



LE GROUPE D'ACTION-SIDA

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ACTION = LIFE

Towards an Ontario AIDS Strategy:

**Four Steps to Deliver Treatment
to People Living With AIDS and HIV.**

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AIDS ACTION NOW! is a Toronto-based activist group fighting for improved treatment, care and support for people living with AIDS and HIV infection. We work to transform HIV infection into a chronic, manageable illness by making the research, health care and social service systems deliver optimal treatment.

Towards an Ontario AIDS Strategy

People living with HIV/AIDS need a responsive, effective and compassionate health care system to help manage their infection and extend their lives. AIDS activists have demanded a co-ordinated strategy from the Ontario government to provide services and to make the health care system deliver the best possible HIV treatment to all who need it.

With last year's election of the NDP, AIDS activists were optimistic that we would have a government that would share the sense of urgency that is needed to bring changes to the health care system. AIDS ACTION NOW! prepared detailed briefs outlining problems with current systems and recommending practical steps that could be taken to deliver improved treatment to people living with HIV and AIDS.

One year later, our optimism has turned to anger and disappointment. Two NDP ministers of health have failed to make concrete changes or provide leadership. While the government delays, people living with HIV and AIDS receive sub-standard health care. Many have seen their health deteriorate. Many have died. When will the NDP take action?

People living with HIV and AIDS can wait no longer. Today, AIDS ACTION NOW! announces four steps to deliver treatment. They are four steps that are practical, efficient and could begin immediately. They would make a substantial difference in providing better treatment - and therefore longer life. They would form the first steps towards a comprehensive, co-ordinated Ontario AIDS Strategy.

Drug Funding

Treatments for people living with life-threatening illnesses like HIV infection are a basic right. Yet that right is often only available in Ontario based on ability to pay.

The current systems for drug funding are not working. Ontario Drug Benefit (ODB) coverage of treatments is only available to people in severe poverty, and only covers a small minority of possible HIV treatments. The result is that many people are forced to quit their jobs in order to qualify for drug coverage, or are forced to forego treatments they need. Others have been needlessly hospitalized so that drugs will be covered by hospital drug plans. Complementary and experimental therapies (which are used by the vast majority of people living with HIV) aren't covered by any plan, so are therefore unavailable to poor people. Even new approved therapies are unavailable or require endless red tape to be covered under the ODB Benefit plan until they are eventually officially approved for ODB coverage.

One HIV therapy - AZT - is widely available and funded by the province, but it is only one of an increasingly large arsenal of treatments.

The lack of drug funding not only shortens the lives of (non-wealthy) people living with AIDS and HIV, it is also costly. People are forced onto social assistance, hospital beds are used needlessly, and people end up in acute care because they've been forced to forego treatments that would maintain their health.

Precedents clearly exist for full coverage of treatments for chronic or life-threatening illnesses, both in Ontario and other provinces. (Cystic Fibrosis patients, for example, have a full range of treatments covered in Ontario).

The Ontario government must announce a comprehensive policy to fund the full range of approved, experimental and complementary treatments for HIV infection.

Standards of Care

HIV treatment is a complex and rapidly changing field. Yet health care workers and institutions have not been given the resources and guidance needed to provide the best possible diagnoses, treatment and care. The result is all too easy to document: people with HIV have had their lives shortened by sub-standard, inconsistent health care.

This situation is even worse for people outside the downtown Toronto gay men's community, where AIDS activists and concerned doctors have been able to share resources and information. Women, people of colour, IV needle users and people outside major centres are left with health care that is lethally inadequate.

The Ontario Ministry of Health does not need to start from scratch on resolving this problem; there are already in existence some scattered initiatives aimed at improving standards of care for HIV infection. Medical schools, professional colleges, the Ontario Medical Association, community groups, the federal government and even the Ministry of Health itself all have projects to educate health care workers or establish guidelines for optimal care. These efforts are, however, unco-ordinated and incomplete.

The Ontario Ministry of Health must take responsibility for this crisis and by bring together all the bodies concerned, including people living with HIV, to evaluate and co-ordinate these efforts. The province must also establish mechanisms to continually monitor standards of care developments and respond to gaps in care.

HIV Clinics

The Ontario Health Ministry has shown some leadership in funding 12 clinics specializing in HIV treatment. Their value is limited, however, by lack of co-ordination and evaluation. With proper direction and expansion of services, the HIV clinics could become world-class providers of HIV health care.

The Ontario government must conduct a thorough evaluation, in consultation with people living with AIDS and HIV, of the current network of HIV clinics. The clinics' mandates should be expanded to meet gaps in HIV treatment services such as:

- complementary therapies
- Chinese medicines
- case management
- hospital advocacy
- experimental treatment support

- services aimed at specific communities (and available in appropriate languages)
- nutrition/diet counselling
- psychiatric/psychological services.

This evaluation should be initiated immediately and completed quickly. Lack of HIV treatments and services is an emergency situation.

Anonymous Testing

Although previous Health Minister Evelyn Gigantes announced an anonymous HIV testing policy in April, there has not yet been a single new test site open. This must proceed without further delay.

In an era of "public health" terrorism of people with HIV through threats of quarantine, contact tracing and public health surveillance, anonymous HIV tests are crucial. Anonymous testing will allow people to learn their HIV status and seek treatment as well as change possible risky behaviour.

Anonymous testing should be widely available across Ontario, available at sites that are appropriate to the community, and should be done with proper pre-test and post-test counselling. Treatment and support services to people who test HIV positive must be incorporated as part of the anonymous testing strategy.

The province must also proceed with changing public health reporting regulations to make HIV non-reportable, as announced by Gigantes in April. This is necessary to prevent over-zealous Medical Officers of Health from collecting surveillance records on people living with HIV. Methods of collecting anonymous statistical data for epidemiological purposes should be standardized. The current consultation with community groups on how to best resolve individual problem cases should be encouraged to provide clear regulations and guidelines.

Summary

These four steps are unique to HIV/AIDS, but they are consistent with the direction that everyone agrees health care must head. Quality assurance, evaluation of services, patient involvement, independent living and home based services, and blending complementary therapies with traditional medicine are all directions that will be increasingly important in health care. But people living with AIDS and HIV can't wait for the long-term overhaul of health care. The Ontario government has an opportunity use the urgency of HIV - and the strength of the community based AIDS movement -to create new and innovative models that health care can learn from.

For too long, people living with HIV and AIDS have been fighting for their lives with little help from the health care system. Our demand is straight-forward: that the NDP government recognize this as an emergency situation. The four steps we have announced today are key to an Ontario AIDS Strategy that will meet the needs of people living with HIV and AIDS. That Strategy must be developed and supported with the urgency it deserves.