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Talking with Your Children about Your HIV Status or Your Children's Status

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Table of Contents

- Letting Your Children Know You Are Living with HIV
- <u>Telling Children About Their HIV Status</u>
- Taking Care of Yourself

When you think about talking to your children about your HIV status or your children's status, you may feel many different emotions. It may help to discuss your feelings with someone you trust, such as a healthcare provider, counselor, family member, or friend. You may want to talk with that person about how and what you will say. You may also want to share your <u>disclosure</u> (telling someone) plans with those who already know your HIV status, so they will be prepared to give accurate, reassuring, calm responses if your children bring it up with them.

Remember what you already know about your family: 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 talk about your and your children's HIV status with other family members. While there may not be an exact best way to disclose, there are some steps you can take to prepare.

Letting Your Children Know You Are Living with HIV

Telling your children that you are living with HIV can be really hard. It can be helpful to prepare yourself by thinking about how your children will react and what they will want to know based on their age and maturity. You may also find it helpful to talk with other parents who have told their children about their HIV status.

If you are taking effective HIV drugs, it may be a good idea to explain to them about how well the drugs work, and that people can live long, full, healthy lives with HIV.

Your children will probably ask about your health. If you are taking effective HIV drugs, it may be a good idea to explain to them about how well the drugs work, and that people can live long, full, healthy lives with HIV. Parents who live with well-managed HIV can do all the same things that other parents who do not live with HIV do with their children. One of the main concerns that may come up during the discussion is what will happen to them if you get sick. Be prepared to provide reassurance that they will be taken care of if something happens to you. They may also find it reassuring to know how you will be cared for if you get sick. For more information, see our fact sheet on <u>Planning for the Future Care of Your Children in the US</u>.

Children may also want to know how you acquired HIV and if they might get it too. Depending on their ages, they will have different questions. They may not have any questions at all or ask questions later as they arise. Regardless of when they begin asking questions, it is best to provide them with honest responses based on facts. Telling them things that are not true can damage your relationship with your children and affect their trust in you.

If your children have already learned something about HIV at school or through the media, you can use that as a chance to build on and reinforce what they already know. Older children or teenagers sometimes learn about HIV in school. Regardless of their knowledge about HIV, children may already sense that something is going on. They may see you taking medications or going to your healthcare provider more often than some of their friends' parents. If your children already sense something, they may feel angry that you have kept this from them. Telling them may help them talk about HIV openly.

Let your children know whom they can talk to about your status, and tell them who else you have already told. Be prepared that they might feel disappointed or angry if a lot of people knew before they did. Your local HIV service organization (ASO) may have a children's or youth group where they can talk with others in similar situations. Your healthcare provider may also have a counselor who can talk with your children or who can facilitate and provide support during or after the discussion. To find ASOs and HIV services in your area, use <u>POZ's directory</u>.

Parenting and Disclosing to Kids: Living with HIV has its challenges and so does parenting. In this vulnerable episode of A Girl Like Me LIVE, three mothers living with HIV – host Ci Ci Covin and The Well Project CAB members leshia Scott and Destiny Smith – discuss how they talk to their children about HIV and their tips for other parents living with the diagnosis.

View other episodes in the <u>A Girl Like Me LIVE</u> series?

Telling Children About Their HIV Status

It is important that all children know they *cannot* transmit HIV to friends or family through casual contact

Before telling your child that he or she is living with HIV, think about why you want your child to know. Perhaps your child has been in the hospital, taking medications, or asking questions. Whatever your reason, make sure that you are okay with your child knowing. If it is not okay with you, your child may sense that, and find it more difficult to be okay with it her/himself.

It is important to have some HIV-related information ready before you begin talking. Look for materials that have an optimistic tone and are appropriate to your child's learning level. Children may want to know if they are going to die, how they acquired HIV, or if they will become sick. It is important to know in advance how you will answer these questions. Also, consider your own feelings about these concerns. You may choose to wait with the conversation until you get some emotional support or talk through the answers to these questions with a friend.

Children need different types and amounts of information depending on their age. Begin with some simple ideas that you think are most important. Very small children may be too young to be told the name of the disease or many details but try to be as honest as possible. You can tell them more and more in age-appropriate ways as they get older and can understand more details.

Young children need information mostly about things that affect them right now. School-aged kids may need some basic information about what to do if they bleed (all children should be taught that it is not a good idea to touch anyone's blood). Teenagers will require more information about <u>how HIV is</u> transmitted and how to prevent this from happening. It is important that all children know they *cannot* transmit HIV to friends or family through casual contact (e.g., hugging, kissing, using the same toilet).

Some US states require disclosure to healthcare providers before receiving services. This may mean that you have to tell a school nurse or pediatrician about your child's HIV status.

It may take some time for children to take in the information. Let your children know that they can always speak freely with you. It is important that your children see you as a trustworthy adult so they will feel comfortable coming to you with questions.

Your children may feel isolated, angry, scared, or depressed by knowing their HIV status. It may help if there is someone else with whom they can talk about HIV. Even before you tell your child that they are living with HIV, you can arrange a <u>support network</u> consisting of healthcare providers, trusted family and friends, and other parents with similar experiences.

While some countries' laws protect people living with HIV from <u>discrimination</u>, you may not want your children to let everyone know their HIV status. You can tell your children that HIV is a private family matter and that you will decide as a family whom to tell and how they should be told.

Your child is probably already seeing a doctor regularly who knows about their HIV status. However, their regular pediatrician or school nurse may not know. It may be a good idea to disclose the child's status to these healthcare professionals, but that is a decision you and your child need to make. Note: Some US states require disclosure to any healthcare provider before receiving services, even if the care provided is not related to HIV.

Taking Care of Yourself

While it can be extremely difficult to <u>disclose</u> information about HIV 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 to try to cover up the diagnosis. Once children are aware of their HIV diagnosis, the family can start discussing things openly and dealing with the feelings that may come up. Here are some tips that may help make disclosure easier for you and your children:

- Deal with your own feelings first. Understand your own emotions about living with the diagnosis (yours and/or theirs).
- Build a strong parent-child relationship
- Seek out support for yourself from friends, social workers, counselors, and others both before, during and after disclosure
- Prepare by gathering HIV-related information, creating an appropriate environment, and arranging support for your children
- Find a time to disclose that is free from interruptions and appointments
- Try to be as relaxed and positive as possible before the conversation begins. Even if you feel anxious or sad, being relaxed and OK with your own feelings can help your children trust you and be open to their own feelings.
- Disclosure is a process. It will likely involve several conversations. Even if your children do not respond the way you hoped right away, with time, support, and information, they may be more accepting.
- Know that your children may respond differently from what you are expecting. Understanding the HIV diagnosis may take some time, particularly with children. Continuously give them space, support and information; in due time, they may be more understanding and accepting.
- Encourage your children to ask questions as they come up.
- Give reassurance and hugs! And make sure you get some, too!

Additional Resources

Select the links below for additional material related to talking with your children about your HIV status or your children's status.

- Telling JJ: She's 10. She Has HIV. And She's about to Learn the Truth. (Washing...
- How Do I Tell My Kids I Have HIV? (plus magazine)
- How to Tell Your Child You Have HIV (Bhekisisa, South Africa)
- How Would You Tell Your Child They Are HIV-positive? (Health-E News)
- Telling Your Child You Have HIV (Speaking Up!)
- How, and When, Do You Tell a Child She is HIV-Positive? (Intrahealth Internatio...
- How to Dance, by Zvandiri and the Superband of Zimbabwe (PEPFAR; video)
- HIV Disclosure Improves Parent-Child Relationships (aidsmap)
- How to Talk About HIV With Your Child (Positive Peers)
- <u>Telling a Child He Has HIV (hesperian health guides)</u>
- <u>What Are Some Ways I Can Tell My Children I Have HIV? (US Office of Women's Hea...</u>



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