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## CHAPTER 8

# How to know if your child has HIV

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An HIV test can tell you if you or your child has HIV. The main reason to find out is to be able to seek the treatment and support you both need to stay well. The sooner you start, the better.

If the mother has HIV or becomes infected during pregnancy or breastfeeding, her baby can be born with HIV infection, though not all babies of women with HIV are infected. Almost no babies are infected when their mothers (and fathers) know they have HIV and take ART so their HIV is well controlled. See Chapter 7 for more about preventing HIV in babies and others.

If a baby is born with HIV, it is important to find out quickly. Babies with HIV are often harmed by it as soon as they are infected, unlike older people who may live years with HIV before they became ill. Even a baby who seems healthy at birth can develop poorly because of untreated HIV infection and quickly become weak and sickly. Most babies with HIV who do not get treatment die before they are 1 or 2 years old.

By getting tested, you can start the treatment and good care that keeps babies and children alive and growing well. With ART for babies and children now more available, many children born with HIV will grow up to be healthy adults who work, marry, and even have children of their own.

See Chapters 10 and 11 for information about ART and other ways to keep children healthy.



*I'll just take a bit of blood from her foot so we can test it.*

## Types of HIV tests

The 2 basic tests for HIV infection are antibody tests and viral tests. Both test a small amount of blood.

**Antibody tests** are the most widely available HIV tests, give results in a few minutes, and are the least costly. They work by looking for the antibodies that the immune system makes to fight HIV infections. So the test will give an accurate result for HIV *except* in 2 cases:

1. Babies under 18 months old or who are still breastfeeding get antibodies for many diseases from their mothers. This includes HIV antibodies if the mother has HIV. So an HIV antibody test only shows if a young or breastfeeding baby was exposed to HIV. Only a couple of months after the baby has stopped breastfeeding does this test show if *the baby* is actually infected with HIV. See pages 134 to 137.

*We can't be sure he has HIV yet. We must do one more test.*



2. Because it takes a few weeks for our bodies to make antibodies after HIV infection starts, a person who just became infected with HIV will not have antibodies, so he will test negative. But a test 1 to 3 months later will show that he has HIV. This time — between infection and developing antibodies — is sometimes called the “window period.”

A new antibody test known as an HIV self-test is now available in many parts of the world. It allows you to test saliva from the inside of the mouth with a swab and get results in a few minutes. It is usually accurate, but if the result is positive you should get a blood test to be sure. While the HIV self-test allows people who cannot or do not want to go — or will not take their child — to a clinic to be tested and know their status, it cannot provide what a clinic can: skilled counselors, access to ART medicines, support groups and social services.

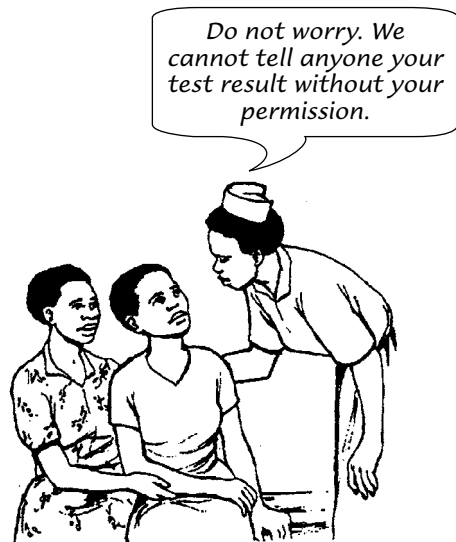
**Viral tests** look for the HIV virus itself, so they can tell for sure if you or your child has HIV. These tests are most important for testing babies under 18 months old, and are recommended to confirm the result of an antibody test. In some places, they are the only HIV test given to babies. But viral tests (sometimes called PCR DNA tests or NAT tests) are generally less available, more costly, and usually take several days or weeks to be processed in a laboratory. Faster, less costly viral tests may be more available soon.

Viral tests may also be used when an adult’s antibody tests are not clear. Usually, to be sure of a positive test result, the antibody test will be repeated on the same blood. If one result is positive and the other negative, the person may be asked to return for another test, which might be a viral test.

## The HIV testing process

An HIV test is more than just the test itself. Good care means the person being tested:

- has **counseling** before and after the test. Counseling should include information about HIV infection, how HIV testing works, and why someone might need more than one test. Counseling before HIV testing may be done in a group.
- gives their **permission** to take the test and, if the person is a child, understands and agrees according to her age.
- has their **privacy** protected so no one will know about the test or the results except those the person wants to know.
- is asked about the **support** they have, such as a trusted friend or relative with whom they can discuss the results of the test.

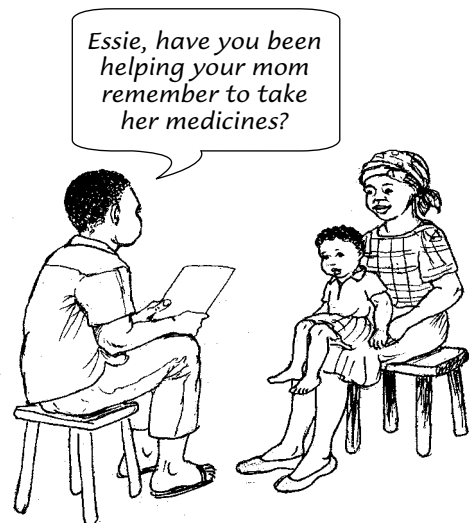


## Counseling

A counselor can be both a teacher and a helper. By listening to and talking with people, counselors help people be better able to make their own choices and cope with problems and concerns.

Experienced counselors are able to give explanations, ask questions, and adjust their manner to fit the ages and needs of the adults or children they counsel. Good counseling will make you feel supported as you take an HIV test and learn the results.

Some HIV counselors know a lot about HIV and how to live with it because they have HIV themselves or have family members with HIV. Many health workers and caring community members have also studied and trained to counsel those who have HIV or worry they might.



A skilled HIV-testing counselor can support a person to:

- understand or decide to take an HIV test.



*I understand how upsetting it is to think your HIV test might be positive. You know, sometimes people who worry about something feel relief when they know for certain, even if the news is not what they want.*

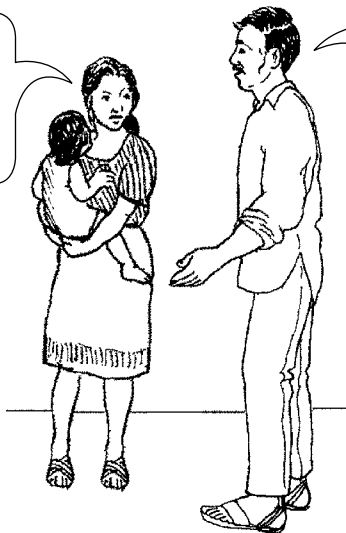
*And if you are positive, now ART medicines can promise you a long and healthy life.*

- cope with feelings about the results of an HIV test.
- convince a reluctant partner to be tested and begin treatment if needed.
- decide who to tell about having HIV and how to tell them.
- talk with their children about HIV.
- learn where to get health care, medicines, and other support.
- meet others who have HIV or have children with HIV.

Some counselors even directly assist people in disclosing their HIV test result to their partners.

If you feel you are not ready to be tested or to have your child tested, the counselor or health worker may help you discuss your concerns. Ask the health worker what she thinks will happen to you or your child if you do not get tested now.

*I know she should be tested but I am afraid everyone will be unkind to her if she has HIV.*



*I hope Ruth does not have HIV. But whatever happens, we will keep the result private. And if we test her today, we can start helping her right away.*

## Understanding the test

Before doing an HIV test, a health worker should explain why the test is needed. If your child is being tested, you might also discuss what he knows about HIV.

The health worker should explain what kind of HIV test it is (see page 124), and how quickly the result will be available. If possible, the health worker should explain how the test will be done. Children do better if they understand what is happening to them.

Younger children, up to about age 6, can understand that they may have an illness and a test will help them get the right treatment. Most school-age children, about 7 years and above, can understand more. See page 138 for how to talk to different-aged children about the results of an HIV test.

Encourage children to ask questions by asking questions yourself, and help them ask their own questions. Children need different explanations depending on how old they are.

Remember you are the expert on your children, and what they can and cannot understand. Even in a busy clinic you and your child have the right to ask questions and know what is being done and why.

There are many ways to use multiple tests to make sure of a result, and the exact process differs in different countries or clinics. If you do not understand why an additional test is being done, ask.

*If Nico has HIV, we can start treatment and this will keep him well. We also have a support group for parents. You are both welcome there.*



There are many ways to use multiple tests to make sure of a result, and the exact process differs in different countries or clinics. If you do not understand why an additional test is being done, ask.

*Would you like to know what this is a test for?*

*Yes.*

*It is to see if you have any germs in you that might make you ill.*

*I will take a little blood with a small needle here. You will feel a tiny pinch. You don't need to look if you don't want to. OK?*



## Giving permission

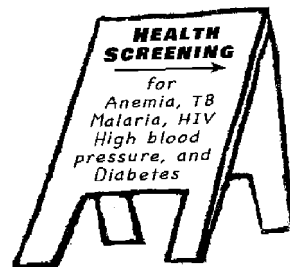
Once your questions about the HIV test have been answered, whether the test is for yourself or for your child, the health worker or counselor should ask if you agree to have the test. If you agree, the health worker will do the test. Depending on local laws, children from birth to between 12 and 16 years old usually need a parent's approval to be tested for HIV. If no guardian is present and the child needs health care, she can usually be tested. In most areas, young people age 16 or older can agree to HIV testing on their own.

## Privacy

You should have the right to say who can know about your test. Test results — and any other information about you and your health — should be confidential. Your health worker should not talk about you to anyone without your permission, except for another health worker when it is necessary for your care.

Often, health workers need training and support to better protect the privacy of the people they care for. Careful procedures can protect privacy by controlling who can see test results and other health records, and by how tests are labeled. Conditions in health facilities must make privacy and confidentiality possible, such as having spaces where others cannot see or hear counseling conversations.

Clinics and other programs that do HIV testing can also protect privacy by providing HIV testing along with other tests and care. Shared entrances and waiting rooms mean each person's reason for being there is not obvious.



## Support

Many testing programs ask what support you have at home, especially when you go to be tested alone. A trusted friend or family member can give you strength to take a test, learn the results, and think about how to manage if you or your child has HIV. If you and your partner are willing, being tested at the same time means you can get information together and support each other. Some people want privacy at an HIV test, while others like to have someone they trust with them who can help ask questions or remember things.

Carefully choose people to talk with about the test result. People who would treat you or your child differently because of your HIV status are probably not the best people to tell first. Choose those who will listen, understand how you feel, and want to help. Another person who also has HIV, or who has children who have HIV, can help in many ways.

## Where to get an HIV test

Many communities have HIV testing centers with trained counselors and people who can give HIV tests. If ART treatment is offered, doctors, nurses, pharmacists, and others may also be on staff. Sometimes support groups or post-test clubs for people with HIV meet at testing centers.

Testing for HIV can also be a normal part of health care for children and adults at clinics and hospitals. Children may be tested at immunization clinics, during regular mother and child health visits, or if they are hospitalized. Pregnant women can get an HIV test during a prenatal visit.

To make HIV testing easier and most available, some communities offer it with referrals to counseling at health fairs and other public events, by mobile outreach to remote areas, or by counselors going door-to-door to counsel and test people in their homes. You can also offer HIV testing at places like factories, schools, and churches, temples or mosques. The new HIV self-test can be purchased in pharmacies and used at home.



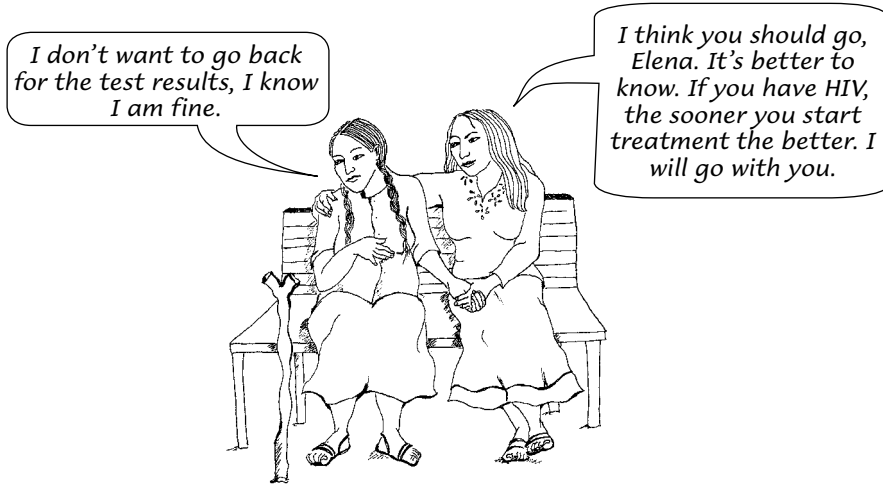
## Testing parents and pregnant women

In areas where many people have HIV, it is a good idea for all adults and children to get an HIV test. If you are sexually active, getting tested once a year or whenever you have a new partner is smart. If you have a child who is ill, you and your child can be tested at the same time, so treatment can start as quickly as possible if either of you has HIV.

If you are partnered and hoping to have children, you can be tested for HIV to learn how to protect your own health, your partner's health, and the health of any children you will have. If you do not have HIV, you can take care to prevent being infected going forward. And if you do have HIV, you can start treatment, which protects your own health and that of your partners.



A pregnant woman should get tested for HIV as soon as possible. If you learn you have HIV, taking ART will protect your health and prevent your baby from getting HIV. You may be tested several times during pregnancy so if you become infected, you can start treatment right away to protect both yourself and the baby.



## Test results for parents

If your HIV test is positive, the health worker will tell you and give you a few minutes to react. People have many different feelings, thoughts, and questions when they find out they have HIV. Often they do not believe the test, or are afraid or angry, or are relieved to know, or begin to worry about what will happen to their children. Sometimes they have no feelings at all, only emptiness. Any first reaction is just the beginning. People's feelings change over time as they learn more about how to live with HIV.





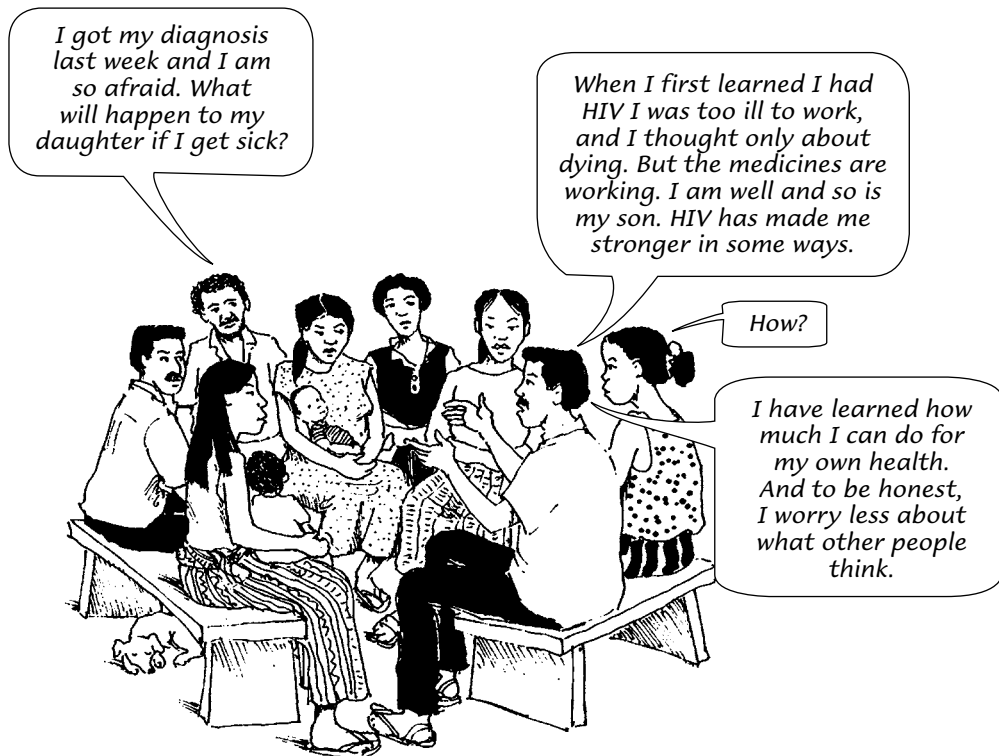
Sometimes the health worker will order a second HIV test to be sure about the result. Be sure you know when to come back for the second test results. Ask a friend to give you support and help you remember.

When a parent has a positive HIV test, it is usually wise to have the sexual partner and any children tested for HIV too. This is most important for any young children in the family.

You might assume that if you have HIV, your partner must also have it. But this is often not true. Although HIV spreads easily through sex, it does not always. In many couples, one person has HIV while the other does not get infected for some time. An HIV test will help you know for sure.

Do not struggle alone with the news. Counseling, treatment, and support can all help. If you have questions or concerns about your diagnosis or treatment, discuss them with your counselor or health worker. Talk to a trusted friend or supportive family member who knows you well. Seek out a support group to meet others in your community who have HIV or who are parents with HIV. For information about HIV treatment, see Chapter 11.

You will also need to decide what to tell your children about your HIV infection, and what to tell your partner if you got tested alone. For how to talk to children about HIV, see Chapter 5.



**If your HIV test is negative**, it means there are no HIV antibodies in your blood. If you also have no risk of a recent infection, this means you do not have HIV.

Because antibody tests may not find a recent HIV infection, you may be asked if you have any risk of infection within the last couple of months, for example, if you had unprotected sex within 1 or 2 months of the test. Because you could be infected with HIV but not have enough HIV antibodies to make the test react, you should plan on taking another HIV test in another month or two (and use safer sex, including condoms, in the meantime).

If you are pregnant and your test is negative, you may be asked to test again in a few months. If your new test is positive, you can start ART quickly, to treat yourself and protect the baby.

## Testing babies and children

Babies with HIV can live healthy, full lives if they are tested and start taking ART early in their lives. Testing saves lives.

Babies from birth to 18 months may need 2 different tests — an antibody test and a viral test — and may be tested several times as they grow. For children older than 18 months who have stopped breastfeeding, HIV testing is the same as testing for adults. See page 137.



## Children who should be tested for HIV

### If a child's mother has HIV

The main way HIV infects children is that it spreads from women with HIV who are not taking ART to their babies during pregnancy, birth, or, less often, breastfeeding. But not all children are infected. If you have a baby and you know you have HIV, have your baby tested.

If any person in a household has HIV, health workers usually want others in the family to be tested, especially other children. Sometimes an HIV-infected child seems to be healthy in the first few years of life and is only discovered to have HIV by testing after a sibling or parent is diagnosed.

*You can have your baby tested for HIV when you bring him for his immunizations.*



### If a child is ill or grows poorly

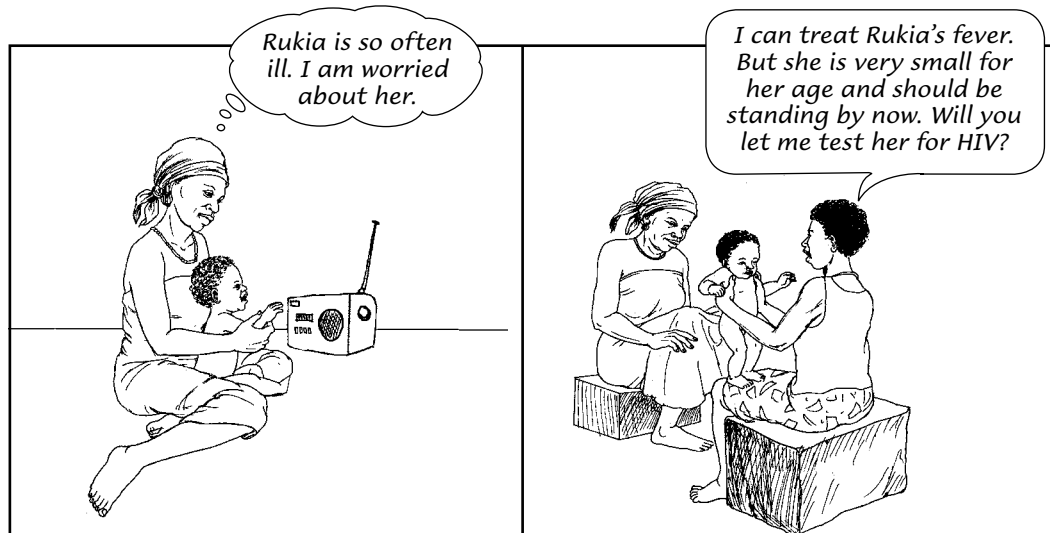
Any child who is sickly or grows or develops slowly — and the child’s mother — should be tested for HIV. Health problems that are very common in children with HIV who are not on treatment include:

- diarrhea, see pages 214 to 223.
- pneumonia, see pages 225 to 226.
- tuberculosis (TB) in the child or the child’s household, see pages 227 to 228.
- ear discharge, see pages 233 to 235.
- swollen glands under the jaw, see pages 235 to 236.
- white spots in the mouth (oral thrush), see page 238.
- very low weight or not growing as expected, see page 245.

See Chapter 12 for more about common illnesses and how to treat them in children affected by HIV.

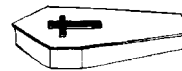
While watching for and responding to signs of illness is important, babies can show no signs of illness but still have HIV infection. They need ART in order to stay healthy.

Some mothers may put off having their children tested because they fear learning the child has HIV, or fear discovering that they have HIV themselves. But HIV will not go away on its own. Knowing a child has HIV means you can do things for her, including guarding the child’s health, getting the right treatment, and watching the child improve as treatment is successful, just as learning you have HIV means you can get the treatment you need to stay well.



### If a child's mother or father died

It may also be a good idea to test children for HIV if one or both parents died from unknown causes, or from pneumonia, tuberculosis (TB), or other diseases common in people with HIV.



### Other reasons to test a child for HIV

If a child has had injections, blood transfusions, was circumcised, or was breastfed by someone other than her mother, the child may have been exposed to HIV. Also, sexual abuse spreads HIV (see Chapter 14). Discuss any concerns with a health worker, who may recommend testing your child to be sure.

## Testing a baby younger than 18 months old

### When to test a baby

If possible, test your baby at 4 to 6 weeks of age, or as soon as possible after that. If your health worker knows you have HIV, she may skip the HIV antibody test and use a viral test for your child.

A baby whose mother has HIV should be tested again at about 9 months old even if she is not small or sickly. If that antibody test is positive, test again with a viral test. If that test is positive, start the baby on ART. See Chapter 11.

### What test to use for a baby

The best test for a baby younger than 18 months old is a viral (PCR or NAT) test. The HIV antibody test is less costly, more widely used, and gives faster results. But in a baby younger than 18 months, an antibody test cannot tell if antibodies come from the mother or the baby. A positive antibody test only shows that the mother has HIV and her baby was exposed to it. More information on these tests is on page 124.

### How they do the test

Hold your baby closely, with 1 hand or foot free so the health worker can take a little blood from it. It helps to talk to a baby and soothe his discomfort, if any, during and after the test.

The health worker will clean the spot where she will take the blood, hold the baby tightly so he cannot move, and prick his finger or foot to take a little blood for the test. She may put a small bandage on the spot.

*Just a quick stick, little one — it will only hurt for a few seconds.*



### **Antibodies protect babies from illness, but can also be a sign of illness**

For the first few years of a baby's life, he cannot fight infection well by himself. Our ability to fight infection develops over a lifetime, as our blood makes antibodies that fight infections and prevent many illnesses.

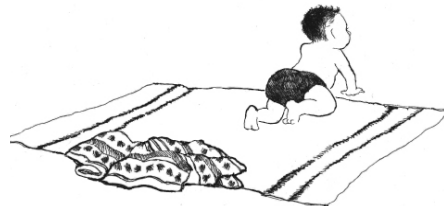
Our first antibodies come from our mothers and protect us from illness while we are babies. Babies get these antibodies during pregnancy and breastfeeding. As a baby grows, his body makes his own antibodies and his mother's antibodies slowly go away. After he is 18 months old and has also stopped breastfeeding, his antibodies are all made by his own body.

A baby's antibody test will be positive for HIV if the baby's mother has HIV, because her HIV antibodies are in his blood. But many babies born to mothers with HIV do not become infected. For these babies, after 12 to 18 months and the end of breastfeeding, their antibody tests will be negative for HIV. This is because the HIV antibodies from their mothers are gone.

So for the first 18 months of a baby's life, if a test finds HIV antibodies in the baby's blood and the mother has HIV, you do not know for sure whether the HIV antibodies are from the mother or from the baby.

Here is another way to think about this.

**A mother sharing antibodies with a baby is like a mother wearing a sweater, but wrapping her baby in a matching scarf to keep him warm.**



**When you find that scarf somewhere, you cannot know whether it is because the mother was wearing it or the child.**

Because mothers share antibodies with their babies, a positive antibody test in the first 18 months of a baby's life does not say that the baby has HIV. Only a viral test can give a true result.

### If your baby has a positive test

A **positive antibody test** means the baby has been exposed to HIV, but does not mean the baby has HIV. The closer your child is to 18 months old, however, the more likely it is that the antibody test results are correct. If a viral test is available, the baby should have that test to confirm the antibody test result. You will have to return for the results of the viral test, usually in a few weeks.

If no viral test is available, your baby may be started on ART after only the antibody test if he has certain illnesses common with HIV (see page 133).

Simply knowing that a baby was exposed to HIV is useful because it lets you know that you must protect the child from illness more carefully. One way to do this is to give children cotrimoxazole (see page 174), which can keep them healthy until you know for sure whether or not they have HIV.



A **positive viral test** means your baby has HIV. Finding out your baby has HIV can cause all kinds of feelings — sadness, worry, anger, or even numbness. Support offered by the health worker or the person you have with you can help.

Children — and parents — can live long and good lives with help from ART medicines, good food, and support from their community. The sooner you and your baby get on medicines for treatment, the better you both will be. More information on medicines for HIV is in Chapter 11.

If viral tests are not available at your health facility, you should have the child tested again with the antibody test after some months have passed. In the meantime, you can protect the baby's health:

- Take your ART faithfully, especially if you are breastfeeding.
- Give the baby medicines, such as cotrimoxazole, to prevent illness.
- Feed your baby well and give him lots of loving attention.
- Watch for signs of illness and respond or seek help quickly if needed.

For more ways to protect your baby's health, see Chapter 10: How to keep children healthy.



### If your baby has a negative test

A negative viral or antibody test almost always means the baby does not have HIV. The health worker can give you information on how to keep yourself and your child healthy. Ask any questions you may have. Your child may need to be tested again, for example, after you stop breastfeeding.

### Breastfeeding and HIV testing

If you have HIV and plan to breastfeed, your baby may still be exposed to HIV. Babies should be tested again 6 to 12 weeks after they stop breastfeeding. But if your HIV is well controlled by your ART, it is very unlikely your baby will become infected with HIV from breastfeeding. For more about breastfeeding safely when you have HIV, see Chapter 9.



### Testing a child 18 months or older

To test a child 18 months or older for HIV, health workers use the same tests used to test adults.

Before the test, tell your child that the health worker will clean the spot where she will take the blood, and hold his hand palm up to prick his finger. After taking a few drops of blood for the test, she may put on a small bandage. Promise to stay close and say that it will hurt for only a few seconds, but you will have to wait for the test results, usually about 20 minutes.

If your child is old enough to understand what you and the health worker say, you will probably want to discuss the test result without the child at first. This will give you a chance to ask questions, talk about how much your child can understand, and discuss how to explain the result to him.



*Do you have any support at home? Who can you talk with about this?*



### If the child has a positive test

A child older than 18 months who is no longer breastfeeding and who has a positive HIV test almost always has HIV. The health worker or counselor will give you this information, and will support you as you have your feelings and think of questions and concerns.

You will be better able to support your child if you take the time you need to let your feelings come out. Accept support from the health worker or the person you brought with you to the test. Discuss your concerns and questions with the health worker, and talk about what to tell your child.

If you do not know your own status, you should be tested yourself.

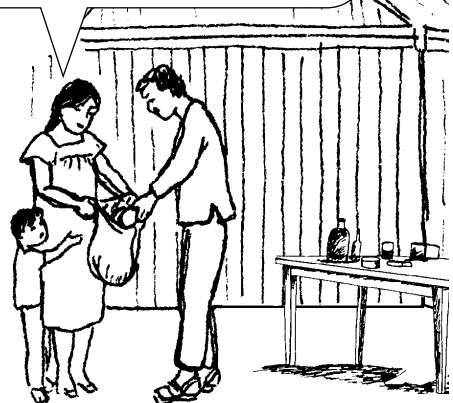
### Help your child understand the positive test

Think about how to talk with your child in ways that fit his age. A very young child may just need to know that he must take medicine every day to stay healthy. Older children will need and want more information. A child who already knows about HIV may be worried about having HIV, even if you do not tell him he has it. If you can be open with him, he will feel less alone.

Telling your child he has HIV may feel difficult. But it is usually better for both of you if you can start thinking about how to be more open about HIV, especially as the child grows. When children know more, they understand more and can participate more in their own care. It can also prevent problems later. Children older than about age 10 do not like to find out that information was kept from them. Children living away from their families need to know who they can talk to and get support from there. See Chapter 5 for how to talk with children about HIV.

Your child may be able to tell if you are sad or afraid. It is OK to be sad with your child if you can talk with him about it. It can help if you are calm and give a simple explanation of what the test result means for the child and your family.

*Silas, the test says you have an illness inside you and you need to take medicine. The medicine will keep you well so long as you keep taking it. OK?*





### If the child has a negative test

A negative test means your child most probably does not have HIV, as long as he has not recently been breastfed, or exposed to HIV in some other way, such as sexual abuse or possible blood contact (see page 134). A child who had a recent exposure should be tested again in 6 weeks or 8 weeks. A negative test then means he definitely does not have HIV.

Tell your child his test results. Encourage him to ask questions.

## What happens next

### If you or your child has HIV

Seek the treatment and support you or your child need to stay well. The sooner you start taking ART, the better. See Chapter 11.

**If you are pregnant** and have HIV, treatment will protect both you and your developing baby from illness. A midwife or other health worker can help you talk with your family about ways to stay healthy, where to have the birth, and how to feed your baby after it is born. More on how to prevent HIV spreading to a baby is in Chapter 7.

Other than ART, everything needed to keep a person with HIV healthy — such as nutritious food, safe water, and good friends — will improve the health of everyone in your family. See Chapter 10 to learn more about the care at home that will help you and your child stay healthy.

*Let me take you to the treatment office. Janet will be glad to meet you today.*



*The main way you can help Shobha is to feed her a little more. I know this is not always easy. Let's talk about how you can do it.*



If you are struggling to talk with your child about HIV, discuss your concerns with a counselor or other caregivers who have children with HIV. Talking about HIV with your child can happen slowly, over many months and years. For now, let your children know they can ask you questions and tell you how they feel. More information on talking with children about HIV is in Chapter 5.

Health workers can help by being patient and encouraging, allowing caregivers or children to express their feelings, and offering to meet again within a few days. Help a caregiver meet others in the community who are affected by HIV. Caregivers with more experience often share this experience as volunteer educators — this is a good way to help people learn over time how best to care for their children.

## If you or your child does not have HIV

A negative test can strengthen a person's resolve to stay negative. Discuss your questions with a health worker and learn more about how to avoid being infected. If you do not feel able to talk with your partner about HIV, ask if there is someone who can help you. If you are pregnant or breastfeeding, the best way to protect both your baby and yourself is to stay HIV negative. Continue to see your midwife or health worker regularly during your pregnancy, and get tested again later. See Chapter 7 for more on preventing HIV infection.

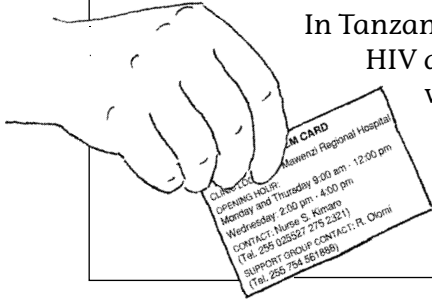
## Other help and support

You may need particular kinds of support because of having HIV. You may need help to have enough food, get your work done, resolve problems with relatives, find transport to health care, keep children in school, and sometimes even to feel part of the community. Other people in your community no doubt have these needs too, and you can form groups to help each other. See Chapter 15 for more on how communities can support each other when children and families are affected by illness or other difficulties.



**Palm cards: Knowing where to get help**

Sometimes a woman with HIV has problems with her marriage, relationships, or family. She may also have problems at work, even when it is illegal to treat someone differently because of HIV.



In Tanzania, health workers give women who test positive for HIV a palm card when they discuss the test result with the woman. These cards, small enough to fit in the palm of your hand, list phone numbers and locations of places to get medicine, other health care, and help with problems. To protect women’s confidentiality, the cards do not mention HIV at all.

Parents and caregivers need to stay strong and healthy to help children grow strong and healthy. Taking care of yourself, taking your own medicines, eating as well as possible and getting enough sleep, and having friends to talk with and work with can all help caregivers to be able to care for children with HIV. See pages 18 to 19 for more on what caregivers need.

*We were really upset when we first learned he has HIV. But look, he is growing just fine!*



**With medicine and loving care, children with HIV can do well.**