

Children and HIV

Many people living with HIV have children in their lives. Some of us may have our own children, while others may have special relationships with nieces, nephews, grandchildren or children of our friends and partners. Whether they are living with HIV themselves or affected by your HIV status, the tips in this chapter will help you to provide care and support to your children.

Sections of this chapter were adapted by Shari Margoese from Amy Buch, *Talking with Your Children About your HIV Status or Your Children's Status* (www.thewellproject.com), July 2005 and from Shari Margoese, *Talking with Your Children about HIV: HIV Awareness for Children* (www.thewellproject.com), July 2005.



About the author

Shari Margoese has been involved as an active volunteer in the AIDS community since shortly after her own HIV diagnosis in 1993. As a mother of an HIV-positive child, her advocacy efforts have often focused on the needs of the HIV-positive family and the rights of women living with HIV to have children. Shari is currently co-principal investigator on several community-based research projects, including the development of a protocol for fertility and pregnancy care for people living with HIV in Ontario.

Currently, Shari's volunteer commitments include working with Voices of Positive Women in Toronto, Blueprint for action on women & girls and HIV in Canada, and ATHENA.

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With effective anti-HIV treatment for both mother and infant, along with adequate prenatal care and no breastfeeding, less than 2 per cent of babies born to women with HIV are actually infected with HIV.

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What if my child is HIV-positive?

In recent years, very few children in Canada have been born HIV-positive. In fact, with effective anti-HIV treatment for both mother and infant, along with adequate prenatal care and no breastfeeding, less than two per cent of babies born to women with HIV are actually infected with HIV. But, for the small number of parents who are faced with the positive diagnosis of their child, these statistics are of little comfort.

The first thing to remember is that it is not your fault! No parents want their children to have HIV. What is comforting, however, is the knowledge that most children born with HIV in Canada live long, productive and healthy lives. Many of these children are now young adults planning for their futures, attending school, playing sports, dating and planning families of their own.

Raising an HIV-positive child is not without challenges. Not only do you need to learn about how to manage your health, but also the health of your child. Having knowledge of how HIV affects children differently is helpful in making informed decisions about your child's health.

HIV in children

You may wonder, is HIV different in children? For the most part, HIV acts the same way in children as it does in adults. However, there are some differences. You may go to the doctor with your child and find that his or her CD4+ cell counts are much higher than yours. This is because children normally have much higher CD4+ cell counts to begin with. This is also true of viral load (the amount of HIV in the blood). Children's CD4+ cell counts and viral load levels usually reach adult levels when they reach puberty.

Another difference between children and adults is that children's immune systems are still developing. There is not much research available to know exactly what effect HIV has on the developing immune system, but we do know a few things. For example, HIV-positive children tend to get more bacterial infections, like pneumonia or sinusitis. They may also tend to have more diarrhea or thrush.

Some HIV-positive children also get warts and molluscum contagiosum (a bumpy skin rash). Adults can get these, too, but they can be harder to treat in children.

Preventing illnesses

It can be scary when HIV-positive children get sick, especially when they are very young. With every snuffle you may feel that your child has a serious illness. Rest assured, while some children do get seriously ill, most HIV-positive children who have access to regular health care, drugs and good nutrition generally enjoy good health. Preventing illness is not always possible, but there are some things you can do to help your child stay healthy.

Many of the things you can do to help keep your child healthy are similar to keeping yourself healthy, but there are some exceptions. For example, just as it is important to find an experienced doctor to manage your HIV care, you also need to find a doctor for your child. Usually, your obstetrician, family doctor or infectious disease specialist can refer you to a pediatric infectious disease specialist (children's HIV doctor) to care for your child. If there are no specialists where you live, you may have to travel for appointments or work with another infectious disease specialist and general pediatrician near your home. You can find out more about the healthcare team in Chapter 3, Your healthcare team.

One of the most important things you can do is to make sure your child is vaccinated and that vaccinations are kept up to date. Most HIV-positive children can receive the same vaccines that other children receive. These include: diphtheria, tetanus, pertussis (DTaP) vaccine; polio (IPV) vaccine; H. flu type B (HiB) vaccine for meningitis; pneumococcal vaccine; and hepatitis A and B vaccines. Other vaccines depend on your child's CD4+ cell count. If the CD4+ cell count is high enough, your child can receive chicken pox and mumps, measles and rubella vaccines. For children who have seriously weakened immune systems, these vaccines can cause illness and should only be used in consultation with your child's HIV doctor.

Good hygiene, including hand washing, along with a healthy diet can also go a long way to reducing your child's chance of becoming ill.

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Recent research has shown that it may be beneficial for children to start drugs as early as three months of age.

Starting early may reduce the chance that your child will become sick in the future. You should make this decision together with your child's doctor.

Getting children to take medicine can be a real challenge.

HIV treatment for children

Making treatment decisions for our HIV-positive children can be very stressful. Adults usually ask themselves and their doctors, “am I ready to start treatment,” “what treatment should I take,” “how often do I have to take it” and “how will it affect me?” The same questions can be asked when deciding on treatment for our children. Finding a knowledgeable care provider and becoming familiar with treatments for children can help in your decision making.

Is your child ready to start treatment? Usually, when adults ask this question they factor in viral load, CD4+ cell counts and their financial and emotional readiness to start. When it comes to making this decision for our kids, there are a few extra considerations. In the past, anti-HIV drugs were started if children had a high viral load or failed to thrive. (This means not reaching normal milestones of growth and development.) Recent research has shown that it may be beneficial for children to start drugs as early as three months of age, whether or not they reach these important milestones. Starting early may reduce the chance that your child will become sick in the future. You should make this decision together with your child's doctor.

What treatment should your child take? There is not as much information available about the use of anti-HIV drugs in children as there is for adults. Many, but not all, of the treatments available for adults are also available for children. Young children usually receive doses of drugs based on their weight. Once children reach adult proportions, adult doses are given. See Chapter 10, Treatments, for more information on anti-HIV drugs.

How often does my child need anti-HIV drugs?

Just like adults, children need to take their anti-HIV drugs consistently. Dosing schedules will depend on which drugs your child is taking. Whatever drug treatment your child is on, he or she should take the drugs at the same times each day. Some anti-HIV drugs need to be taken with food while some do not. When talking with your child's doctor about which anti-HIV drugs your child will take, think about your day and your child's schedule. Think about how you will fit work, school and childcare into your child's drug dosing schedule.

Getting children to take medicine can be a real challenge. Children might not like how the drugs taste or might have trouble swallowing pills. Older children, especially teenagers, may hide pills or pretend to take them. Try to involve your child in filling dosettes, preparing liquid formulations and other medicine-related tasks. Remember that you are training your child for a lifetime of taking medicine on his or her own. You may want to reward your child after he or she takes the medicine by offering a small food treat or sweet drink, such as chocolate milk or a favourite juice, to wash it down. Many parents feel tremendous guilt when giving their children drugs. Remember, by giving your child anti-HIV drugs regularly you are helping to keep him or her healthy and doing what is best for your child. (Even if it doesn't feel that way sometimes!)

How will anti-HIV drugs affect my child?

Generally, anti-HIV drugs should make your child feel better, have fewer infections and grow at a normal rate. However children, like adults, can also experience side effects from anti-HIV drugs. Some children are too young to tell you just how they feel so it is important that you keep track of changes in eating habits, body functions, skin changes (such as rash), sleeping patterns and other functions and habits. These can give you a hint that your child may not be tolerating his or her drugs. Older children should be instructed to tell you if they are not feeling well or if their bowel movements change. Be sure to discuss any changes with your child's doctor. Just like adults, how children experience side effects is very individual and will also depend on which drugs he or she is taking. Your child's doctor can tell you what side effects your child may experience. If your child is not tolerating the anti-HIV drugs well, you can also talk to your doctor about the possibility of switching to a different drug combination (see Chapter 11, Side effects and symptoms).

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Talking to children about HIV

Talking to children about HIV is a scary idea for most adults, especially when there is HIV in the family. The thought of disclosing either your HIV status or your child's can be overwhelming and full of emotions. Rest assured that what you are feeling is normal and that most parents feel frightened, anxious or guilty.

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Talking to your kids about HIV takes thought, timing and planning.

It's never too early to talk to your children about HIV.

Just like telling another adult that you are HIV-positive, talking to your kids about HIV takes thought, timing and planning. You may want to enlist the help of a friend, family member or healthcare provider, such as a doctor or counsellor who knows you and your child. Here are some other helpful tips to consider before you disclose:

- share your disclosure plan with people who already know. They can support you and your child;
- know the facts about HIV, including basic information such as how HIV is transmitted (and how it is not);
- consider timing: are you ready to tell, and is your child ready for this information?

Every parent has his or her own style when talking about important subjects. Some parents choose to have a specific time when the family will sit down and formally discuss HIV. They may present pamphlets or other resources to help children understand the facts.

Other parents take cues from their children and the environment to introduce the subject of HIV. For example, they may try to bring up the discussion when their children see or hear something about HIV on TV. Ask what the children have heard and what they know about HIV. This will help you figure out what they already know and what is left for you to explain.

Take some comfort in what you know: how your children learn new information, what your children may already know about HIV and what feels most supportive to your family. Use this knowledge to decide how to disclose about HIV to your family. While there may not be an exact best way to disclose, there are some steps you can take to prepare. For more information on disclosure, see Chapter 6, Your emotional health, and Chapter 21, Legal issues.

Talking to children of different ages

It's never too early to talk to your children about HIV. In fact, by the third grade, most children have already heard about it. Talking to children about HIV is not a one-time-only conversation. Children will be ready to accept different levels of information at different ages. Talk early and talk often to ensure your children have age-appropriate information throughout their childhood.

Toddlers/preschoolers Very young children are unable to fully understand things such as disease, death or sex. They are, however, able to learn basic

infection control information such as washing their hands and using a tissue. They can learn in the simplest of terms to keep their germs to themselves. This is also a good age to teach children the correct names for their body parts and lay the ground for a supportive and open relationship with them.

School-age children Children 5 to 8 years old are just learning about health, sickness, death and sex. They can understand that HIV is a serious health problem that is caused by a virus, and that their chances of getting HIV are very small. In fact, by the third grade, most children have already heard about HIV. You don't have to discuss sex at this age. However, you can continue to reinforce to children that some body fluids carry infection and should not be exchanged. Use opportunities such as scrapes and cuts to teach about how HIV can be transmitted. Children with HIV may begin to ask questions such as "why do I have to go to the hospital and my cousin/sister/friend doesn't?" and "why do I have to take medicine?" Be prepared to answer these questions with full or partial information. Answers such as, "because you have a virus in your blood or because you need medicine to stay healthy" often will satisfy the curiosity of school-age children.

Disclosing your child's HIV status to others

Many parents of children with HIV feel that the most difficult decisions that they face are related to the disclosure of their child's HIV status to others. Disclosure to day care, schools and similar settings is of particular concern. The laws which protect the rights and confidentiality of all people with HIV mean that you do not have to tell anyone that your child has HIV.

However, many families feel that the best situation for their child in these settings is one where they can disclose fully or partially in an atmosphere of trust. Families who have successfully disclosed their child's HIV status in schools and day care settings have often been supported by the child's healthcare providers, who can provide any information that is required. Free from fear of discrimination, the benefits of disclosure include increased confidence and reduced fear for the child; reduced isolation and anxiety; increased support for the family; and increased HIV/AIDS awareness and sense of community for the school.

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Teach pre-teens that they have choices in life and that decisions they make today could have an effect on the rest of their lives.

Help your teen connect with other HIV-positive children his or her own age.

Preteens Children 9 to 12 years old think a lot about their bodies. This is the time to tell them exactly how HIV is spread. Since HIV is commonly spread by sexual contact, now is the time to give your children correct information about sex. Warn them of the dangers of casual and unsafe sex. Let them know that needle or syringe sharing for intravenous drug use, steroid injection, tattooing or body piercing can put them at risk for getting HIV. Teach pre-teens that they have choices in life and that decisions they make today could have an effect on the rest of their lives. HIV-positive pre-teens often know their own status by this age. Help them devise coping techniques if HIV is a secret outside of your home. Telling a child that he or she may face stigma due to his or her HIV infection is often more difficult for parents than telling the child he or she has HIV. Children at this age may become angry if they are being told they are HIV-positive. HIV-positive parents can expect challenging questions such as “if I got it from you, then how did you get it?” For some parents, disclosing how they were infected is more difficult than telling their children they are HIV-positive. It is helpful to have support from your own counsellor to work through any disclosure fears you may have.

Teens Children aged 13 to 19 are more concerned with their self-image and friendships than what their parents have to say. Many teenagers take risks and feel that “it won’t happen to me.” This could mean many things, including not practising safer sex and becoming infected with HIV for HIV-negative kids, or for HIV-positive kids, not taking anti-HIV drugs regularly and getting sick. During this crucial time, it is important to continue to provide your teen with accurate information about HIV and safer sex. HIV-positive teens must also be told about the legal implications of non-disclosure. They will also begin to make decisions about disclosing to friends. Try to give them helpful tips on whom to tell and when. If possible, help your teen connect with other HIV-positive children his or her own age. You may wish to provide resources such as books and videos that they can view on their own. Teenagers who are just finding out that you are HIV-positive or they are HIV-positive may feel that you didn’t trust them enough to tell them. Try to reassure them it is not about trust, but rather not wanting them to worry too much.

Disclosing to children

While it can be extremely difficult to disclose HIV information to children, it is better to tell your children as early as you can, especially once they start asking questions. It is usually easier to tell the truth than try and cover up the diagnosis. Once children know, the family can start discussing things openly and dealing with the feelings that come up. The following tips may ease disclosure for you and your children:

- deal with your own feelings first. Gain control over your own emotions and learn to live with the diagnosis;
- build a strong parent-child relationship;
- seek out support for yourself from friends, social workers, counsellors and others both before and after disclosure;
- prepare by gathering HIV-related information, creating an appropriate environment and arranging supports for your children;
- find a time to disclose that is free from interruptions and appointments;
- try to be as relaxed as possible before the conversation begins. Your children might notice if you are feeling anxious, sad or angry;
- disclosure is a process. Even if your children do not react the way you hoped right away, with time, support and information, they may be more accepting;
- encourage your children to ask questions as they come up;
- give reassurance and hugs!

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Resources

Websites for parents and children living with HIV

- The Well Project (www.thewellproject.com)
- The Teresa Group (www.teresagroup.ca)
- Youth HIV Site (www.livepositive.ca/english/default.asp)

Pediatric Treatment Issues

Collection of articles and resources for families and children living with HIV (www.thebody.com/index/treat/children.html)

