted. I have nothing but praise for the Human Resources department of Pacific Newspaper Group (PNG) in all of this. They've been amazing.

"Over the past seven years, I have gone to a four-day work week, with insurance covering one day a week, expanding to more days as needed if I have a bout of bad drug reactions. This has continued through several insurance companies.

"Human Resources at PNG have explained that, with my 25 years of experience with the company, I am valuable to them. They know full well I could be off on full-time disability anytime I so choose."

Ian's story

"For the last seven years, I have worked at my job on a 40 percent basis. This was made possible by a provision in my disability insurance coverage that allowed for partial disability coverage. With the consent of my doctor, I returned to work part-time after being completely away from it for a period of about five months. This arrangement has now continued through two insurance carriers and will probably continue through a third.

"The drawback to this situation is that I'm being paid disability payments based on my 1996 salary. Any increases in funds or salary increases that may be forthcoming from my employer are deducted directly from the tax-free payments from the disability plan. The paradox is that if I get a raise, I am worse off financially.

"The other dilemma is my pension fund: it's being contributed to on the basis of a 40 percent salary and therefore is correspondingly small. So the opportunity to keep my hand in and to have a reduced work week, while welcome from a health point of view, does have some strong economic downsides. These are becoming more worrisome as I contemplate that I might make retirement age, when all payments from the disability insurance would stop. I would then be required to retire and would have a very modest pension."

People with HIV need to support efforts to reform health care so that it remains accessible, for example by ensuring there is access to primary and specialty medical services on weekends or in the evenings for people who are working. Models such as community health centres, local community service centres (centre local de services communautaires, or CLSCs) in Quebec and Spectrum Health in Vancouver serve PWAs well: doctors provide care in integrated community-based primary care settings in conjunction with healthcare practitioners, including nurse practitioners, pharmacists, social workers, and dietitians.

Community organizations accommodating working PWAs

There are also ways that community-based organizations could better respond to the needs of working clients by developing healthy living programs and services and by improving existing programs. Examples include ensuring that programs and services are available outside of the typical 9 to 5 office hours, and building partnerships with fitness centres and community centres to offer fitness classes and programs for PWAs that are accessible to those who are working.

Community-based organizations could also explore ways for busy single working people to eat nutritious meals. Ideas include community kitchens for working PWAs who need to eat well but are too tired to shop and cook when they get home from work, and buyers clubs or co-ops with bulk groceries, vitamins, and supplements, in order to lower consumer costs.

These are just some of the questions and a few of the answers that might contribute to an ongoing discussion about living and working full-time with HIV.

Supporting HIV-positive people to stay at work is a win/win situation. Fewer people will be dependent on income security programs, employers will get to retain their investment in human resources, and more HIV-positive people will continue to contribute to the workforce. ☺

Moffatt Clarke works for the Public Health Agency of Canada.

