CHAPTER 3
Communicating with Children and Talking about HIV

Children who feel listened to and understood are happier and healthier. When your baby cries and you respond, this helps him feel loved and secure. Feeling secure helps him grow and learn well. As children get older, we need to listen and explain things to them, answer their questions, comfort them, and help them express their ideas and feelings. If we do, their health, learning, and cooperation will all be better.

Good communication is especially helpful for children affected by HIV because they experience things other children may not. Children need help coping with experiences such as the loss of a parent, being ill, taking medicines, or unfair treatment because of stigma. Communication is one way we help children know they matter, understand what happens, and feel less alone.

HIV changes the lives of caregivers and families. Illness, fear, grief, worsening poverty, anger, depression, and the isolation and shame from stigma can all make paying attention to children and communicating well with them more difficult. But simple ways of reaching out for help can make a difference.
How we communicate
Communication is a two-way action. Someone sends a message, and someone else receives and understands the message, and responds, if needed.

We use our whole body to communicate
Wherever we live, we have a language we speak (sometimes more than one). As children listen and grow, they first learn their local, family language. But we also say a lot with our hands and what we do with our bodies (body language), and by how our faces look. We also communicate through sounds, touch, and action, especially our actions toward each other.

Babies and young children communicate more using their bodies and actions than with words. To understand a child, watch her carefully:

- What does her face look like? Is she crying, smiling, afraid, or curious?

- How does she hold her body? Is it tense or relaxed? Is her energy active, wild, quiet, nervous, or weak?

- How does she respond to others? Who or what does she watch? Does she hold her arms out to someone, or push something away? Does she move into a group or does she hide?
Children are very sensitive to the body language of the people around them. You may communicate things you do not mean to if you talk loudly or harshly to a young child, or if your face looks worried or angry as you care for him.

• To communicate well with a child, get down at his level and speak gently with him.

Children learn to communicate in stages

As with learning other skills, babies and children learn to communicate in stages. Simple skills lead to more abilities to communicate.

In the first 3 years child’s ability to communicate usually develops through these stages:

• Shows needs through body movements, looks on the face and crying, and begins to make happy sounds

  
birth to 3 months

• Babbles—listens to sounds and tries to imitate them

  
4 to 8 months

• Says a few words and uses gestures

  
9 to 12 months

• begins to put words (and ideas) together

  
1 to 3 years

No, nothing is wrong.

You can be Auntie’s big helper.
As a child grows, and sees and hears language being used in daily life, her understanding of language and her ability to express her thoughts and feelings grows too.

A child who cannot hear well needs extra help to learn how to use things he can see to communicate, such as signs made with the hands and watching people's lips. If he is to develop well, his family must learn to communicate with him in the way he can best understand. See *Helping Children Who Are Deaf*.

**Communicating with children as they grow**

**Babies from birth to 1**

Babies communicate as soon as they are born, though they do not know they are doing so. A baby cries, moves his body, smiles, gurgles and makes other sounds. These tell you he is hungry, sleepy, wet, uncomfortable, or not feeling well, or that he is happy or curious. As you care for your baby, his sounds and movements tell you about his needs.

*What could be wrong?*

*His diaper is dry, he just woke up and I fed him. Is he sick again?*

*She loves this game.*

When you think you know what your baby is telling you, and respond by giving her what she needs, you are communicating. If the first thing you try does not help, try something else. All this teaches a baby that her communication can make something happen, and she will want to keep exploring how to do it.
Activities to help your baby

- Sing or talk to your baby while you work or care for her. Respond to your baby’s noises when she babbles at you.

- Play with your baby and talk about what you are doing.

- Ask others to hold, play with, and talk to your baby.
Problems responding to your baby’s needs

Sometimes your baby may need something you cannot give him. He may be sick, and you cannot make his pain go away, or he may miss someone who has gone and you cannot bring the person back. Holding your baby, walking with him, and speaking or singing softly to him usually helps soothe him, even if you cannot fix his main problem.

Babies around 2 to 4 months old sometimes cry and cry and nothing seems to help. When this happens, mothers may fear the baby is crying because they do not have enough milk. This is almost never true. Most babies cry more at this age, and as another month or 2 passes they cry less. No one knows why. Walking, rocking, or sitting with your baby will comfort him, even as he cries.

If you are ill yourself, you may feel worried or low, or suffer from pain, itching, or tiredness. These can make it difficult to have the patience you need to respond over and over to a baby. Try to find support from others so you can rest each day, or do something that gives you pleasure. An HIV-positive mothers group can help you solve problems and feel less alone.

Sores in the mouth, common with HIV infection, can make talking and communication more difficult for both children and caregivers. See page XXX for how to treat and soothe mouth sores.
Children from age 1 to 3

Children these ages find it difficult to understand and trust unfamiliar people. So they do best and communicate more easily if they and their caregivers know each other well.

By talking with and listening to their close caregivers and others, children age 1 to 3 learn to understand and start to use at least 500 words.

But even as they talk more, watch how they look and act. This is still the main way they show how they feel and what they need.

Children who lose loved ones show grief in many ways. See Chapter 4.

Young children understand a lot of what is going on around them, even if they do not understand all the words people say.
Activities to help your child

- Tell children stories and sing songs with them.
- Talk about what you do as you care for them, or what you see as you go places, and encourage others to do so as well.

- Play games that have some back and forth between you.
- Encourage older children to talk and play with your child.

Keesha is talking more and more. You can help her, by using more words. Don’t worry about correcting her. She will soon speak very well.

What’s this Keesha? Can you say spoon?
Problems understanding your child

Sometimes you will not know what your child is trying to say, either with words or actions. You might be a new caregiver and not know the child well. And sometimes a child may be trying to communicate in a new way or about a new need. Do your best to guess, and try different things to help the child. The most important thing is that you keep listening, watching, and trying to respond with love and patience.

I wish Mom was here to help. She always knew what you wanted. You have been fussy all day! Are you hungry?

What do you want Kofi?

You just slept, so you cannot be tired.

Maybe you are just missing Mom like me. I could sing you the song Mom used to sing to us.

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Comm. Children as they grow
Sores in the mouth and ear infections can affect both speech and hearing for children these ages, especially those with HIV. For how to care for problems in the mouth and ears, see Chapter 9.

Between ages 1 and 3 is a good time to make sure your child can hear.

- Check to see whether or not she turns her head toward a sound whose source she cannot see.

For more about finding out how much a child can hear, and what to do if she cannot, see *Helping Children Who Are Deaf*.

If you are ill yourself, or caring for too many children, you will be better able to manage if you can get help. Keeping young children safe, clean and fed while they explore and learn can exhaust even a healthy caregiver with lots of energy.

A friend or neighbor may be able to watch the children sometimes. Or a helper from an HIV support organization might visit regularly to see how you and your children are doing. He or she may be able to help you with problems like not having enough food, getting to the clinic, or how to help a child who wets the bed or has nightmares.

If you can join an HIV-positive mothers’ group, other mothers may be able to help you understand your child or find some household help.
Children age 3 to 5

Children these ages are learning to understand and communicate more and more. Most children learn and can use about 2000 words by age 5—and they prove it by asking a lot of questions! A child learns best when her family and others include her in activities of daily life, listen to her with interest, answer her questions, and talk with her freely. Keep hugging and holding children these ages close, to communicate love and acceptance without words.

Activities to help your child

- Draw with your child, and ask him to tell you about his picture.

- Spend time with friends who ask children riddles and questions. Let children tell parts of stories they know well.

- Let children play together.

- Take children out with you and introduce them to others. Let them listen and talk.
Use good communication yourself. When adults and older children can talk about their feelings and show how to listen well, it helps young children see how to do these things.

**Problems understanding your child**

Children ages 3 to 5 become more aware of problems in the family, and they sometimes worry they are responsible. These years are sometimes called a time of “magical thinking” because children often believe they can make something happen with their own thoughts or actions. If they feel guilty or worried, we need to reassure them they did not cause bad things to happen.

Children may become quiet or withdrawn if they are worried or sad. Think about what may make a child quiet or stay apart from other children. Gently talk to him about what you think may be on his mind. Show you accept the child’s feelings, and let the child answer in his own way. Do not hurry the child if you ask a question.
There may be reasons a child is upset that you can do nothing about. Even so, if he can let his feelings out it can help him feel better, especially when you show him you understand and accept his feelings.

- If a child cannot talk directly about what he is feeling, he may be able to express it by drawing or play-acting.

*What if the Mama goes away?*

*Now the children fight because there is no Mama to stop them.*

- Pretending to be someone else allows children to communicate feelings and ideas they might find too difficult otherwise. Sometimes “play” can be very serious.

*And then she ate the magic pill and she wasn’t sick anymore.*

Another way to help children express themselves is by telling a story. With a story, you can explore a child’s problems without using real names. Or use animals in place of people. Talk with the child about the story as you tell it or afterwards.

See the story on the next page.
The 2 Lion Cubs

Papa and William were walking to the store. William had been fighting with his brother and he would not talk and just kicked rocks on the road. They walked in silence for some time and then Papa began to tell a story.

In this pride there were many cubs including 2 brothers, Abas and Abdulla, who were very close in age and had the same mother. The 2 brothers played together and laughed and splashed in the river and rolled in the tall grass. And sometimes they would fight. When they fought they scratched each other with their claws, and how they would roar!

One day they had a big fight and scratched and roared until their mother came and told them to stop. Abas, the younger, ran and hid behind a rock. After awhile, the mother lion came and sat with him.

The mother lion listened as Abas talked about his brother. Finally, she asked ‘How do you feel when your brother says these things?’ ‘MAD! Really mad!’ His mother then said ‘Well, Abas, that would make me mad too. Have you told Abdulla how mad it makes you? He is your brother and he loves you. Sometimes what is a funny joke to a big brother is not very funny to a little brother. Would you like me to help you speak to Abdulla?’

Papa and William talked for a while. William told Papa about things that make him mad. And he told Papa about some things he does to make his brother mad too. Soon William was done talking, was not so angry any more, and ran ahead to play.
Use puppets to learn about feelings

To help young children have more words to describe and understand feelings, try using puppets. To make paper puppets, you need something to draw with, paper, scissors, sticks, and glue. Sit with your child and ask her to draw a person who is sad, a person who is happy, a person who is angry, and a person who is afraid. After the drawings are done, talk about them with the child. How do you know a person is happy? How does a sad person act? What does an angry person do? When do we have these feelings? Cut out each “person” and glue it to a stick. Then see if your child wants to make up a story using her new puppets.

Work with your community to set up a preschool

When caregivers are ill or must work away from home, children may not get the attention they need.

Preschools (also called nursery schools or creches), are places where children ages 3 to 5 can play with each other and be supported by adults who talk with and encourage them. Teachers can plan games and activities for the children, and caregivers can work and not worry about their children.

By providing meals, nursery schools can also help children get enough to eat.

If young children can go to a preschool, older girls may be able to stay in school longer.

Sometimes several families share the care of their children by setting up a cooperative daycare, where each family takes turns minding the children. A basket of toys can move with them from house to house.
Children ages 5 to 8

Children ages 5 to 8 are more able than younger children to think, talk, and remember. They usually want to know more about everything that happens around them, and want people they trust to talk with them. They can do more for themselves, but they still need love and support from a main caregiver.

Many children these ages affected by HIV want to know more about illness in the family, taking medicines, and why other people will or will not talk to them or include them in activities. They may be upset about things that happen to them or their family, and be angry, sad, worried, fearful or frustrated. Talking with them about why they are upset can help. For ways to talk to children these ages about HIV, see page 27.

Activities to help your child

• Spend time together, and show interest in what the child says and does.

• Show your child how to make or do things, and give him opportunities to help you and others. Recognize his abilities.

• Encourage your child to have fun and play games with friends.

• Help your child find ways to let out her feelings, like drawing, music, games or other activities.

• Work together with children and others to build a playground, or plant and tend a vegetable garden.

• Encourage your child to go to school.
Problems responding to your child

Many caregivers worry they will not know how to respond to a child who is upset.

This is why we often say “Don’t cry, everything will be fine” to a crying child. But children need to know their feelings are normal and nothing to be ashamed of. Children are comforted simply when an adult stays with them while they cry, perhaps rubbing the child’s back softly. Try to accept a child’s feelings and reactions, rather than making light of them or urging them away.

If you are ill, or struggling with some of the same problems and feelings your child has, you may need support in order to talk with your child openly about his feelings. Your child’s painful feelings or worries might bring up your own sadness, anger, guilt, or worries. Try to talk to a friend or counselor about this.

It is fine to be sad along with your child. When a child sees an adult who has painful feelings and has learned to cope with them, this can help the child.
When children behave badly

All young children are difficult at times. Babies are too young to know any better. Babies want things right away, throw and break things, hit others, cry, and wet their clothes. They need to learn to wait, to handle some things carefully, to use words, and use a toilet. Learning these things takes time, and requires a lot of patience from caregivers. This is why it helps to share the work of caring for a child younger than 4 or 5. Few people can be patient with a small child all the time!

When children older than babies are behaving badly, it can be hard to remember they are not able to behave differently at that moment. They are overwhelmed by feelings they do not know how to handle or communicate in other ways. Although their behavior may make you angry or hopeless, what they need is your help learning:

• how to deal with anger, sadness, hurt, frustration, or too much excitement.
• other ways to communicate their feelings.
• how to calm themselves down.

Many adults do not learn or use these skills well. For children, especially children who are experiencing problems from HIV in their families, it can be even more difficult. But you can help children learn to communicate in ways that are easier for them and for you. Communication can help when children:

• fight going to sleep, wake in the night, or have nightmares

  ![Mama! Mama!](image)

• have tantrums or cry over small things

• complain of aches and pains

  ![My tummy hurts!](image)

• hit or hurt people, destroy things, disobey more or act too wild

• complain of aches and pains
Responding to tantrums

A tantrum (or temper tantrum) is an outburst that usually happens when a young child is very frustrated and cannot get something he wants. The child may scream, cry, lie on the ground kicking, or hit or bite the person who is not letting the child have what he wants. Many children between 1 and 4 years old have tantrums, either often or rarely, and usually stop having them regularly by the age of 4 or 5. Hungry, tired, or ill children have tantrums more easily.

Young children do not have tantrums on purpose to annoy parents, make caregivers angry, or in revenge for some way the caregiver treated the child. Children do not like having tantrums.

What to do when a tantrum happens

When a tantrum happens, it means a child is having more feelings than he can handle. So asking more of the child at that moment will not help. Hitting, yelling, threatening, or spanking a child can make a tantrum worse. Even though you too may feel frustrated or angry, you have to wait for the child to calm down enough so your communication can reach him.

1. Stay calm. Take a deep breath.
2. Stay near your child, even if you are not speaking to or looking at him.
3. Give your child time to calm down.
4. Be clear with the child that you will not give him what he wants. Do not bribe or give into tantrums. Doing so only teaches that a tantrum will get a child what he wants.

If your child has a tantrum in a public place, such as at the market or clinic, take the child outside and away from others until the child has calmed down. Once you and the child are calm, return to the activity. Do not teach a child that throwing a tantrum will get her out of an important activity, such as going to the clinic, working in the fields, or doing the washing.
To prevent tantrums

- Try to watch and talk with children so you know how they are feeling. You may be able to see frustration building or know when a child always wants something, such as when you walk by a certain shop. You can often distract children before an upset takes hold by turning their attention to something else.

- Make sure children have regular naps, and try to feed them before they get too hungry. Keep to routines as much as possible and prepare children for changes.

- Be clear and reasonable with your expectations. Give simple and clear directions, with only a few steps.

- Praise good behavior.

- Plan ahead whenever possible. For example, if you know you will be away from home and have to wait at the clinic all day, bring snacks or toys to keep your child fed and occupied while waiting.
The Boy Who Became Mean

Josiah is 6 years old and does not know about HIV, but he knows his mother is ill. He walks with her to the clinic and they wait all day for her turn. Sometimes he plays with other children there. But recently his mother has been very ill and they go often to the clinic. She coughs a lot and sometimes stays in bed all day. Now he has fights at the clinic, tells lies, and makes up mean stories about other children.

Josiah’s mother thought about how she could talk to her son. As they walked home she talked a little about her illness and then let Josiah ask questions. She tried to answer simply but as best she could.

What can I do? I am so tired and ill. I don’t have the strength to raise a child who causes so much trouble!

Many children are like this when their mother is sick. He sees you are weak and is worried about you. But he is too little to know what to do, so he acts badly. Do you talk to him about your illness?

When I stay in bed all day how do you feel?

Like this, mama.

I know how that feels—it’s like a stone inside you. I am sorry, baby. Whenever you feel that stone, you come give my hand a squeeze. When I feel that way, it helps if I tell someone.
Responding to hitting, fighting, or destructiveness

Often, when children older than age 3 or so fight a lot or break things, it is because they hurt inside. They may be angry, frustrated, or scared about bad things that happen to them, and do not have better ways to express those feelings. Children struggling with these feelings relate poorly to other children and do not make friends. One of the worst things about this way of acting is that it pushes others away when children need support very much.

To help a child who fights or hits:

- Talk with him about things that might be upsetting him, including death and illness.
- Show him affection and praise him when he is helpful.
- Make sure he has company during the day and things to do.
- Try to stop other children from teasing him or starting fights. See if you can enlist friends of his or older children to help with this.
- Help him learn self-control and find better ways to express feelings of anger or frustration. Talk about how to ask for help, walk away from whatever is upsetting him, and do something he likes instead.

Show a good example by staying calm and firm with the child when you are frustrated with her, rather than hitting the child or losing your temper. If you punish her, give a fair punishment that helps the child learn.

If a child has become very used to fighting, hitting or kicking as a way of handling feelings, it can take some time for him to learn other ways. Try to be patient and keep working on it.
Responding to sleeping problems

Some problems with sleeping may be helped by having a good routine at night. Do not let the child play very active games or watch TV right before going to bed. Turn down the radio or TV. Make her comfortable and tell her a quiet story or talk about a good thing that happened that day.

If your child wakes from a nightmare, comfort her and calm her down. Tell her it was only a dream and she is safe. Let her tell you about the bad dream, but make sure she sees that she is safe in her bed first.

Sometimes children wake in the night screaming and cannot be comforted or touched. These are night terrors, and are harder on the caregiver than the child. To help, just watch the child and see that she does not hurt herself. Wait until the screaming stops and the child is fully awake. She will not remember her screaming and will usually go back to sleep quickly.

Responding to bed wetting

Children dealing with difficulties may slow in their development or move backward. They may lose abilities they had developed and act like younger children. One of the most common of these is wetting the bed. Bed wetting is hard for both children and caregivers.

Do not beat or scold a child who wet the bed. He does not do it on purpose and usually he is already upset and ashamed. Make sure he has clean clothes and bedding, and does not smell of urine when he goes to school.

To make wetting the bed less likely:

- do not let your child drink too much in the evening before bed.
- have him go to the toilet right before bed.
- wake him and have him go to the toilet again before you go to bed yourself.
- Keep a bucket in the room if he is afraid to go to an outside latrine.
Talking with children about HIV

Talking with your child about HIV can be difficult for many reasons. It is normal to want to protect children from worries. And in most cultures, some topics connected with HIV, such as sex and death, are not commonly discussed with children—or talked about 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.

Talking to your child about HIV is important for her health. Children who know about HIV are better at taking medicine and living healthy lives. Children who have grown to understand HIV, little by little over several years, accept it better and are less angry than those children who learn about HIV in the family when they are adolescents. Talking about HIV with your child helps her trust you.

If a woman who has HIV gets pregnant and has a baby, sometimes the baby gets HIV from her. This is how most children with HIV got it.
Talk to children about HIV even if no one in your family has HIV. This is especially needed in communities where there is a lot of HIV. You may need to explain why your child’s friend at school is often sick, or why the shop owner down the road died so young. Although it may not be for many years, eventually you will need to prepare your child for becoming an adult who will have sex in a community where many people have HIV.

Teaching babies up to age 2 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 and AIDS.
Teaching children ages 3 to 5 about HIV

Children these ages cannot understand HIV, but they can begin to understand illness. Starting about 4 years old, children can compare things that are different. They begin to notice if they or someone in their family goes to the hospital or clinic more often than other people. They may wonder why they have to take medicine and others do not.

Young children can be told they (or a sibling or caregiver) have an illness, without saying it is HIV or explaining much more. Caregivers and health workers do not use the words “HIV” or “AIDS” until children are older and can understand them better, and know how to keep information private.

**Why do I have to take medicine every day?**

*Because it keeps you strong and well.*

**Why doesn’t Sarah have to take medicine?**

*She wants to be strong too.*

**You and I have a sickness that Sarah does not have. It can make us very ill, but not if we take our medicine. Because Sarah does not have the sickness, she only needs to eat her vegetables.*

**But I don’t feel sick.**

*Good! That is because you do a good job of taking your medicine every day like a big boy!*
Teaching children ages 6 to 8 about HIV

Children these ages will be able to understand more about illness and death. They will most likely have heard about HIV and AIDS. They may know what HIV and AIDS are, and that HIV cannot be cured. They may have seen or experienced stigma and understand why HIV is often kept secret.

Sometimes children this age who are HIV positive are still not told they have HIV by name, but rather that they have a sickness in their blood. This level of understanding can help them protect and care for themselves and be more willing to take medicines.

A Mean Little Bug

Little one, I am glad we have time to talk today, just you and me. I want to tell you more about why you must take medicine every day.

You know you have something in your blood that can make you very sick if you do not take your medicine. This thing is like a mean little bug that eats the part of our blood that guards us from illness.

Everyone has protector parts in their blood that fight any germs that get inside you. These protector parts keep you healthy. Most people have lots of these protectors inside them. But you and I have this mean little bug that eats these protectors.

Our medicine makes this little bug go to sleep. But our medicine cannot kill the bug 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?

Your Aunt Salima knows all about this too, so you can feel free to talk to her about it. But other people do not understand about this little bug that we have in our blood. So it’s better to speak to only me and Aunt Salima about your medicine. OK?

See page 35 for more about teaching children about stigma and secrets.
When you teach children about HIV, tell them the truth about the virus and how it is spread, in simple ways they can understand. They may have heard that you can get HIV from sharing food or that HIV is caused by witchcraft.

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

As children get older and start school, keep talking to them about HIV, about how it is spread, how to stay healthy, and about the harm of stigma and what children can do to fight against it.

See Chapter XX for more on the basics of HIV.

Teaching older children about HIV

As your child matures you will be able to explain more how HIV affects a person who has it, how someone with HIV can stay healthy, and how HIV is spread and people can protect others from becoming infected through sex.

Talking about HIV can be difficult, and talking with young people about sex can be too. If you have a strong and honest relationship with your child, these conversations will be easier. This learning will help children with new challenges they will face as adolescents living with HIV, such as learning to care for themselves at school, pressure to have sex, and fear of rejection from friends and teachers.
When talking to your child about sex, the most important thing is to be honest. Young people need accurate information about sex, relationships, and their health if they are to become healthy and responsible adults. If you do not know an answer to one of your child’s questions, tell her that you do not know. It is okay to ask for help from a nurse or someone at the clinic. Let your child ask whatever questions she may have, and try to not react with judgment or anger. Just as you told them about other adults they could talk to about HIV, suggesting another adult they can talk to about sex can be very helpful.

Help older children become more independent by talking to them about their medications and encouraging them to take responsibility for taking their pills. Encourage them to talk to their health worker at the clinic about their medicines or lab tests so they will 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 whether this person needs to know, and whether the person is trustworthy. Discuss what might happen if the person were to tell others. Your child needs to learn to make these decisions on her own, and you can help her learn by helping her think them through.
When to tell 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 it. But no matter how old a child is, you can try to have more open communication. By doing this, you can lay a good foundation for disclosure later.

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 are told about a parent’s HIV, or that someone else they are close to has HIV, can better understand why that person might need more food or is often sick. And they may be able to learn to help, such as remind the person to take their medicine.

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

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

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 the child telling someone else, who does not know yet. Disclosing HIV can bring up feelings of guilt and shame if a parent blames herself for the fact that her child has HIV.

Parents may already worry for their child’s future—that he will be teased or rejected in school, will be ill and weak, or will die. Telling the child about HIV may feel like giving him a burden he should not have yet. Parents and caregivers may also think about their own illness and death. All of this can make people delay telling a child he has HIV.
Telling your child about someone else’s 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**

Children may have some of the feelings you fear when they first learn they have HIV. But most children are able to accept hearing this news. It helps 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 be ready to discuss HIV at a young age. For other children, you may feel that you should wait until they are older.

Many children who only learn they have HIV when they are nearly grown wish they had been told earlier.
How to tell a child she has HIV

Children do not learn about HIV all at once, especially small children who cannot fully understand HIV. 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.

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.

• Thinking through your own feelings about HIV and illness in your family will let you better accept your child’s feelings. It is common for a caregiver to feel guilt, fears for a child’s future, and sadness or anger. First talk to someone 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!

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

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?

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

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

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

• Listen and let the child’s questions guide you.
• Receive their reaction – no matter what it is – with patience, love, and acceptance.

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 happen over many years and your child may react differently each time HIV is discussed.

• Stay hopeful when you talk about HIV.

You will need to take treatment every day and go to the clinic, but many things in life will not change. You will still go to school, find a job, and may get married. I can look forward to seeing you graduate. You can have many hopes for the future too.
Talking about stigma and secrets

Even though you may have taught your child to tell the truth and not keep secrets 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 secret. 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 neighbor.

Children can talk more freely at a support group.

How did mommy die?

You are old enough now to know about that. They both had HIV. Do you know what HIV is? It is like a really bad germ that can make a person really sick.

Why didn’t you tell me before?

The reason we keep it a secret is because many people do not understand HIV. They think only bad people have HIV. HIV used to make everyone who had it die, so people are scared of it. Sometimes people treat someone very badly if they think the person has HIV. That is why we only talk about the HIV in our family with Uncle Abraham or Mrs. Bukenya.

Yes, I heard Mrs. Yienya tell Sammy not to play with George because he has AIDS.

Have you ever seen anyone treated badly because of their HIV? Or heard people say mean things about AIDS?

YOU! And Uncle Abraham, or Mrs. Bukenya.

Exactly. That’s why mom and dad never said anything to us about it. They did not want us to tell anyone or for us to be mistreated. So, if you have questions or want to talk about HIV - who can you talk to?

Right!
Ongoing support for children

A child of any age may know she is sick or that there is a problem in her blood, and still have a strong reaction 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.

Eventually 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 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 XX for more on starting support groups, and pages XX and XX for more examples of children providing support for each other.