

HIV: Talking to Your Child

This handout offers guidelines and support to help you think about how and when to tell your child that she is living with HIV infection.

Telling your child that she is living with HIV infection can be a scary thought. Even parents who have already been through this process will tell you that it can be hard.

Some parents find that there are no “just right” times or ways to tell their child. Other parents have said it is helpful to:

- Start talking with your child early. Bring up a little at a time over time, such as why she visits the doctor often or takes medicine.
- Think of telling your child as a process, something that takes time and a number of talks.
- Be open to talk to your child any time and try to create a loving, caring and supportive atmosphere.
- Always be honest.

You may use the ideas from this handout to help you prepare. If you need more information, talk to your child’s health care provider or another trusted adult.

Why would I want to tell my child?

There are many good reasons to tell your child he is living with HIV infection. Some of the loving and caring reasons to tell your child include:

Building an open, warm and loving relationship with your child.

Often, children with HIV already know on

some level that they are sick. When parents don’t talk to them about their illness, they may become even more scared, feel lonelier or feel that they have done something wrong. Talking to your child about his HIV shows that you respect your child’s feelings and ability to be involved in his own care. Also, many parents say that telling their child helped their family feel closer,



stronger and more supportive of each other. Lots of parents have said that after the diagnosis was shared with their child that they felt a sense of relief, that a burden had been lifted.

Making sure the correct information is given.

Children may learn misinformation from friends, well-meaning adults and/or the media. You can make sure your child receives accurate information. To learn more, see our handout on *HIV Facts*.

Trusting the research that has been done.

Studies have shown that children who have been told about their HIV infection feel less lonely, scared and worried, and feel more supported and respected. Other studies have found that children who know their diagnosis have higher self-esteem, lower rates of infection and do a better job of taking their medicines.

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Helping to prevent the spread of HIV.

Talking with your child about his HIV status helps him have all of the information needed to not pass on the infection. Read our handouts on *HIV: Infection Control – Guidelines to prevent the spread of HIV*, *HIV: Talking to Your Child About Sex* and *HIV: Teens and Sex*.

Why can telling my child be so hard?

Telling your child about her HIV infection may be hard for some or all of these reasons:

- It is a painful and emotional issue for you.
- If you are infected, you may feel responsible for your child’s infection. It is important to know that no one ever wanted to infect her child. You didn’t intend for it to happen. And, like almost all parents, you love your child and want what’s best for her. You have to be able to face your own illness to help your child face hers.
- If you are infected, you may be concerned that telling your child means you are also telling about your own status. You may feel shame or guilt about past lifestyle choices. Keep in mind that you may choose which details of your past to tell your child and which ones to keep to yourself.
- You may fear that your child will be angry with you or with someone else.
- You may be filled with worry about how telling your child will impact her. Will it rob her of a “normal” childhood? Will it burden her? Will telling her force her to grow up too quickly? Will telling have a negative impact on her mental health?
- You may be worried that your child will tell others and be teased, shunned or discriminated against.
- You may fear that you won’t be able to tell her the “right” way or that you won’t be prepared for your child’s questions or reaction to the news.

- You may have natural feelings of wanting to protect your child. Sometimes we think we are protecting our child and helping her to feel safe by not talking about the tough topics. Instead, we are actually making it harder because our child feels alone and sad because she cannot talk about and ask questions about her illness. Any child seeing a doctor often and taking medicine every day *knows* that something is wrong.

What steps should I follow to prepare for talking with my child?

These steps may help you decide how and when to tell your child about living with HIV infection.

Step 1: Think about telling your child and decide if and how you will tell him.

- Telling is a process. It involves more than one talk.
- Part of telling your child is that *you* need to be ready to share the information and to figure out *when* your child is ready to hear *what* information.
- Think about whether you want your child to keep information private and if he will be able to do so.
- Talk with your child’s doctor, nurse or social worker beforehand. They will support you and help you in any way that they can.
- It may help you to talk with other parents who have already told their child. Your child’s doctor, nurse or social worker can help you make this connection.

Step 2: Plan what to say and prepare for questions.

- Tune in to your child’s level of understanding. This will help you know what approach to take and which words to use.
- Prepare for questions. Think about what your child may ask and think of answers ahead of time. For example, he may ask:

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- How did you get it?
- How did I get it?
- What is HIV/AIDS?
- Why do you have it?
- Why do I have it?
- Am I going to get better?
- When can I stop taking my medicine?
- Did you or I do something bad to get it?
- Who can I tell?
- Who else has it?
- Are you going to die?
- Am I going to die?
- If your child does not ask many questions, it does not mean that he is not interested.
- At younger ages, you do not have to use the words HIV or AIDS. You can be truthful without telling every detail.
- Think about who your child can talk with about his HIV infection.
- You may want to practice your first talk with your child's nurse or social worker.
- Read our handout on *HIV Facts* for some concrete facts to tell your child.
- There is no "formula" for what to say at what age. The next section of this handout, "What words might I use based on my child's age?" offers some guidelines.

Step 3: Plan the first talk.

- Choose a time to talk that is good for you and your child. Allow plenty of time for talking, as it may take five minutes or it may take an hour or more.
- Find a good place to talk. You may prefer a place that is familiar, comfortable, safe, private and that has few distractions.
- Think about your approach. It is important that your child know that this is a two-way conversation in which he can ask questions.
- While it's good to have a plan, sometimes it turns out that the best time and plan just happens because your child asks you a question. So sometimes telling is unplanned. And it's best to just go with it, rather than fumble through by telling lies.
- It is best if you and your partner or your child's other caregivers talk to your child alone. If you need help, ask your child's doctor or nurse to help you.
- Be sure to avoid talking to your child about this sensitive topic when you are angry or in a time of crisis.

Step 4: Having the first talk.

- Help your child feel safe, loved, cared for and listened to.
- One idea is to start by building on a past talk. For example, say: "Do you recall when I told you that you had a germ in your body? Well, that germ is called HIV." Ask your child what he remembers about that talk. If it is correct, then you can add more specific information.
- Follow your child's lead to decide how much detail to provide. Some children want lots of details, while others want very few.
- Ask your child what he knows about HIV and correct any misinformation.
- Encourage your child to ask questions. Listen to what your child is thinking and feeling. This can help you know what to say or guide future talks.
- Assure your child that it is not his fault that he has HIV or that his mom or dad has it.
- Tell your child who he *is* allowed to talk to about HIV/AIDS. If you would like him to keep this information private, be sure to tell him.

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- Ask your child to tell you what he just learned. With this approach, misconceptions can be cleared up right away.
- Give hope for the future and leave the door open for more talks and questions.

Step 5: Follow-up and future talks.

- Because talking to your child about HIV is a process, your child will have different questions and concerns as he grows up.
- Offer to help your child think about ways to deal with questions, concerns and comments from his peers. He may want to practice talking to his peers with you first.
- Your child may want to keep a journal or diary or write letters about his thoughts and feelings. Many people say that writing things down helps them sort through their feelings and deal with their problems in a positive way.

What words might I use based on my child's age?

It helps to understand the process as it relates to all ages. It's never too late to start. For example, if your child is school-aged, it may be helpful to review what younger children need to know in case you need to fill in any gaps. And it may be helpful to read the sections about what pre-teens and teens need to know so you can plan ahead.

For children ages 3 to 4:

- In general, for younger children, keep it simple, yet honest.
- Your child may begin to ask why she needs to go to the doctor or clinic, have procedures done or take medicine. Give brief answers. For example, explain that there is a "germ in your blood" and that "you can get sick more easily than other kids, so we need to visit the doctor often to keep you healthy." Or, "The doctor needs to take your blood so she can look at it."
- Simple statements usually meet the needs of a curious preschooler.

- Your child does not need to hear the words HIV or AIDS. If you choose to say HIV, be aware that your child may repeat what you said and/or tell others. Children at this age are not able to keep private information private.

For children ages 5 to 7:

- It is also hard for children this age to keep information private. You may want to give more information about the disease without using the term HIV if you want her to keep HIV private from some people.
- You may want to say this to help explain HIV to your child: "The germ fighters in your blood do not work as well as they should so you get sick more easily than other children."
- If you wish to use the term HIV, you could say: "HIV is a disease that is caused by a tiny germ called a virus. In people who do not have HIV, their bodies fight off diseases, like a superhero fighting the enemy or bad guys. With HIV, your body can't fight diseases well, sort of like a tired superhero. You can get sick more easily and it's harder to feel better."

For children ages 8 to 13:

- This is a good age range for telling your child all about HIV and using the words HIV and AIDS. Children at this age are more capable of keeping information private. They can understand more detailed information about HIV and AIDS.
- You may want to say: "Having HIV is something private and something that you can decide about telling others. You don't have to tell other people if you don't want to. On the other hand, it is OK to tell people who may need to know, such as a teacher or school nurse. HIV is nothing to be ashamed of."

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For teens:

- If your teen does not already know that she is living with HIV infection, *now* is the time to talk about it. She needs to know about her infection. Use the guidelines in this handout and talk to your teen's doctor or nurse if you need help telling your teen about her HIV infection.
- You may want to say: "You have the HIV virus. You have the power to control the virus by taking your medicine every day. Knowing about HIV and having it in your blood gives you a special responsibility to not pass the virus to other people." Explain how to prevent the spread of the virus based on your teen's current risk situation and sexual maturity. See our handout on *HIV: Teens and Sex*.
- You may also want to say: "You can live a full life with loving, sexual relationships. Having HIV means that you need to plan carefully about your future with others so that you can make good decisions about your safety and the welfare of others."
- Some teens with HIV have found that living with the virus gives them a special kind of strength — to educate others about HIV, to prevent the spread of the virus and to change people's misinformation and prejudices. Some teens decide to use their HIV status to make a positive difference in other people's lives.
- Some children ask lots of questions; others may not ask any; most will have questions in the future. Do what you can to make sure your child knows that he can come to you with questions he may have later.
- Your child may not appear to care or to have even heard you. He may choose to be quiet for a time to think about what you have talked about and then come back at a later time to talk more.

How do I tell my child's brothers and sisters?

- Follow the same steps outlined in this handout. Keep in mind that telling is a process. As you would for any child, show love and offer support. Be open to questions and talk about keeping information private. Reassure your child and speak of hope.
- Each child will respond in a different way. That's OK. Let each child respond in her own way and in her own time.
- It is probably best if brothers and sisters are told about their sibling's infection if your child living with HIV receives a lot of attention due to her illness. Your other child or children may want to know why they are not getting the same type or amount of attention.
- Telling is a process, and it can be hard. See the resources listed on the next page and feel free to talk to your child's doctor, nurse or social worker about any questions or concerns.

*(Continued on next page)***How might my child react?**

- Each child is unique. Children react to the news differently based on their age, level of understanding, how much you have told them, how much they already know and many other factors.
- Your child may be sad, angry, scared, relieved or curious.

FOR MORE INFORMATION

- Your child's health care provider
- Visit these Web sites:
 - www.kidshealth.org
 - www.seattlechildrens.org
- Read our handouts on:
 - *HIV: Children 0 to 2 years old*
 - *HIV: Children 3 to 4 years old*
 - *HIV: Children 5 to 7 years old*
 - *HIV: Children 8 to 10 years old*
 - *HIV: Children 11 to 13 years old*
 - *HIV: Teens*
 - *HIV: Helping Children Understand the End of Life*

References used to prepare this handout include:

- FXB Worldwide – www.fxbcenter.org
- ICAP Pediatric Clinical Manual
- Pkids' News – www.pkids.org
- *Pocket Guide* published by Pediatric AIDS Clinical Trial Group
- Francois-Xavier Bagnoud Center at University of Medicine and Dentistry of New Jersey

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Disclaimer: The inclusion of any Web site link (or resource accessed through a link) does not imply endorsement by Children's Hospital and Regional Medical Center. Seek the advice of your child's health care provider before you act or rely upon any information from these resources.

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