



The high co\$t of aging with HIV/AIDS

by Melissa Davis

When 51-year-old Walter unexpectedly fell ill while vacationing on the west coast in the spring of 1991, he went to the emergency department of a nearby hospital in White Rock, BC. The last thing he expected, following a series of routine questions, blood tests, and a physical examination, was an HIV diagnosis. "My first reaction was total shock," he said. "Back then, things were different with AIDS. I thought I'd be dead within a year." So Walter did what others

in his position did at that time: he put his affairs in order. He cashed in his life insurance policy, wrote a Will, arranged and pre-paid his funeral expenses, and made the most of the time he had left.

Fourteen years later, Walter still makes the most of his time. His CD4 cell count hovers near 320, his viral load remains undetectable, and in late February, he and his partner of almost 15 years celebrated Walter's 65th birthday together.

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Facts, figures, and factors associated with HIV and aging

Walter's story reflects an emerging trend in North America: the experience of aging with HIV. Statistics from the US-based National Institute on Aging (NIA) show that the cumulative number of AIDS cases in American adults aged 50 and older has more than quintupled, from 16,200 to over 90,600 between 1990 and 2003; the NIA further claims that 19 percent of Americans living with HIV are over the age of 50. Canadian statistics are similar. According to Public Health Agency figures, although the actual number of reported *new* HIV diagnoses among older Canadians is not statistically significant and has, in fact, declined slightly in recent years, the proportion of HIV-positive people over the age of 50 has increased from just over 11 percent in 1994 to slightly more than 20 percent in 2002.

"This isn't really unexpected," says Suzan Krieger, an individual advocate with the BCPWA Society. "Although we're just beginning to see the trend reflected in our membership." Presently, 12 members out of slightly less than 2,500 in the advocacy department's database will reach the age of 65 this year. However, an additional 769 are currently between the ages of 50–63, indicating that the membership demographic—and the need for age-appropriate treatment information and advocacy services—will shift significantly over the next several years.

Until recently, the entire notion of aging with HIV was unfathomable. Twenty years ago, the stretch of time between diagnosis and death could be a matter of weeks or months. Even a decade later, in spite of a handful of AIDS drugs and improved management of opportunistic infections, quality of life and life expectancy for PWAs were still diminished by severe drug toxicity and disease progression. But for the survivors who lived to witness the advent of antiretroviral therapies (ART) in the late 1990s—and those diagnosed thereafter—AIDS has evolved from a devastating, terminal illness into a chronic, manageable disease. Since then, people with HIV have been living longer and healthier lives.

In addition to widespread availability of ART, several other factors have contributed to the increasing numbers of older people living with HIV/AIDS in North America. Targeted HIV prevention efforts neglect older men and women and, consequently, ignorance and misinformation about the disease are common for people over age 50. And while sex education appears restricted to a younger demographic, sexual activity most definitely is not. In fact, this population group has experienced something of a second wave sexual revolution in recent years due to the popularity of Viagra for men, coupled with greater sexual freedom without the worry of unwanted pregnancy, for post-menopausal women. Nevertheless, cultural assumptions and prejudices desexualizing older people have resulted in inadequate targeted HIV prevention education and

support services, as well as numerous cases of undiagnosed or misdiagnosed HIV infection by healthcare providers.

As one might expect, socio economic issues affecting seniors are exacerbated for older people living with HIV and AIDS. About a year ago, Walter began wondering about how his monthly income might be affected once he reached the age of 65. Realizing that provincial income assistance would be discontinued, he made some inquiries through Social Development Canada (formerly HRDC). "When I started making calls, it was like going from pillar to post. No one could give me a straight answer," Walter said, exasperated.

Disability benefits for PWAs in BC

In BC, an HIV-positive single person under the age of 65 receives income assistance as a Person With Disability (PWD). Disability benefits pay \$856 per month (\$10,272 per year) and entitle recipients to enhanced provincial healthcare coverage, including medical services, prescriptions, vision care, dental care, and related health costs. Individuals on PWD assistance who experience excessive weight loss or wasting may be eligible for an additional Monthly Nutritional Supplement Benefit (MNSB), paying up to \$225 per month, to purchase essential food items, vitamins, and bottled water. MNSB recipients on disability benefits support themselves, then, on \$1,081 per month (\$12,972 per year).

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Prior to the implementation of the MNSB, hundreds of PWAs and other people with disabilities in BC applied separately for a monthly health allowance known, under the provincial legislation, as Schedule C. The amount awarded varied in each case, based on the applicants' circumstances, but recipients of Schedule C received monthly allowances in the \$200 to \$500 range, and continue to receive these benefits.

This was Walter's situation. "Before I turned 65, I'd get my disability cheque and my Schedule C [allowance] every month. It wasn't a lot of money, but I managed. Subsidized housing really helps. And I stick to my budget." In spite of living on very limited resources, Walter claims the provincial system provided for his basic needs. "I can't really complain. I'm not someone who takes advantage of things. And when I've really needed something—like my scooter to get around, or home care when I couldn't do certain things for myself—I've always received the help I need."

Inadequate federal income support for seniors

Unfortunately for Walter, the same does not appear to be true with respect to the federal system. Older PWAs face a decrease in income when responsibility for their financial support is transferred from provincial to federal jurisdiction. Yet the federal government's most recent statistics on disability in Canada suggests otherwise. Social Development Canada reported that the average annual household income for seniors with disabilities in 2001 was a remarkable \$46,708 and, evidently, only slightly less (\$800) than the average household income for seniors without disabilities. Persons living with HIV or AIDS, under the disability umbrella, are more likely to find their experience reflected in the statistic of 18 percent of Canadians with disabilities whose incomes place them below the low income cut-off amount.

Federal income security programs for seniors provide slightly less financial support than provincial income assistance for persons with disabilities. For people entirely dependent on these government programs, with no additional sources of revenue, the maximum annual income for a single person remains between \$12,000 – \$15,564—a far cry from the \$47,000 national average (thanks to independent retirement savings plans) that the federal government boasts.

Eligibility for federal programs is based not on financial need or medical requirements, but on factors related to length of residency and/or employment in Canada. For example, the maximum monthly allowance for Old Age Security (OAS)—an abysmal \$471—requires a minimum ten year prior residency in Canada. The Canada Pension Plan (CPP) is directly related to the applicant's employment history and the amount contributed to the plan during the individual's employment; even so, the maximum monthly CPP payout is only \$826. The Guaranteed Income Supplement (GIS) is a top-up fund for individuals whose combined OAS and CPP revenue totals less than \$1,000 per month. Finally, OAS and CPP revenue are both considered taxable income according to Canada Customs and Revenue Agency, an additional financial burden that has seniors like Walter extremely concerned.

"In hindsight, I wish I had been more prepared and put some money away for myself," Walter says, reflecting on his predicament. BCPWA Society advocate Suzan Krieger sympathizes. "Many of these people never expected to live this long," she explains. "For health reasons, they left their jobs years ago so they haven't contributed to CPP for a very long time. Now, edging their way to 65, they're wondering what they're going to live on."

Making a case for additional support

As the situation stands now, Walter is entering his golden years in the red. His present income, under the federal system (including a modest GIS top-up) still remains 20 percent less per month than he was receiving through his provincial disability

benefit and Schedule C health allowance. And without that additional money to purchase essential health-related nutritional items, his health could be seriously compromised.

Teaming up with the BCPWA Society advocacy department, Walter submitted a request to his provincial Employment Assistance Worker (EAW) seeking approval to receive a portion of his Schedule C monthly allowance to make up for the shortfall in income paid under the federal system. His request was denied.

Presently, Walter's case is being reviewed at a higher level, with the reconsideration officer at the Ministry's health assistant branch. "It takes time to get an answer," explains Cheryl Colborne, another advocate with the BCPWA Society. "They're looking at this case carefully, I'm sure, because we all know that the outcome will set a precedent for similar appeals in the future." And with at least 769 current BCPWA members expected to qualify for seniors benefits over the next decade or so, that's a lot of unplanned paper work for the provincial government—and a lot more money than they had budgeted for.

Let's hope the government does the right thing and respects their elders. ⊕

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Information

▼ Social Development Canada — Income Security Programs:

www.sdc.gc.ca/en/gateways/nav/top_nav/program/isp.shtml

▼ Government of Canada —

Online Publication: Services for Seniors Guide:

www.communication.gc.ca/guides/seniors_aines/index_e.html

▼ Public Health Agency of Canada —

HIV/AIDS Epi Update (HIV/AIDS Among Older Canadians):

www.phac-aspc.gc.ca/publicat/epiu-aepi/epi_update_may_04/6_e.html

Advocacy

▼ BC Persons With AIDS Society Advocacy Department

Email: advdesk@bcpwa.org

▼ Vancouver HIV-Positive Peer Advocacy Action Group

Email: vhpaag@yahoo.ca

Support

▼ Association on HIV Over Fifty:

www.hivoverfifty.org

▼ HIV Wisdom for Older Women:

www.hivwisdom.org