

Supporting a Child Whose Parent is Living with HIV or AIDS

By Janet Madsen

It may seem to be a daunting task to take on the role of a Big Sister to a child whose parent is HIV-positive, and it will be different than being a Big Sister to a child whose parents have stable health. The child may have issues to face that children from other homes don't have to deal with, and yet there are also some commonalities. This article will present some facts, issues and questions to consider if you would like to be a Big Sister to a child who comes from a family affected by HIV illness.

Am I at risk for contracting HIV? What is it like to know someone with HIV?

In becoming a Big Sister to a child whose parent is living with HIV, you will not be at risk of contracting HIV (the virus that is believed to cause AIDS) yourself. HIV is not an airborne virus, and you will not contract it through casual contact – conversations, hugging, or touching a glass or plate a positive person has touched. HIV is passed on through intimate contact with bodily fluids – blood, semen, and vaginal fluids. This exposure can be through sexual contact, sharing of hypodermic needles, or occupational exposure (e.g. needlestick injuries).

You may be concerned about what it will be like to know someone with HIV. Even though your relationship will be with your Little Sister, and not her parents, you may worry about being around someone who is in ill health, and who may die in the time that you are acquainted with them. These are understandable concerns, especially if you have little experience with HIV illness. HIV is a progressive disease. An individual infected with the virus can live a relatively healthy life with few opportunistic infections (OIs) for up to twelve years after initial infection. Many HIV+ people find, however, that fatigue is an ongoing challenge. Many people have to cut their work hours, and eventually leave their jobs, because they cannot continue to work at the pace they could when they were uninfected. They may request a Big Sister because they cannot participate in activities with their children the way they used to.

Most of the HIV+ people you will meet will not be dying. They have had to make changes in their lives as a result of HIV, but they are not dying. Should their health decline, there will be support people and resources in place for you. You will not have to deal with it alone.

What are some of the issues that make HIV different from other chronic diseases?

Part of the difficulty in supporting people affected by HIV is the secrecy that evolves around the illness. HIV is still highly stigmatized in our society. Some people believe HIV is a moral punishment for people who are sexual in "inappropriate" ways, or who use drugs. They categorize those who deserve to be punished (individuals who contract HIV through sexual contact or drug use) and innocent victims (individuals who contract HIV through blood transfusions, occupational exposure, or children who get it from their mothers). The reality is, HIV is an equal opportunity virus. It does not pick and choose its carriers through moral screening. As one activist put it, "I got HIV from being human." There is no point to blaming someone with HIV, saying their behaviour was unacceptable and they deserve their illness. Do we blame people who develop lung cancer from smoking?

The child you are supporting may have a sense of some of these issues, or she may have none at all. What she will probably understand is that her parent's illness is a secret, and she may have a degree of shame and anxiety about it. We still have a long way to go in educating people before society will understand that HIV is not a moral illness. She will need to know that you will not judge her for her parent's illness, and that you understand that being HIV+ is not a shameful thing.

What issues face a child affected by HIV?

A child whose parent is living with HIV may be facing numerous issues that children of parents with terminal diseases face. Fear, grief, denial and anger are common emotions.

The age of the child will play a part in the child's understanding of the illness. Younger children may have a limited understanding of HIV. They may know their mother has a serious illness, but they may not understand the complexities of HIV. Older children may know a great deal about the illness, and be able to tell you about different doctors and treatments. Parents make different choices about how much and at what time they tell their children. It will not be up to you to tell the child details about their parent's situation; that is the decision of the parent. Confidentiality is key.

The child may be afraid of their parent's condition, as they do not know what it means for the future of the relationship. They may be in denial, and become angry that their parent cannot do all the things with them that they used to. At times, they express grief. These are all elements of dealing with changes in the parent-child relationship. Also keep in mind that you may not see any of these behaviours.

Where can I learn more?

If you have questions or concerns about working with a child whose parent is HIV infected, there are resources available. The library at the Pacific AIDS Resource Centre is open to the public. It houses books, journals and videos on the complexities of HIV and AIDS. The Positive Women's Network provides support to women living with HIV/AIDS, so we meet a lot of children too. If you need to talk to someone, feel free to call.

Working with people infected and affected by HIV can be difficult at times. It can be joyous, delightful, educational, sad, and challenging. The thing is, it is real. Whether we know someone living with HIV or not, we are all affected by the epidemic.

Resources:

Pacific AIDS Resource Centre Library
1107 Seymour Street
Vancouver, BC V6B 5S8
Phone: 604-681-2122 ext. 248

Positive Women's Network
Suite 614, 1033 Davie Street
Vancouver, BC V6E 1M7
Phone: 604-692-3000
Toll Free: 1-866-692-3001
Fax: 604-684-3126
Email: pwn@pwn.bc.ca
www.pwn.bc.ca