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THE GLOBE AND MAIL

THE NEARLY FORGOTTEN PLAGUE
By ROD MICKLEBURGH

Cutting-edge AIDS medications have lengthened patients' lives and given many a better existence than they would have had 10 years ago, but these advances have helped push the disease out of mainstream consciousness. Health-care workers point to continuing problems that need attention: 'premature aging,' lack of bed space and failure to make sure everyone - especially the poor - gets medicine

VANCOUVER -- In the lobby of the gleaming Dr. Peter Centre for patients with AIDS, a man of indeterminate age is moaning.

"If I go out there, I'll die," he says to himself.

Another man shuffles past, his face pinched and gaunt. He looks 75 years old but isn't.

Later, a third man, Tom Griffin, came into a room to talk. Or rather, he was wheeled in by his friend, Spencer Dane. He has difficulty keeping his head up. His voice is weak. Conversation often drops off from fatigue and emotion. And this is a good day for the once-vigorous restaurateur, Mr. Dane said.

It's a face of AIDS not seen much any more. As breakthrough medications lengthen lives, saving tens of thousands of infected Canadians from a terrible, premature death, the news media have moved on to other stories.

But a visit to Dr. Peter's, or a talk with anyone on the treatment front lines, is a sobering reminder that Old Man AIDS, the deadly viral trickster, hasn't gone away.

People are still being infected, still suffering and still dying.

The picture is not pretty. Although more people than ever before are living with AIDS and HIV, many are far from healthy.

Woeful gaps in care remain, between those stable enough to maintain life-prolonging antiretroviral therapy and those who remain on the wild side. Despite the best efforts of dedicated outreach workers and physicians, 40 per cent of the 1,436 British Columbians who died of HIV-related causes from 1997 to 2005 made no attempt to access the drugs, even though they were free.

Another 2,500 individuals in B.C. are estimated to be HIV-positive without knowing it, greatly increasing the risk of passing the lethal virus on to others.

Among aboriginals who inject drugs, the rate of contracting HIV infection is twice that of non-native drug addicts and not far off that found in parts of hard-hit Africa.

And there are new issues. The medically beaten up bodies of some long-time AIDS survivors are beginning to suffer from a syndrome known as "premature aging."

Osteoporosis, strokes, brittle diabetes, renal failures, cardiovascular troubles - conditions normally associated with older people - are showing up in AIDS patients ahead of their time.

Maxine Davis, the energetic executive director of the Dr. Peter Centre, sees the compounding problems firsthand. She is sombre about the future.

There is a desperate need for more care, more facilities, Ms. Davis said. The waiting list for the 24 beds at the centre, the only one of its kind in B.C., keeps getting longer.

As a result, hospital beds are often plugged with AIDS patients who should be elsewhere. That denies beds to other needy patients. The situation is not dissimilar to the plight of senior citizen "bed blockers," forced to languish in hospitals because there is nowhere else for them to go.

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"Our last two admissions each spent five months in the hospital," Ms. Davis said. "That is unconscionable, and it drives up health costs.

"Yes, in a lot of areas, we are winning the battles, but here, we don't see the healthy people. We see the failures, the day-to-day struggles."

St. Paul's Hospital, the core of AIDS treatment in the province, is caring for more patients now than it did during the height of the epidemic in the early 1990s, she said.

"There are people needing more and more care, but there simply isn't enough of it," she said. "It's all very painful to see."

A MODERN LAZARUS

Of course, there is also a rosy side, a very rosy side, to the state of AIDS in 2008.

Just ask Tiko Kerr.

Two years ago, the Vancouver artist was at death's door after battling AIDS for more than 20 years. "I was weakening. It was constant, constant, constant."

An all-out campaign was launched on behalf of Mr. Kerr and four other patients to gain access, refused by Health Canada at the time, to the latest advance in AIDS treatment. It combined three powerful drugs into a single, powerful pill, with a complementary, equally powerful capsule.

The campaign succeeded, and to say the then-experimental pills TCM114 and TCM125 also succeeded would be an understatement.

Mr. Kerr is back from the dead, a self-proclaimed Lazarus. The AIDS virus has virtually disappeared from his body. His painting is thriving. He's even resumed rowing, three or four times a week.

"After 20 years of misery, I feel 25 again," he said. "It's just great."

Paul Lewand, who joined Mr. Kerr on the new "miracle" medication, has a similar story. "I can now get up and do things. I'm mobile again. I always dreamed of this kind of recovery but I never really believed it. Now, spring is coming and life is good," Mr. Lewand said.

A study last year showed that highly active antiretroviral therapy adds an average of 15 years to the life expectancy of someone infected with HIV, compared with patients infected in the early 1990s. And that was before the appearance of the wonder pills taken by Mr. Kerr and Mr. Lewand.

A stone's throw away from the Dr. Peter Centre, at aging St. Paul's Hospital, one of the world's most renowned AIDS experts and president-elect of the International AIDS Society feverishly documents the astounding advances in treating a disease that not so long ago was considered an almost certain death sentence.

Julio Montaner pioneered a key AIDS breakthrough in 1996, the first to advocate the so-called cocktail combination of antiretroviral drugs that proved astonishingly successful in bringing down viral levels. He is equally excited these days about the new single pills that are increasingly becoming the treatment norm, despite their cost.

"The progress we have made in the last 2½ decades is absolutely amazing," he said, his left leg pumping up and down, his words spilling out in rapid fire.

"I am experiencing the same joy I had in 1996. With these new drugs, we can actually reduce the viral load almost to nothing, even in the most resistant infections."

There are also fewer side effects, and the convenience impact on patients of having to take just one or two pills a day can hardly be overstated.
The ongoing succession of effective anti-AIDS drugs has prompted Dr. Montaner to dream what was once the unthinkable - an actual end to the spread of HIV.

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Because most of those who take the treatment have their HIV levels reduced so low they are incapable of transmission, having everyone on the drugs from the moment of their infection could conceivably wipe out the virus, according to Dr. Montaner. He calls it "seek and treat."

Yet it's not even close to happening. The political will to transform dramatic medical successes into a comprehensive program to curb AIDS once and for all simply isn't there, leaving thousands of HIV-infected patients in B.C. with no treatment at all. It drives Dr. Montaner mad with frustration.

"We have a nearly 100-per-cent ability to control viral replication and put HIV into remission," he said. "Yet in our midst, there are people dying of AIDS, unnecessarily. No Vancouverite could ever be proud of that. It is simply unacceptable."

WHERE THERE'S A LACK OF WILL

Mark Tyndall sees the problems firsthand, during his twice-weekly stints at the Vancouver Native Health Centre clinic in the grim, drug-ravaged Downtown Eastside, where many troubled HIV and AIDS patients reside.

It's not so much that they never seek treatment, Dr. Tyndall said over a coffee at a bright, well-run neighbourhood café. It's that so many patients have such confusing, chaotic lives, particularly those who inject drugs, they simply can't maintain the strict regimen AIDS medications require.

The result is a lot of failure. He often sees patients with opportunistic infections such as pneumocystis pneumonia (PCP) and cryptococcal meningitis that have almost disappeared elsewhere with improved treatment.

"We get visitors from Toronto who are fascinated to see them," Dr. Tyndall said. "They come across them only a few times a year, but we see them every day. And it's because people don't take their medications regularly."

At St. Paul's, one of every eight beds is usually filled by a patient with AIDS-related problems, Dr. Tyndall said. And nearly one-third of those who have registered at the native health clinic for antiretroviral drugs since 1998 have died.

"We can get people started on treatment, but they fall off," he said.

While the number of new HIV infections in the province dropped marginally in 2006, Dr. Tyndall said there is no chance of the virus petering out. The rate of new infections among injected-drug users, now a major cohort of HIV, is simply too high. "That means the epidemic is going to continue to grow," he said.

Governments, however, have been loath to commit to the large sums necessary to combat the threat. A major reason is that AIDS has become mostly invisible. There are no more demonstrations on legislative lawns by mostly middle-class gay men who demanded action in the 1980s and early 1990s. They were the early victims of AIDS, but they now have the drugs they need.

In the 21st century, HIV-AIDS is more and more the preserve of the poor, the homeless, the addicted and aboriginals.

"We know just about everything we need to know to stop [the disease]. So why haven't we? Part of it is the expense," said Michael Rekart, a long-time expert on the spread of the virus.

"But part of it is that we don't see these deaths on the front page any more. They're in the alleys, on a reserve, or in some hellish single room somewhere. It's not right there in our face. People are still getting AIDS, but they are not the people society values the most."

Back at the Dr. Peter Centre, Tom Griffin haltingly tried to put into words his long struggle to tolerate many of the early AIDS drugs, his decision to abandon them for a time, and the shape he's in now.

"It's been pretty tough," said Mr. Griffin, 50. "I'm very weak, I've got some pain. Insomnia. I just try to take it day by day."

He has been at the centre since October, battling a dire, AIDS-related infection known as MAC. The strength-sapping condition requires up to two years of strong antibiotics to fend off.

"They still don't know everything I've got," he said. "But I still hope to get my quality of life back. I'm getting stronger, and one day I would like to get out of here."

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The next day, Mr. Griffin was readmitted to hospital, suffering from intense pain and swelling in his legs. He's out now, but the struggle continues.

GETTING HIV/AIDS UNDER CONTROL

Positive Test Rates

Men and women newly testing positive for HIV in B.C.

Rate per 100,000 population: Men: 2006: 13.5 Women: 2006: 3.3

WHO IS GETTING TREATMENT?

Of the estimated 12,000 people infected with HIV in B.C., 37.5% are on antiretroviral therapy:

Known HIV positive receiving antiretroviral therapy: 4,500 (37.5%)

Undiagnosed HIV positive: 2,500 (20.8%)

Known HIV positive, not eligible for antiretroviral therapy: 3,000 (25%)

Known HIV positive, eligible for -- but not receiving -- antiretroviral therapy: 2,000 (16.7%)

SOURCE: B.C. CENTRE FOR DISEASE CONTROL, 2006 HIV/AIDS ANNUAL REPORT