

Teens and HIV

The transition to adult care and responsibilities can be a rocky ride

by Dr. Christos Karatzios



Teenagers living with HIV face a great number of challenges all at once. Surging hormones, and the need for peer acceptance become hugely important at this stage of life. Having HIV becomes more of a challenge as sex enters the picture. As well, with greater independence, teens must assume responsibility for sticking to their antiretroviral (ARV) regimen.

The support of family members, doctors, nurses, social workers and AIDS service organizations (ASOs) specially geared for youth can help teens make a successful transition. This is especially important as they prepare to move from pediatric to adult clinics and may feel abandoned by the care teams they've known since childhood.

Before we knew

A great majority of the teens living with HIV today were infected from birth, at a time when doctors didn't know how to prevent transmission of the virus from a pregnant or breast-feeding mother to

her child. It was only in 1994 that a major study by Dr. Edward Connor and his colleagues found that the risk of transmission could be cut from about 30% to 7% if women took AZT (Retrovir®) during pregnancy and didn't breastfeed their infants.

Today, with maternal HIV screening programs and better ARVs, mother-to-child transmission of HIV in Canada is almost non-existent. In Québec, the HIV-positive children we see today are primarily babies of HIV-positive women who recently immigrated from countries where HIV is endemic, and a few children infected outside of Canada.

People who had the misfortune of being infected at birth are now surviving into adulthood. With proper medical care, they can look forward to near-normal life expectancy and to having their own children who aren't infected with HIV! But this

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happy scenario depends on getting through the difficult teen years without rebelling against drug regimens and precautions.

Teen sex

Studies on the sexual practices of teens reveal that up to half don't use condoms. Nor do sexually active HIV-positive teens always tell their partners about their infection. Furthermore, they're notorious for their lack of adherence to treatments for chronic diseases, including HIV. Poor adherence to ARVs can lead to drug-resistant HIV, with the potential to spread rather quickly among young people. We haven't seen this yet, but in the US the HIV epidemic is now driven by young adults aged 20 to 24. A substantial number of new HIV infections may be due to unsafe sexual practices by teens who aren't even aware that they have HIV and don't get diagnosed until their early adult years.

AIDS as abstraction

For many teens, HIV is something the doctor tells them they have, not something they feel they need to worry about. It can appear as a virtual disease — seen on paper but not felt in reality (until later on).*

Unlike someone with diabetes, who will be hospitalized within a few days if they don't take their medicine, there's no instant gratification from taking ARVs. It's possible to feel well for years without medications, and side effects like stomach upset may convince some they're worse off taking ARVs than going without treatment. That makes it easy to feel invincible and reject the idea that you have a potentially fatal condition that can be transmitted to others.

You want to be just like your HIV-negative friends. Why should you take pills every day and see your doctor so often?

As a doctor, it's very difficult to watch teenaged patients develop drug-resistant HIV and experience medication failures as a result of not taking their ARVs. Even a temporary phase of missed medications can cause lasting damage. It's very tempting to use whatever means we can to get people through their teen years safely.

Transition to adult clinics

When they turn 18, teens living with HIV must be transferred to adult HIV clinics. This can be a difficult transition. Ideally, preparation starts at least six months before the transfer and some links are kept up between nurses and social workers at the pediatric and adult clinics.

There are some major differences in the way people are treated at an adult clinic. The new doctor is unlikely to chase after you when you don't take your medicines or call you at home when you miss appointments. Youth protection services can no longer be called in to prevent or stop dangerous behaviour. The adult clinic considers newly arrived patients as adults, and if adults don't want to take care of themselves, that's their right. As well, when you look around the waiting room, the harsher realities of HIV may be more obvious than they were in the family-oriented pediatric clinic.

It's a lot to deal with at a difficult time of life! But efforts to make the transition successful are highly worthwhile. Adult hospitals should work closely with pediatric centres so that teens never feel abandoned or misunderstood and parents can help maintain links. Teens should never hesitate to ask for what they need to make a smooth transition into adulthood confident about their future. **R**



Camp Moomba

For kids affected by HIV/AIDS

Sometimes a break from it all can make all the difference. Camp Moomba was started in 1997 and now provides a number of camp experiences throughout the year to kids and teens from across Canada. The Western Pediatric AIDS Society is a registered charity that raises money to fund the camp. Programs are free of charge for all participants, including transportation to and from all Canadian provinces.

The Camp is run by the Moomba YMCA in Port Moody, BC. Canoeing, hiking, new friends and adventures are on the program.

To find out more about their schedule of activities this year, contact

Camp Moomba YMCA
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Tel: 604-939-9622 (Will accept collect calls)
Email: campmoomba@vanymca.org

* An insight I learned from my mentor, Dr. Normand Lapointe.