



CHAPTER 5

Talking with children about HIV

Talking with your child about HIV can be difficult for many reasons. It is understandable to want to protect children from worries. And some topics connected with HIV, such as sex and death, commonly are not discussed with children – or talked about much at all! So it can be hard to even begin the conversation. And talking with your child about HIV can mean answering a lot of questions.



Why knowing is good for a child

Children who know they are HIV-positive are usually healthier and take better care of themselves as they grow older than children who do not know about their HIV. Children who understand a little about their HIV are often more willing to eat healthy food and take medications every day.

Children who know about a parent's HIV, or that someone else they are close to has HIV, understand why that person might need more food or is sometimes tired or ill. And they may be able to learn ways to help, such as reminding the person to take their medicine.

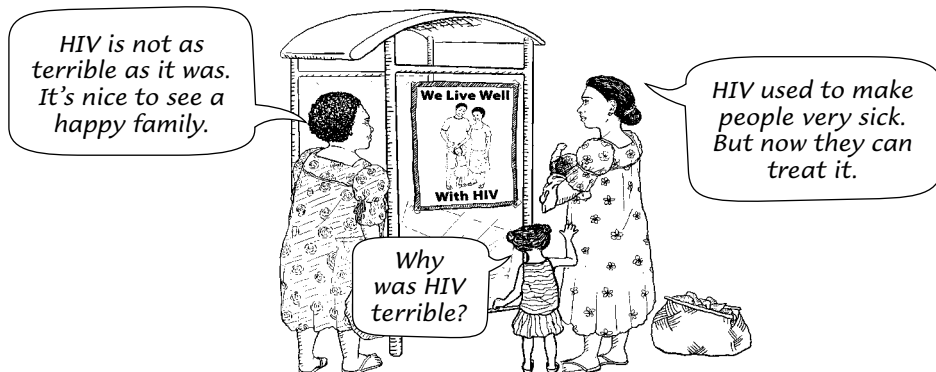




Children can usually tell if something is wrong in their family, and will worry about what it is. Children who are not told about HIV will search for other reasons why someone is ill or gone, and they may blame themselves. Children who learn their HIV status (or that of a family member) from a sibling or neighbor often do not get the full information and support they need. Worry and other feelings can affect a child's relationships with friends and family, and cause him to behave badly or get into trouble.

A child who understands HIV also may protect herself better from infection later on when she is exposed to sex or other ways HIV spreads.

Talking with all children about HIV is important for fighting stigma, especially in communities where there is a lot of HIV. You may need to explain how illness can happen to anyone, or why it is wrong to blame people or avoid them because they are sick.



Children do not learn about HIV all at once, especially small children who cannot fully understand HIV. You may feel so afraid of disclosing your HIV status — or your child's — to her that you wait too long to do it. It is better to think of disclosure as many conversations that happen over a period of time. At first, explain as much as your child is able to understand. As she grows, learns, and matures, you can tell her more.

Teaching a child from birth to 3 years old about HIV

Babies and small children cannot understand HIV, illness or death. But there are ways you can begin to make your home a safe place to talk about HIV, even for small children.

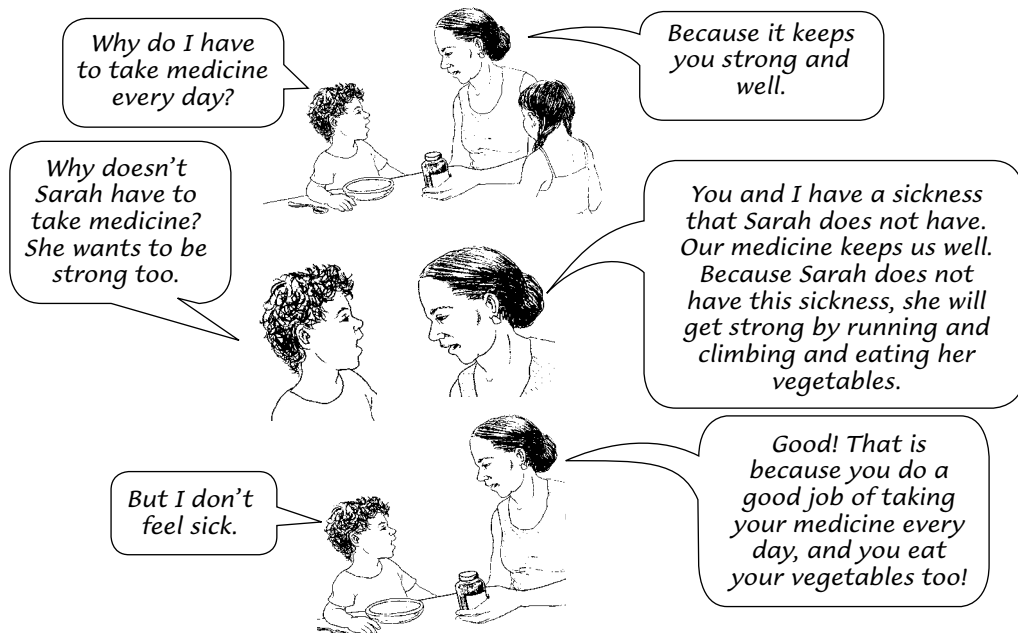
- Talk about medicines and be open about illness in the home. This can make taking medicine a normal part of life for children, even if they cannot understand what medicine does.
- Take your baby with you to the clinic and to community events about HIV.

Teaching a child from 3 to 5 years old about HIV

Children this age cannot understand HIV, but they can begin to understand illness. You can talk with them about avoiding germs and illness as you teach them to wash their hands before eating and after using the toilet.

Starting at about 4 years old, children can compare things that are different. They notice if they or someone in their family goes to the clinic more often than other people. They may wonder why they take medicine and others do not.

Young children can be told they (or others) have an illness, without saying it is HIV or explaining much more. Caregivers and health workers usually do not tell a child he has HIV until he is older and can understand better, including how and why to keep information private.



Teaching a child from 5 to 8 years old about HIV

Children this age are able to understand more about illness, death, and how our bodies work. They most likely have heard about HIV and AIDS, and perhaps ART, or medicine that people with HIV take every day.

When you teach children about HIV, tell them the truth about the virus and how it is spread, in simple ways they can understand. This level of understanding can help them protect and care for themselves and be more willing to take medicines.

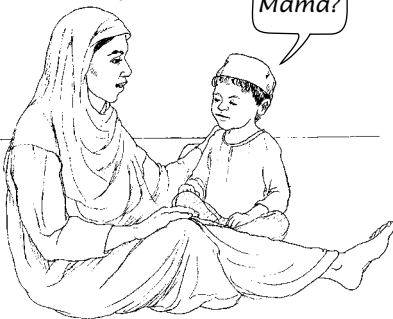
Sometimes children this age who are HIV positive are not yet told they have HIV by name, but rather that they have a sickness in their blood. They may have seen or experienced stigma and can understand why HIV is often kept private.

Children this age can learn that you do not get HIV from hugs, bad luck, sharing food or toilets, being near someone with HIV, or witchcraft. Growing up in a home where HIV and medicine are a normal part of everyday life makes this easier.

A little germ

Yesterday you asked me how long you must take medicine.

Yes Mama?



I want to tell you more about why your medicine is so important.

You have something in your blood that can make you weak and ill if you do not take your medicine. It is a little germ and it weakens and tries to destroy the part of our blood that protects us from illness.

Everyone has protectors in their blood. The protectors fight any germs that get inside you. This is how we stay healthy. Most people have lots of these protectors inside them. But you and I have this little germ that harms our protectors.

Our medicine makes this little germ go to sleep. But it cannot get rid of the germ completely. So we must take our medicine every day. When we do, we have many strong protectors in our blood. What do you think about that?

Aunt Salima and your teacher know about this too, so you can talk to them about it. But other people do not understand about this germ in our blood. So it's better to speak only to Salima, Teacher Tang, or me about your medicine. OK?

As children get older and start school, keep talking to them about HIV, about how it does and does not spread, how to stay healthy, and about the harm of stigma and what children can do to fight against it.

See Chapter 1 for more basic information about HIV, and pages 16 and 70 for more about stigma.

No, HIV cannot spread in food. You boys can all eat together and get big and strong.



Teaching older children about HIV

As your child matures, you can explain more about how HIV affects the person who has it, how someone with HIV can stay healthy, how HIV spreads through sex, and how people can protect others from becoming infected.

Talking about HIV can be difficult, and talking with young people about sex can be even more difficult. If you have a strong and honest relationship with your child, these conversations will be easier. One way to have conversations with children is to read stories or news articles together, listen to the radio, or watch videos that talk about HIV. Personal stories about living with HIV or struggling to disclose to someone else are engaging and offer a lot to discuss.

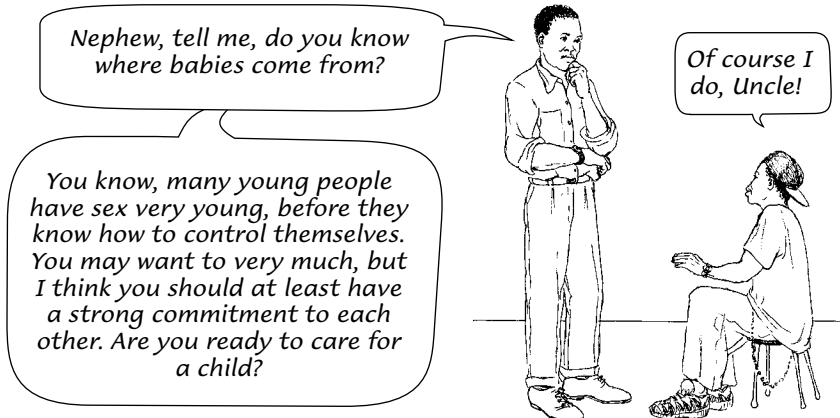
In the past, another family member, such as an uncle or aunt, was often responsible for discussing sex with a young relative. This is not common now, though asking a counselor or health worker to talk with your child may help her. Young people need to prepare for the challenges they will face as young adults living with HIV, such as learning to care for themselves at school, pressure to have sex, and fear of rejection from friends and teachers.

The girls on my road said that only prostitutes have HIV. They said I was dirty!



Oh, Sika. I am so sorry they made you feel bad. You know what they said is not true. Many people in our community have HIV, and they have gotten it different ways — anyone can get HIV. Those girls were just being mean and ignorant!

When talking to a child or young person about sex, it is important to be honest, even if you are uncomfortable. If you speak untruthfully, and the child eventually learns the truth, they may not trust what you say to them in the future. Young people need accurate information about sex, relationships, and their health if they are to become healthy and responsible adults. You may feel it is important for them to wait before having sex. If so, try to explain why in ways they will understand.



If you do not know an answer to one of your child's questions, tell him that you do not know. It is OK to ask for help from a nurse or someone at the clinic.

Let your child ask whatever questions he may have. Try to not react with embarrassment, judgment, or anger. If your conversation is difficult, you can suggest another adult they can talk to about sex.

Support older children to become more independent. Explain their medications and help them be responsible for taking their pills. Children ages 13 to 18 go through many intense changes and often need help developing systems to remember to take daily medicines.



Encourage young people to talk with their health worker about their medicines or lab tests so they can learn how to take care of themselves.

You may need to help your child decide whether to tell a friend or teacher about her HIV status. Help her think about if this person needs to know, and if the person is trustworthy. Discuss what might happen if the person tells others. Your child needs to learn to make these decisions on her own, and you can help her by having her think through the steps of making a decision.

Telling a child he has HIV

Telling a child about his HIV status — or yours — is called disclosure. Children younger than 5 years old are not usually told about HIV by name because they are too young to understand. But no matter how old a child is, you can try to have more open communication. By doing this, you lay a good foundation for disclosure later.

Fears about disclosure

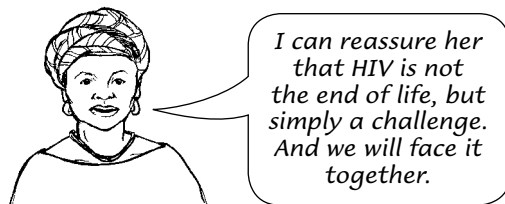
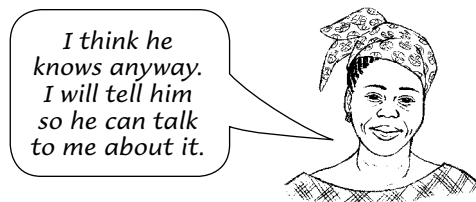
Most parents and caregivers fear telling a child he has HIV. They worry about how the child will feel. They worry about difficult questions the child may ask. They fear the child will tell others. Disclosing HIV can bring up feelings of guilt and shame if a parent blames herself for the fact that she and her child have HIV.

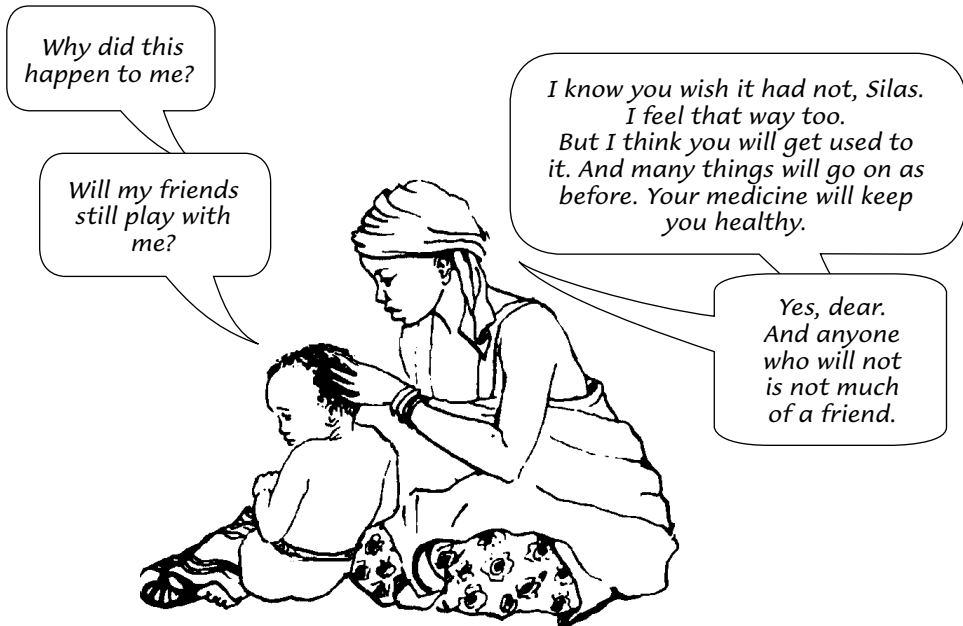
Parents may already worry for their child's future: Will he be teased or rejected in school? Will he be ill or weak? Will he die while still young? Parents and caregivers may also fear thinking about their own illness and death. All these reasons can delay people telling a child he has HIV.

Telling a child someone in his family has HIV can also be difficult. Some parents and caregivers worry that their child will become depressed and worry too much. Some fear they will be rejected by their children.



What helps parents disclose





When they first learn they have HIV, children may have some of the feelings you fear. But most children are able to accept this news, especially if you are willing to accept their feelings, can be calm and strong yourself, and answer their questions patiently and honestly. Most parents feel a huge sense of relief once they have disclosed their HIV to their child.

Only you can decide when you and your child are ready to talk about HIV. Some children are very mature and curious and will seem ready to discuss HIV at a young age. For other children, you may feel that you should wait until they are older. But keep in mind that, usually, children are ready to learn about their HIV sooner than you think.

Many children who learn they have HIV when they are older wish they had been told earlier.



How to tell a child she has HIV

When preparing to tell a child about his HIV, here are some things to do or think about:

- How will you answer questions the child may ask? Think about the difficult questions, and what you can say. Consider how much your child can understand, and how you can be both honest and comfortable with your answers.



If he asks how he got it, I will say I was infected while I was pregnant and did not know it.

- Thinking through your own feelings about HIV and illness in your family will help you accept your child's feelings. It is common for a caregiver to feel guilt, fear for a child's future, and sadness or anger. First talk to others you trust to get your own support.

I feel so guilty sometimes! I know my child has HIV from me. I am sure she will hate me!

Sarah, I felt the same way. My son was very depressed when I first told him. But now he knows and we help each other stay well and positive about the future.



- Practice what you will say with someone.

I will pretend to be your daughter. How will you start?

I was thinking of saying "Remember when you asked me why you have to take medicines, and I said you had a problem in your blood? Well the problem is a virus. And the virus is called HIV."

That sounds good. What if she says "How did I get it?" What will you say?



- Make sure you have a good, private place to speak with your child. Set aside enough time for the child to take in and react to what you say, and for you to answer the child's questions.

Now that we are going home, let us talk. I have something to tell you.



Papa, I don't understand. How did something get into my blood? What about my brother? Does he have it too?



- Listen and let the child's questions guide you.
- Help children know they are not alone. Tell them there are many other children like them who have HIV and are living with it.

- Respond to their reaction, no matter what it is, with as much patience, honesty, love, and acceptance as possible.



Sometimes a child will be silent, sometimes he will be angry, or sometimes he will have lots of questions. Very often a child will act as though nothing has happened, but later his mood will change to sadness or fear. Remember that talking about HIV will continue over many years and your child may react differently each time HIV is discussed.

- Stay hopeful when you talk about HIV.

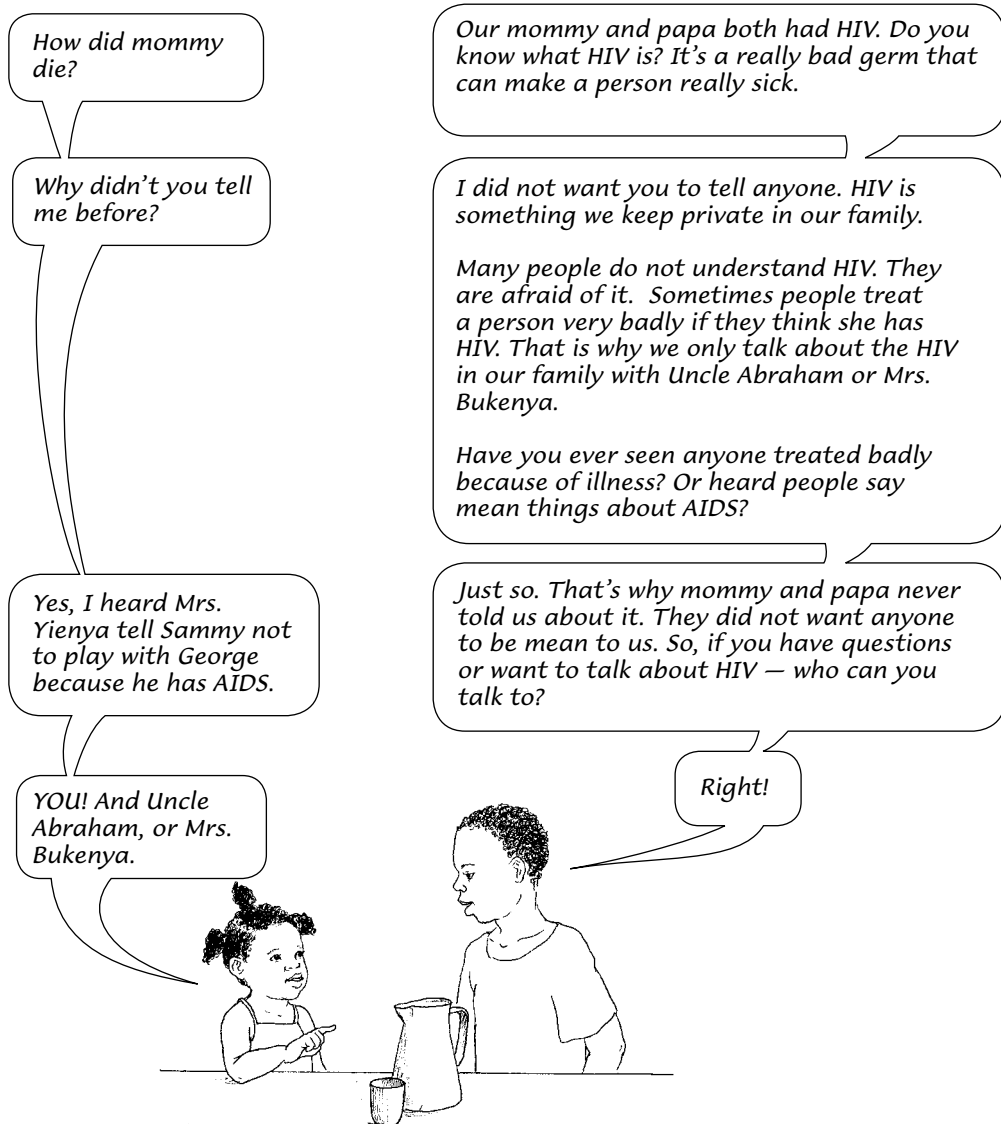


Talking about stigma and privacy

Even though you may have taught your child to tell the truth and not keep things from you, you will also need to teach your child that HIV is something she can only talk about with certain people. Talk to your child about how sometimes HIV is a private matter. Explain that HIV is not something to talk to all her friends about. As your child gets older, you can help her decide when a friend or teacher at school might be a trusted person that she can disclose to.

It helps children to have more than one adult to talk with about their HIV. This could be a family member, a friend, a counselor, or a trusted neighbor.

Sometimes children can talk more freely at an HIV support group.

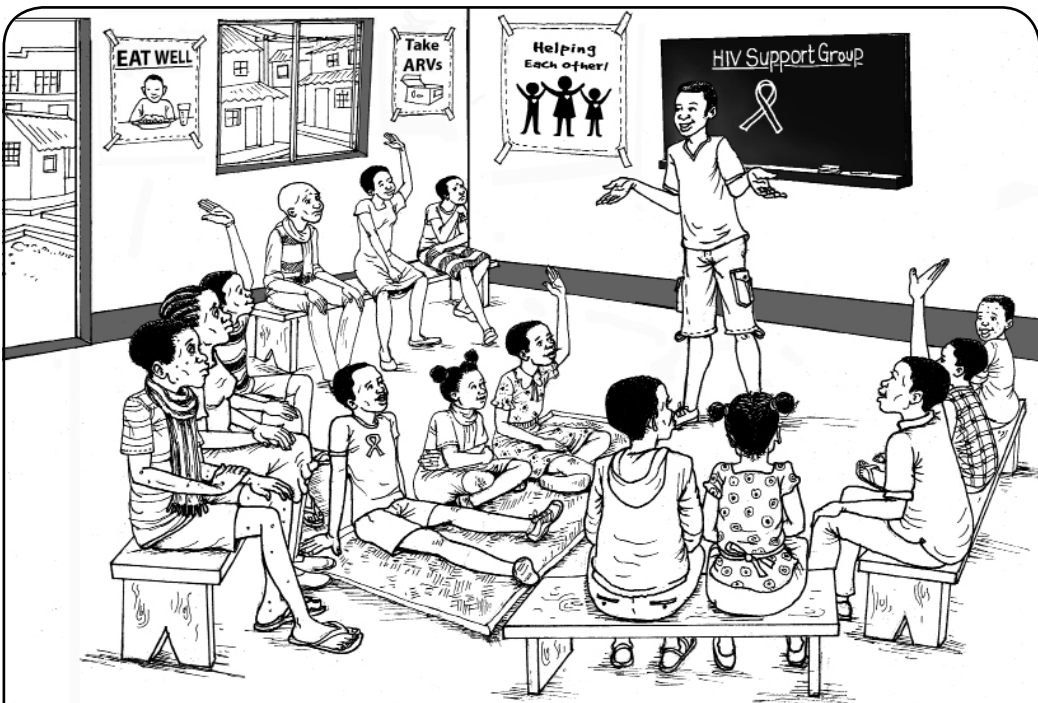


Ongoing support for children

A child of any age may already know she is sick or that there is a problem in her blood, and still react strongly when she learns it is HIV. After finding out she is HIV positive, a child will usually go through stages, from shock and fear to sadness and acceptance. These reactions are similar to those of an adult but can be stronger and less predictable in children. You may need to repeat information and answers to questions, especially for a younger child. Remind children they are not alone, and find other supportive adults for them to talk to.

Most children learn to cope with the worry and pain that come with HIV infection and any problems from the medicines that treat HIV.

Find other children with HIV or who live in families with HIV for you and your children to talk to and play with. There may be children's programs or support groups at HIV clinics. If your clinic does not have one, start your own. See page 286 for more on starting support groups, and pages 181 and 293 for more examples of children providing support for each other.



Zvandiri (which means “as I am” in Shona) is an HIV and AIDS support group in Harare, Zimbabwe. Children ages 8 to 18 participate to share their experiences with HIV and how to live with it. The group helps them feel less alone and have hope for the future.