KNOW YOUR RIGHTS

Guide for Parents Living with HIV

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Canadian HIV/AIDS Legal Network | Réseau juridique canadien VIH/sida

All people have the right to make their own choices around reproduction, including becoming pregnant and having children, regardless of their HIV status. In Canada, women living with HIV are increasingly becoming pregnant and having children. Advances in HIV treatments have resulted in the successful reduction of HIV transmission during pregnancy, at the time of childbirth as well as postpartum.

Pregnancy and parenthood are often accompanied by feelings of excitement and anticipation as well as experiences of stress and fear of the unknown. Parents living with HIV face unique stressors that are often related to decisions that may have implications for both themselves and their children. Some parents living with HIV may experience judgement and discrimination in their decisions to become pregnant and have children, making access to multiple forms of support particularly important. The presence of HIV-related stigma, however, complicates access to and experiences of both HIV and pregnancy supports.

This resource was produced for parents or prospective parents living with HIV, including women, transgender men and non-binary people. Its aim is to provide practical information and to foster knowledge about some of the main areas of concern that parents living with or affected by HIV may have.

This resource provides legal information. Remember that many different people and organizations can provide you with information and support, but *only* a lawyer can give you legal advice. If you require legal advice about your specific situation, you should contact a lawyer.

What is the chance of HIV transmission during pregnancy and childbirth?

Vertical transmission has been dramatically reduced in Canada as a result of the success of antiretroviral therapy. Being on antiretroviral therapy while pregnant reduces the chance of HIV transmission to the fetus or baby to less than 2 percent. Transmission can be reduced further to 0.4 percent when the HIV-positive parent begins antiretroviral therapy more than 4 weeks before delivery.

Could people living with HIV face criminal charges for failing to prevent the transmission of HIV to their children during pregnancy?

There has never been a reported case in Canada of criminal charges being laid against a person living with HIV for not taking steps to prevent the transmission of HIV to their child during pregnancy.

Should a parent living with HIV breastfeed?

Parents living with HIV face a complicated dilemma about feeding their babies. Contradictory messages cloud the picture on infant feeding for parents living with HIV and guidelines vary around the world.

Health Canada encourages breastfeeding as the best way to ensure protection, growth and development of babies and toddlers. This message conflicts with HIV clinical practice guidelines and Canadian recommendations for persons living with HIV. In Canada, it is recommended that people living with HIV avoid breastfeeding and use formula in order to prevent HIV transmission, which is possible through the consumption of breast milk.

In 2016, the World Health Organization (WHO) acknowledged the accumulating evidence showing that giving antiretroviral medicines to the person living with HIV or the infant can significantly reduce the risk of transmission through breastfeeding. For the first time, WHO recommended that HIV-positive parents or their infants take antiretroviral drugs throughout the period of breastfeeding and until the infant is 12 months old. This means that the child can benefit from breastfeeding with very little risk of becoming infected with HIV.

WHO recommended that national health authorities from each country refer to this evidence when formulating their strategy on infant feeding. Health Canada had not issued new guidelines in response to the updated WHO recommendations at the time this resource was published.

Could a person living with HIV face criminal charges for not taking steps to prevent the transmission of HIV to their child during delivery or while breastfeeding?

Legal interventions arising from breastfeeding are unlikely, but not impossible. There is precedent indicating that a parent living with HIV who risks transmitting HIV to a child during delivery and after the birth (e.g., by not informing health care providers attending the birth, refusing preventive medications for the newborn infant, or breastfeeding) could potentially face criminal charges and intervention from child protection authorities.

In 2006, a woman in Ontario plead guilty to the charge of *failure to provide the necessities of life*. During pregnancy, the woman did not take treatments to prevent transmission of HIV to her infant. She did not inform the medical staff of her HIV-positive status when she gave birth. She breastfed the infant, who subsequently tested positive for HIV.

Typically, the charge of failure to provide the necessities of life is reserved for cases of child neglect. In this case, the woman's conviction stemmed from not what she did or did not do during her pregnancy, but her behaviour after the baby was born.

While criminal charges in such circumstances are unlikely and are generally not in the best interest of the child (the key consideration in child protection proceedings), it is important to know that such legal interventions are possible. It is also important to be aware that, even in the absence of criminal charges, child protection authorities may intervene in cases where they believe that a child is in need of protection, meaning that the child has suffered or is at risk of suffering physical harm.

What is disclosure?

Disclosure, in the context of HIV, is the simple act of a person informing another individual of their HIV status. In most cases, people living with HIV are not under a legal obligation to disclose their HIV-positive status. However, Canadian law requires disclosure of an individual's HIV-positive status to certain sex partners, and in certain other limited circumstances.

Are parents required to disclose their HIV-positive status or their children's HIV-positive status to social workers?

In most situations, parents are not required to disclose their HIV-positive status to social workers, unless knowledge of the parent's HIV status is required for the protection of the child or someone else who has been exposed to a significant risk of infection.

With regard to child protection workers, these workers are specifically mandated to protect children from abuse and neglect by provincial and territorial laws. In most cases, knowledge of a parent's or child's HIV status is not necessary for child protection workers to do their work. However, certain HIV-related issues may be relevant considerations (e.g., whether the parent or child is taking recommended treatment and accessing support services or whether ill-health or periods of disability are affecting a parent's ability to meet their child's needs). If an HIV-positive child is being taken into care by a child protection agency, the child's medical information should be provided to the agency or foster parent to ensure that the child receives uninterrupted treatment and support.

In any case where disclosure is required to a social worker or child protection worker, a parent has the right to set limits and only reveal relevant information or consent to workers accessing relevant information from third parties. Parents may

seek legal advice before disclosing their status to social workers or child protection workers and can request a reasonable amount of time to think through their options. However, these reasonable requests cannot be used to delay the process and must be followed through.

Are parents required to disclose their HIV-positive status to their children?

Parents are not required to disclose their personal health information, including their HIV-positive status to their children. This is because almost all household interactions and parenting roles pose no real risk of transmitting HIV. If a parent does disclose their status, it should be on account of their own choice to do so.

Can children be taken away from a parent because the parent is HIV-positive?

No. Being HIV-positive should never be used as a rationale for child welfare involvement or for child apprehension.

Does HIV status affect custody or residence arrangements?

A parent's rights and responsibilities to their child do not change because they are HIV-positive. That being said, a parent's HIV-positive status may be taken into consideration when determining custody agreements, child support payments, or primary residence of the child. The key consideration in determining custody or residence arrangement for the child is the child's best interests. Therefore, if a parent has HIV-related disabilities, for example, that affect their ability to care for their child, these limitations and any subsequently necessary accommodations that must be made are legitimate considerations in deciding what arrangement is in the best interests of the child.

Still, a parent's HIV status should not be a determining factor in deciding custody or residence arrangements. As such, if a parent feels as though their ex-partners may be using the parent's HIV-positive status to demoralize, discredit, or stigmatize them, then the affected parent should speak with either a lawyer or support worker if a breach of privacy may potentially result. Where any breach of privacy has occurred, in these circumstances or otherwise, the HIV-positive parent affected should seek legal advice.

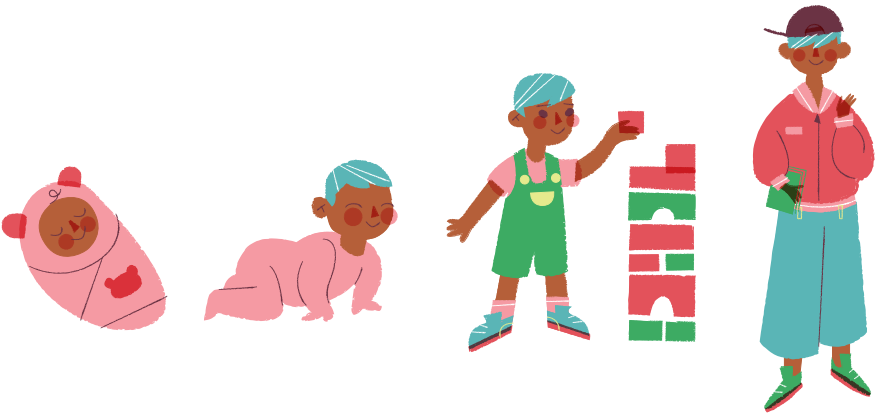
When should parents tell their children that the children are HIV-positive and what are the implications for a parent's scope of decision-making with respect to their children?

There is no specific age at which a parent must legally tell a child that they are

living with HIV, but the child should be informed by the time they are able to make their own medical decisions. There is no set age when a child becomes capable of consenting to medical care. Doctors have to use their best judgment in each case to decide if a child is capable. Courts have decided that children of different ages are capable of consenting. Generally, children are considered legally capable of consenting if they understand the need for a medical treatment, what the treatment involves, and the benefits and risks if they receive the treatment.

If the health care provider explains these things and decides that the child understands them, and that the health care is in the child's best interests, the health care provider can treat the child without permission from the parents or guardians.

Another consideration about the timing of disclosure is sexual activity. As HIV can be sexually transmitted, youth should be informed of their HIV-positive status before they are sexually active so that they can make informed decisions regarding their sexual activities and meet any potential disclosure obligations stipulated by Canadian criminal law.



Do children have to disclose their status to their teachers and/or their classmates?

In most cases, there is no legal obligation for children to tell their schools that they have HIV and it is entirely their choice whether or not to disclose this information. HIV is not transmitted through casual contact, vomit, sweat, stool, urine, tears, or nasal secretions. Additionally, there is no risk of transmission from scratching another person or through spitting. Disclosure may be useful, however, under circumstances where doing so would facilitate access to HIV care and support, or to otherwise protect the HIV-positive child.

Will a child's HIV status be kept confidential by their schools?

In the event that disclosure is required, school authorities should ensure that only the minimum number of staff members required are made aware of a student's condition. If a student's status is disclosed to a school authority (e.g., principal, teacher, counsellor, or administrative staff), either because the student has disclosed their own status or because a parent or some other source has done so, that school authority must keep the information confidential. The individual's status must not be shared with other school staff. If the student is a minor, their medical record cannot be released by school personnel without their parent or guardian's permission.

This legal obligation of confidentiality, however, does not extend to classmates or any other person at the school who is not acting in an official capacity. Privacy laws rarely restrict the flow of information between individuals.

In some provinces (specifically, Alberta, Ontario, Newfoundland, Nova Scotia and Prince Edward Island), school authorities are legally obligated to report a student in the school who has or may have HIV to the provincial Medical Officer of Health, who is obligated to keep this information confidential. Additionally, school authorities may record a student's HIV status in their record, but this information should remain exclusively with the required personnel in a secure filing system to protect the student's privacy.

Will a student's activities be restricted because they have disclosed their HIV status?

Given the negligible risk of HIV transmission through casual contact, a student should be able to participate in activities without restriction. The school will still be required to employ standard precautions in all activities that involve contact with blood or bodily fluids. However, the Medical Officer for Health in the appropriate province or territory may find that there are special circumstances that necessitate some restriction.

If a student requires special accommodation, the school has a duty to meet this need up to the point of "undue hardship." The standard for undue hardship is high, and the burden of proof lies on the school claiming undue hardship; that is, the school must provide sufficient evidence to support its claim that your child's need for accommodation causes undue hardship. Generally speaking, though, to help the school meet a child's needs, a student should provide information about their HIV-related needs. However, disclosure of a student's actual HIV status or a diagnosis is not needed nor is it relevant.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ADDITIONAL RESOURCES

Bitnun et al., "Prevention of vertical HIV transmission and management of the HIV-exposed infant in Canada in 2014," *Canadian Journal of Infectious Diseases and Medical Microbiology* 25, 2 (March/April 2014): 75–77.

Canadian HIV/AIDS Legal Network, *Disclosure in School and Daycare*, 2014.

Canadian HIV/AIDS Legal Network, *Disclosure, Privacy and Parenting*, 2014.

P. Khosla, A. Ion and S. Greene, *Supporting Mothers in Ways that Work: A Resource Toolkit for Service Providers Working with Mothers Living with HIV*, The HIV Mothering Study Team & The Ontario Women's HIV/AIDS Initiative, January 2016.

Society of Obstetrics and Gynaecology of Canada Clinical Practice Guideline, *Canadian HIV Pregnancy Planning Guidelines*, No. 278, June 2012.

Society of Obstetrics and Gynaecology of Canada Clinical Practice Guideline, *Guidelines for the Care of Pregnant Women Living With HIV and Interventions to Reduce Perinatal Transmission*, No. 310, August 2014.

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