



Growing Old Gracefully

Recent advances in treatment mean people with HIV are not only living better, they're living longer. Here's how to cope with the new reality.

BY LAURETTE LÉVY

For a person diagnosed with HIV in the 1980s, celebrating a 60th birthday in 2007 is something of a miracle. Before the advent of highly active antiretroviral therapy (HAART) even optimistic estimates of life expectancy didn't exceed 10 years. But times have changed and living well into old age is now a likelihood for people living with HIV. This, of course, has its own ramifications.

Being infected with HIV is no longer a death sentence. For most, it's now a matter of living with a chronic disease, getting older and preparing for retirement—something that for HIV-negative people usually evokes thoughts of a well-earned rest after many years of work. Along with that comes the freedom to choose new activities (such as sports, hobbies, travel) or to spend time with family and friends. In short, it's about embarking on a new stage of life replete with pleasure and leisure. But is it realistic for people with HIV/AIDS (PHAs) to dream about a happy retirement?

Is it AIDS or Aging?

It would be a mistake to think that everything is rosy for aging PHAs, even if their health is relatively good, at least in terms of HIV infection (undetectable viral load and stable CD4 count). Aging comes with its own health concerns, which tend to pile up more often for PHAs than for the general population: heart issues, high cholesterol, osteoporosis, lung disease, cancer, kidney failure, diabetes and more.

Take Danièle B, now 59. After beginning antiretroviral treatment at age 50 during the throes of menopause, she suffered four bone fractures in six months. The question immediately arose: Were these problems the result of HIV itself, were they drug side effects or were they simply part of the normal aging process? There is no easy answer. However, we do know that PHAs who took the first antivirals in the early days of HAART—with their high toxicity and nasty side effects—are now experiencing earlier onset of many symptoms generally associated with aging.

When your fatigue worsens and your quality of life shrinks, it is normal to wonder if all the medication you've been taking for years has contributed to your liver, kidney and heart problems. While it may be difficult to track precisely the side effects of long-term treatment for HIV/AIDS, one must consider the role played by HIV and anti-HIV drugs given the accelerated aging of the patients who have been taking antivirals since they were first made available.

Dr. Roger LeBlanc, who works in the Immunodeficiency Unit of the Montreal Chest Institute, explains that the body's cells are constantly being bombarded by both HIV and anti-HIV drugs. In response to this assault, the cells reproduce more quickly and attempt to draw on their reserves. However, because these reserves are limited, the system becomes exhausted more quickly and the body begins to age prematurely. So, whether it shows in your skin, joints or organs, the physical aging of the body can be accelerated by 10 years because of HIV.

Healthy is as Healthy Does

Thankfully, there are possibilities for countering at least some of that acceleration. According to nutritionist Michèle Cossette of the CLSC des Faubourgs, a Montreal health clinic whose clientele consists primarily of PHAs, virtually everyone experiences a metabolic slowdown after age 50 (slower blood circulation, more sluggish pancreatic, liver and intestinal functions). As a result, nutrients aren't absorbed as well and toxins are eliminated less efficiently. How profound these changes are really depends on individual lifestyle.

During the early years of the epidemic, people didn't live long enough for their lifestyle to become a concern—the focus was solely on surviving HIV. We now know that the risks associated with alcohol, tobacco, drugs and poor nutrition have a huge impact on one's health. Just as in the general population, for PHAs the personal realities of aging depend a great deal on lifestyle. In fact, lifestyle plays a more important role in aging PHAs than we thought a few years ago. And the older we get, the more crucial that role becomes.

A person's genetic makeup also has a major impact on his or her health. Even when HIV is well controlled, deaths among PHAs due to cancer, heart attacks and cardiovascular disease continue to occur at higher rates. "People are no longer dying from HIV but from complications related to their lifestyle and genetic background," says LeBlanc.

"Of course, HIV has its effects, as does the medication, but to what degree remains unclear," says nutritionist Cossette. "A person's genetic baggage has to be considered as well, so it is very difficult to ascertain which of these different factors determine outcome."

In one large study conducted in Denmark researchers showed that the incidence of HAART-related cardiovascular disease decreased considerably when other risk factors, such as smoking, alcohol use and obesity, were eliminated.

LeBlanc stresses that physicians must change their attitude toward their patients: "Instead of commiserating with them about their condition, we should urge them to adopt a healthy lifestyle as soon as possible. Obviously, patients have to do their part because they are responsible for staying healthy. Doctors and antiretrovirals cannot do everything. It's no longer enough to rely on your doctor. Patients have to change their lifestyle now." He also recommends that PHAs be monitored like any other patient, with regular blood-pressure tests, weight control measures and blood work to check cholesterol and lipid levels. An infectious diseases specialist is no longer enough—older PHAs need a general practitioner and basic primary care as well. Psychologist Joanne Cyr from the Immunodeficiency Clinic at the Montreal Chest Institute has even proposed to her colleagues that a gerontologist join their team.

Exercising your Brain

If the physical aging of the body can be accelerated by 10 years because of HIV, the same appears to be true of "cognitive aging," says Cyr, whose ethnically diverse body of clients at the HIV clinic includes men and women aged from 18 to 72. Work needs to be done by PHAs on this front as well. Ed on the West Coast is a good example. He is 65 and, suffering from short-term memory loss, he realized he needed to take on a range of mental activities or exercises to guard against further decline. As a result, he does volunteer counselling work in his Vancouver Island community despite the fatigue that sometimes prevents him from being active.

For Ed and many others like him, staying engaged and informed about new developments and clinical trials can accomplish two things at once. It helps keep the mind limber and at the same time it is important for PHAs needing to stay on top of their condition and medical care, especially those who have experienced treatment failure. It is all a question of finding something that will motivate you: For 62-year-old Lynn, from Nova Scotia, the need for intellectual stimulation and engagement prompted her to join the Community Advisory Committee of the Canadian HIV Trials Network.

Despite good intentions, however, some people understandably do experience a kind of lethargy. It's not easy to remain energetic and committed after years of regular

appointments, blood tests and pill popping, especially when day-to-day issues (concerns about the future, money and loneliness) can play such prominent roles.

Fiscal Fitness

Turning 65 and facing retirement obviously presents big challenges for everyone, but most Canadians are assured of a decent lifestyle thanks to their pension or savings, and many have the means to realize some of their dreams. However, for those who were forced to stop working at a young age as a result of becoming positive and had to manage without benefit of a private pension, with only meagre disability benefits to rely on, survival and poverty walk hand in hand. Still, a certain outlook can help even with that. Although it's a safe bet that 52-year-old Danièle L. of Quebec is not going on crazy spending sprees on her \$850 monthly income, she insists that she is not poor: "I pay my bills and go out for dinner from time to time with friends."

The two questions regarding aging that Joanne Cyr hears most often from her patients are: "What will happen to me financially?" and "Who will be there to help me?" Indeed, for many PHAs, their financial situation remains complicated and even precarious. The little bit of money people had managed to put aside before getting sick has been spent. Why save money or invest in RRSPs, the thinking used to be, when you were expected to survive only a few years. Many who once were simply not rich have now become downright poor. "At first I could deal with the lack of money because my health was such a huge concern," says Brian, 60 and living in Ontario. "But 18 years later, money has become a bigger issue. With inflation and little or no increase in disability benefits, it's actually worse. You don't get used to it."

What's more, depending on where they live, some people's retirement income may be lower than their

disability benefits. Ed, from British Columbia, saw his monthly income shrink by several hundred dollars as a result of the mandatory switch to retirement benefits from the federal government. Some benefits such as dental may even be cut. And when it comes to drug coverage, people really have to understand the system. "You have to pay attention to pension-related issues because those things are complicated," says Brian. "If you get sick or have emotional and psychological problems, it's easy to let things slide. Then big problems follow."

In situations like this, every dollar counts and access to affordable housing is vital. Lynn, for whom "finances have been a big, big worry," hopes to move to a subsidized residence for seniors soon. As for Brian and Ed, they consider themselves lucky to live in subsidized co-op apartments where their rents account for about 30 percent of their net income—a bargain in today's inflated urban housing market.

"The economic reality affects everything," says Brian. Obviously, having less money means fewer social activities, and even buying clothes is kept to a minimum. "There's a constant pressure. You have less to spend so there's less money for entertainment—eating out, movies, books, a new iPod...it's a different reality. In a way it feels like your potential is gone." The simple life, so to speak, but against your will.

It's paradoxical to think that many of these "poor" people have contributed for years to the survival of countless community, provincial and national AIDS organizations as reliable and indispensable volunteers. These women and men have fought against discrimination, promoted prevention and battled for the improved health of all PHAs—all without any financial recognition for the invaluable time they have contributed to the fight against HIV.

The people who age best have fewer fears and worries.



- CATIE: search “aging” on the CATIE Web site at www.catie.ca or call **1.800.263.1638** to speak to a Treatment Information Educator
- CONNECT Canadian HIV/AIDS Information Gateway: www.hivinfovoh.ca
- National Association on HIV Over Fifty (U.S.): www.hivoverfifty.org
- HIV Wisdom for Older Women (U.S.): www.hivwisdom.org
- The Body (U.S.): search “aging” on www.thebody.com

A Place for Passion

It's inspiring that despite these kinds of setbacks PHAS still strive successfully for rewarding, meaningful daily lives. As Ed puts it, “My world is small, but there is passion for life in it.” And Lynn says of her hip replacement last year: “It rejuvenated me. My quality of life has significantly improved since. I am moving on.”

Local community groups help make poverty more manageable, offering initiatives that allow PHAS to participate in society and enjoy a better quality of life, such as reduced-cost food buyers clubs, free vitamin programs and complimentary show tickets.

And other tactics can help, too. Many PHAS have attended workshops on “how to stretch your dollar” that have helped them manage their budget. However, a healthy diet rich in fruits, vegetables and friendly fats is getting more and more expensive, and discount stores and food banks seldom offer these products. As a result, coupon clipping and hunting for specials eat up a lot of grocery shopping time when you live below the poverty line.

The need for retirement planning workshops is great nowadays, especially in light of estimates that put one Canadian PHA in five in the over-50 crowd 10 years from now. Ed regrets never having had access to this kind of training. Brian, on the other hand, recently attended a forum sponsored by the AIDS Committee of Toronto dealing with aging with HIV, including financial matters. “The information was very good,” he says. “They covered the specific issues surrounding old-age benefits. If you do get sick, it could be tricky, so you must be on top of these things.” It's this kind of constant worry that has prompted Ed, who retired recently, to consider getting a low-stress part-time job to beef up his meagre pension.

The Fear Factor

Fear of poverty and fear of being alone go hand in hand. For some, having no partner is a huge source of sadness. Danièle L. would love to rebuild her life with a partner; Brian laments the lack of sharing daily communication; and Danièle B. finds her solitude weighs heavily. “These emotions are shared by everyone who ages,” explains Joanne Cyr. “But they are more difficult to manage for PHAS because they didn't expect to get older and now it's happening sooner than expected.” Many have made peace with their sexual inactivity—due not only to a lack of desire but also to drug side effects that affect sexual performance—and channel their passion into different life pleasures, both big and small, like becoming a grandparent or attending a concert.

For some, solitude and isolation are the consequences of the devastating effects of lipodystrophy. Danièle B. sees only her colleagues and family: “I can't let anyone see me anymore.” Others no longer want to go out: “I'm afraid of the day when it will show on my face,” says one interviewee privately. The effects of lipodystrophy, including facial wasting and fat redistribution, all aggravate aging and generate fears of becoming less desirable and of being rejected.

No wonder the Quebec advocacy group Lipo-Action has called for the reimbursement of liposuction treatments and cosmetic injections. It's not a matter of vanity, but merely a quest for dignity, renewed self-esteem and an end to the endless questions about the cause of the weight loss that's as visible as the nose on your face.

“Getting older is already a challenge in our culture, and to see HIV playing a major role in it distresses people even more,” says Cyr. Especially in a society where facilities specific to PHAS with diminished autonomy are scarce. Brian, who lives in Toronto, knows that being in a big city is an advantage. He says he is not worried because “if one day I become dependent, I can call Casey House. Services are good in a big city. I have had the same doctors for many years and I can talk with them. I feel secure.” That is unfortunately not the case for all PHAS. The existing care infrastructure will have to accommodate the complex needs of aging PHAS, and new rural facilities need to be created so that PHAS in rural areas can also have access to living environments where they can receive the kind of care they require.

As a psychologist, Cyr has observed that the people who age best have fewer fears and worries and adapt more easily. They are also less isolated, continue to have life goals and are actively involved with other people. “Part of my job,” she says, “is to convince people that the decisions they make about lifestyle and health will have an impact on how well they are aging and how they adapt over time.”

The experts have a lot of advice and common sense to offer. Everyone—positive or otherwise—needs to adopt the same prevention strategies as they age, but for PHAS, these strategies are vital: manage your stress, exercise your grey matter, eat healthily and take appropriate supplements, seek strong social support, quit smoking, avoid excessive use of drugs and alcohol and, above all, learn to accept your new limitations.

Brian has an attitude any aging person would do well to adopt. After recent bypass surgery, he says, “I've got a new lease on life. I have learned to live with my health issues on a daily basis. You continue to learn—you have to. Everybody goes through it. You need a good sense of humour. You've got to have a good laugh with good friends. We are still pioneers that way.” +

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