

Chapter Two

From HIV to AIDS

Most people find that information about HIV transmission and AIDS is very difficult to teach to others. The technical details are hard to grasp even for doctors, so it is no wonder that people in the community have problems understanding the important points and acting on this information in ways that are helpful.

A story can be a very useful and effective way of explaining the key issues surrounding HIV and AIDS. This handbook tells a story about a family affected by HIV and AIDS that you can use to teach. It is a story similar to one told by a wonderful storyteller working with The AIDS Support Organisation (TASO) in Uganda. The first part of the story is told below. This is followed by teaching notes that look at the story in detail, explaining what has happened and providing more information about HIV and AIDS.

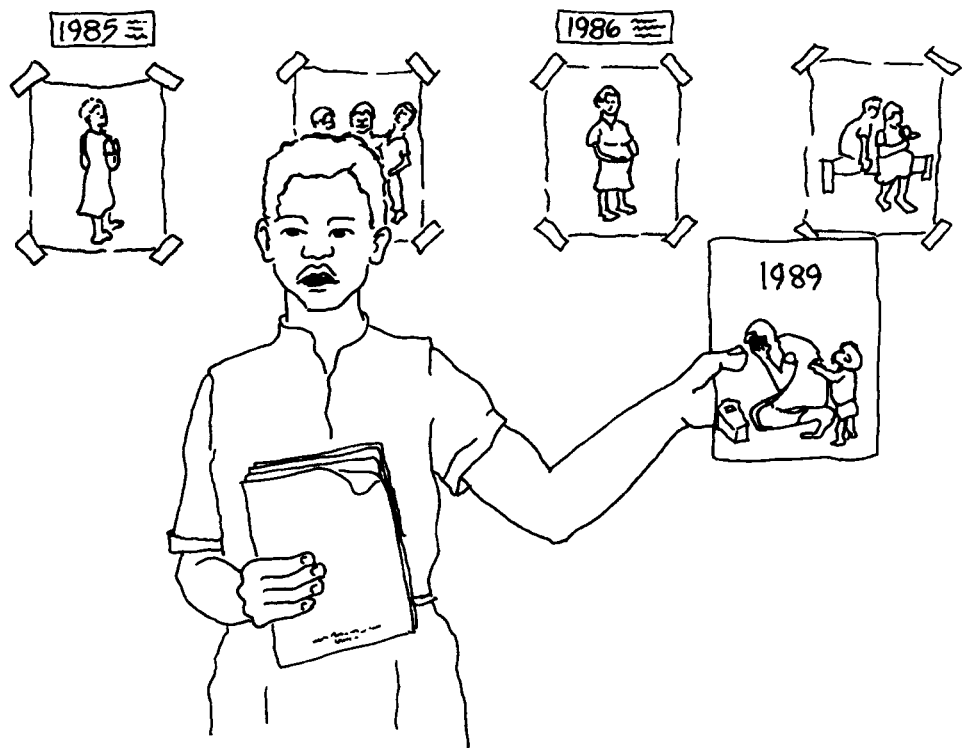
The story continues in Chapter Three and is completed in Chapter Four.

Here are some suggestions for using the story:

- Tell the story (or your own variation of it) and then go through it again slowly, asking questions and providing information. You can tell the story in three parts, as suggested here, examining each part in detail before you go on, or you might prefer to tell the whole story right through first. You can keep coming back to the story in your teaching sessions, reminding your audience of what happened to the family – this will help you to explain the different issues involved.
- Full-page versions of some of the pictures used here are provided at the back of this book. You might find these larger pictures useful when telling the story.
- Be sure that you change the story to make it familiar to the people you are talking to. For example, change the names to ones that are common in your area. If you are telling the story in a rural setting you could say that the

people are from the village where you are and then describe a journey to a city that is familiar to everyone in the village. **You want the people hearing the story to think “Yes, I know these people”.**

- Review background information before telling the story so that you are clear on the facts and prepared to answer questions as they arise.
- Make the level of information and the words you use suitable for the people hearing the story and for what they already know. The questions given along the way in the story are a guide. However, encourage your listeners to ask their own questions too.
- Give your audience time to answer questions and tell you what is happening before explaining things clearly yourself.
- Tell this story with the pictures and make sure that the time at which the events occur is clear. To do this, you might first want to put the dates up on the wall, and as you tell the story and show the pictures you can then place the pictures on the wall under the date on which the events described happen. Please note that you should change the dates in the story to suit the date of the storytelling.



A story: Yulia and Mukasa



This story is used to show how HIV comes into a family, and what happens over several years. The characters are shown in pictures to make it more interesting.

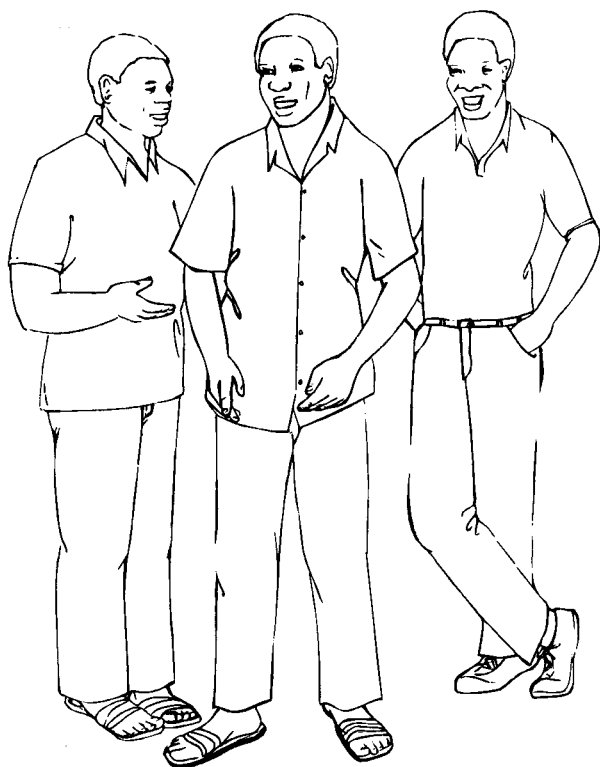
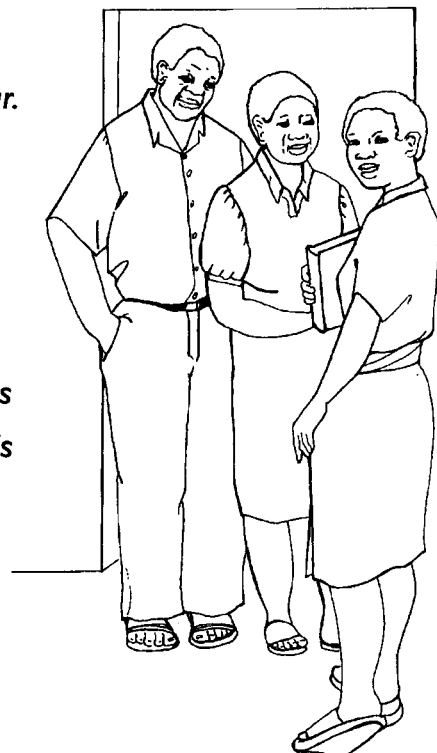
The original TASO story, from which this has been adapted, used symbols to help explain the processes of HIV infection, HIV transmission and development of AIDS-related conditions – using circles for HIV infection, squares for HIV antibodies and triangles for AIDS-related symptoms. If you feel this makes the story easier to explain to others, you can add these symbols to the pictures intended for use during teaching, which are presented at the back of the book. Other possibilities are to colour the clothing in some way or try to draw what is happening inside the body but cannot be seen on the outside.

Now let us start our story.

Early 1985

This is a girl, you know her, she lives just near. So beautiful as you see her. Her name is Yulia, and she is finishing school soon. Her parents are proud of her and know she will have a good life.

Soon she is to marry a man she cares for. This makes her very happy. And her family is pleased with her choice.



This good man is Mukasa.

He is doing well in his business – the shop down the road. You know him. He makes his friends laugh and is generous. Last year (1984) he went to the city for his business. It was a lonely time in the city, he stayed in a hotel and knew no one there. One night he drank some beers and he found a woman to ease his loneliness. He does not remember her name.

Now he is back here and will marry Yulia.

- ◆ **Mukasa does not know it, but during his stay in the city he was infected with HIV.**

Mid-1985

Yulia and Mukasa are married – there is a big celebration, everyone comes. Soon Yulia and Mukasa are living in their home and both help to run the business.



Late 1985

One day Yulia doesn't feel well – it isn't important, it feels like the flu and Mukasa makes her rest.



Late 1985 – shortly afterwards

Yulia has recovered from her illness and is back to work. She feels very well.



- ◆ Although neither of them are aware of it, Mukasa has now passed HIV to Yulia.

Early 1986

Yulia knows she will have a child. She and Mukasa are both very happy.



Late 1986

After some time the family is blessed with a child. A boy, named Yokaana, is born.

- ◆ **Yokaana is not infected with HIV.**



1988

Things have gone well for this family, they feel very lucky and the business is going fine. They have now been blessed with another baby.

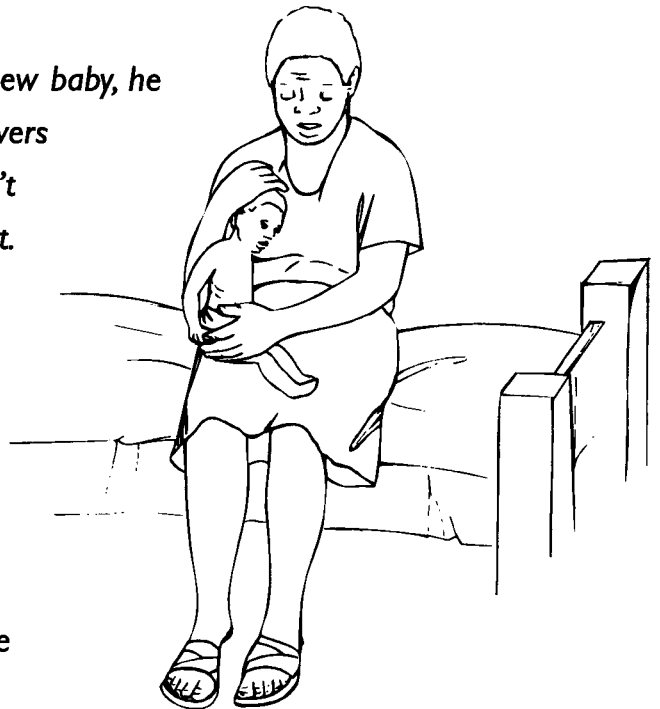
- ◆ **The new baby is infected with HIV.**



1989

Yulia is worried about her new baby, he doesn't look well. He has fevers and diarrhoea, and doesn't seem to be able to gain weight.

She buys many medicines for the baby but he doesn't seem to get better. Finally she becomes afraid – the child cannot eat without vomiting and he has diarrhoea again. She takes him to the doctor at the local clinic.

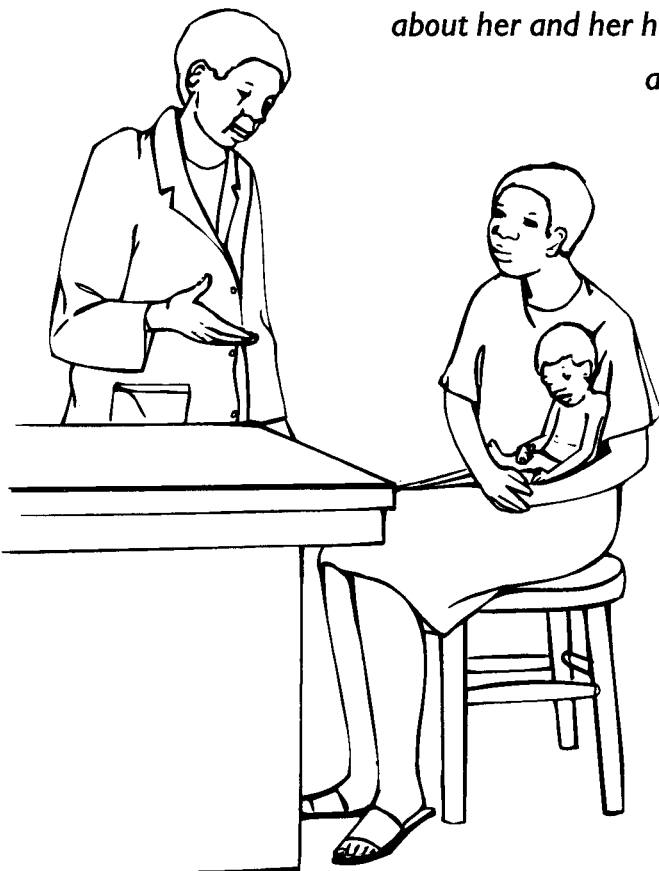


The doctor is very concerned.

He asks Yulia many questions about the baby, and he asks questions about her and her husband. He asks questions about their health and about their private life. She is embarrassed – no one has ever asked her questions about sexual things before. But this day is bad: the doctor tells Yulia he believes the baby could have AIDS. He says he cannot tell from a test until the baby is fifteen months old.

He tells her to have a blood test herself and talks with her about this. Yulia cannot believe what she hears and her mind refuses to accept what the doctor says. But, she agrees to the test so that the doctor will not be angry with her.

The doctor says her husband should also come to the clinic and be tested.



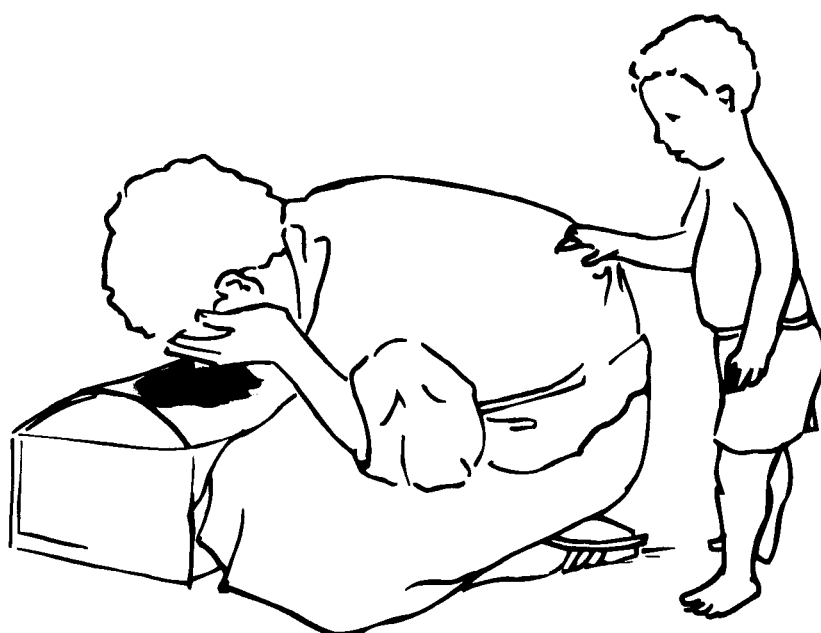
While she is having her blood taken in the clinic Yulia is worrying and does not know how she can talk to Mukasa about this or what to do.

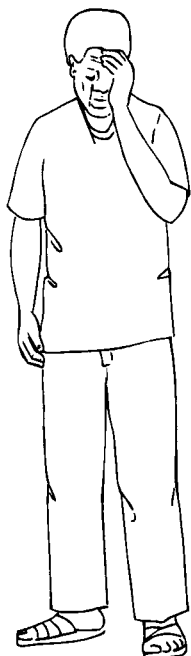
The doctor gives Yulia medicine for the baby to help with the vomiting. He also tells her many things but she cannot remember much. She is told to return in two weeks for the result of the test.

At home Yulia cannot tell her husband what the doctor said. She is sure that the doctor is wrong. She has known too many women and families destroyed by this disease and she tells Mukasa that the doctor gave her medicine for the baby to make him well. She does not go to find out the result of her test.

Late 1989

One night the baby dies, he got a fever and was suddenly gone. The family is very unhappy, but luckily Yokaana is healthy and tries to help his mother with her sorrow.

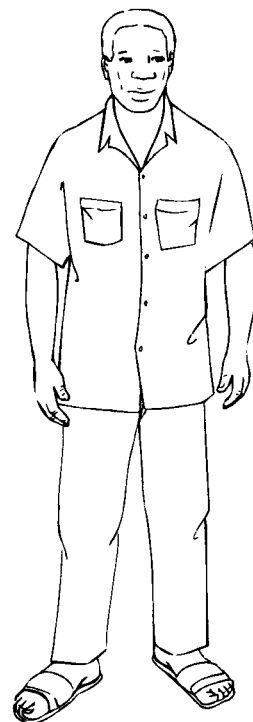


1990

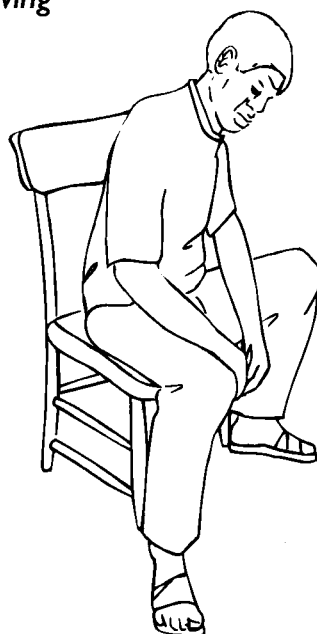
Poor Mukasa. It seems like he is always coughing now and he says he feels tired all the time.

He goes to the doctor and is given medicines for tuberculosis and instructed in how to take them. Mukasa follows the instructions and after some time he feels better and even returns to work.

Here he is after treatment for his tuberculosis was started.

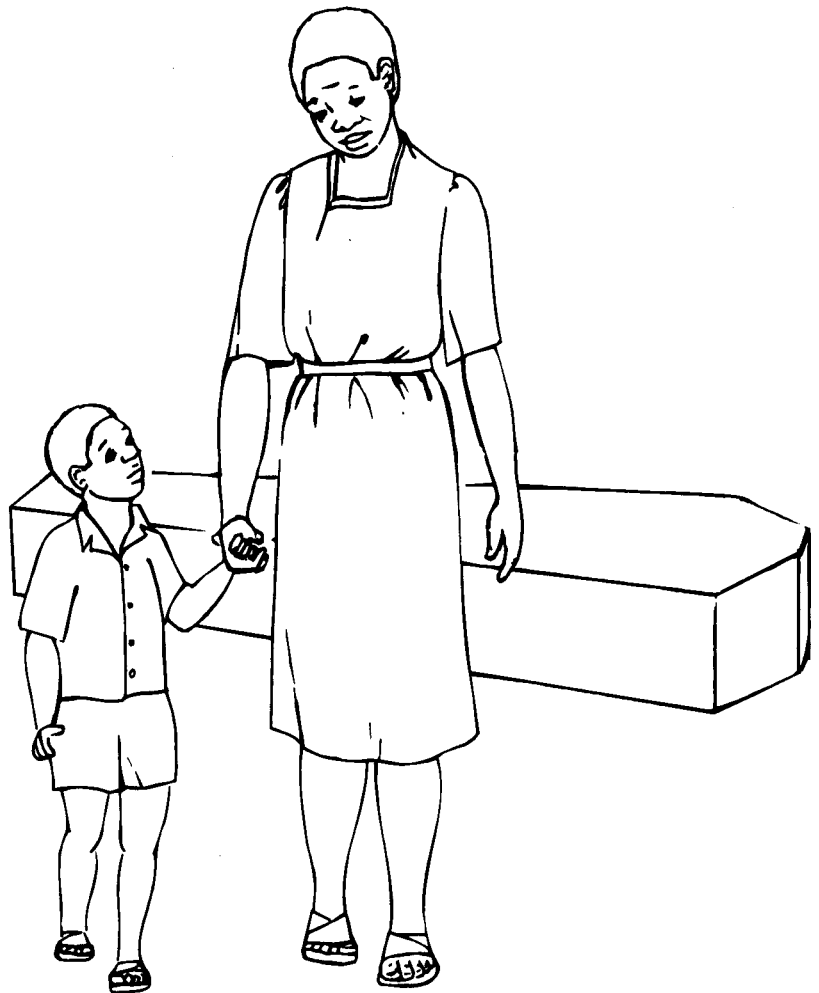
**1991**

Yulia is having to do more and more at the shop. Mukasa is often ill and too tired to help with the work. He loses weight and keeps having diarrhoea. Yulia has so much to do looking after the shop and the home as well. Mukasa gets medicines from the doctors and they help for a time but it seems he soon falls ill again.



Later in 1991

Mukasa died this night and was buried just near here.



The six months before Mukasa died were so very hard for Yulia. Mukasa was very ill and often harsh and irritable. It was a lot of work caring for him and Yokaana. She is very scared and sad. She feels well but in her heart she now knows that her family has been found by this terrible disease that has taken so many of their friends and neighbours. She is afraid for herself but even more for her child – what will happen to him and how will they support themselves?

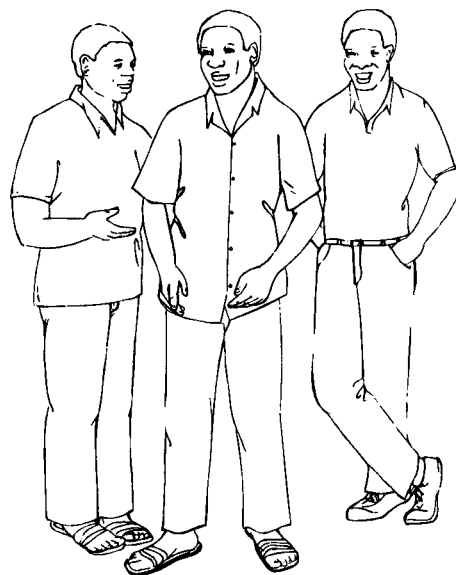
◆ Let us leave our story here for now and think about what has happened.

Teaching notes on HIV and AIDS

Take your audience back through the story, follow the course of the infection in this family and talk about what their story shows. An example of doing this is presented below in a way that you can use directly or adapt when teaching.

◆ What has happened to the family?

The story started when Mukasa had unprotected sex with someone who looked healthy but was infected with the human immunodeficiency virus (HIV). The virus was passed to him during sex. Look again at the picture of Mukasa after he came back from his trip to the city. By looking at him, you cannot tell that Mukasa is infected with HIV.

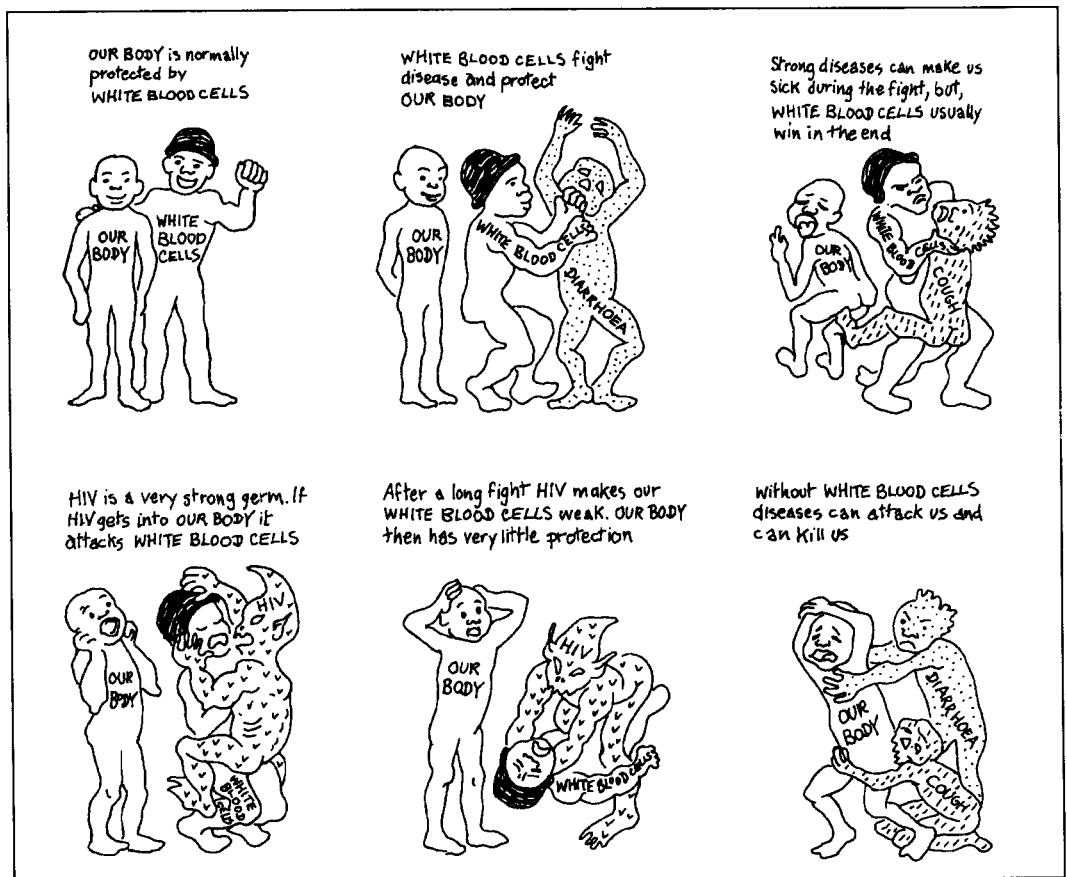


What are HIV and AIDS?

The disease AIDS – the **acquired immunodeficiency syndrome** – is caused by a virus, the **human immunodeficiency virus (HIV)**. Viruses are very small living organisms that cause many different diseases in humans, animals and even plants. Poliomyelitis (polio) is another example of a disease caused by a virus. Viruses are so small that even if thousands of them are put together they cannot be seen with the naked eye. In fact, viruses are among the smallest and simplest living things. They cannot reproduce on their own but depend on the animal or human they infect to act as a host. HIV reproduces in certain cells in human blood, called white blood cells (WBCs). These WBCs are a very important part of what is called the immune system. The immune system, with its WBCs, defends the body from infections – it recognizes things that are foreign or dangerous to the body and begins to attack them. It also starts to make specific substances called **antibodies** which are very active against the particular disease-causing organism that has infected the body.

When a person becomes infected with HIV, the virus begins to live and reproduce in the WBCs, multiplying until there are millions of viruses present. The WBCs begin to make antibodies to HIV which are found in the blood about six weeks after infection. Unfortunately, these antibodies cannot eliminate the virus completely from the body. The virus gradually damages the WBCs so that they can no longer do their job of protecting the body from infections, which healthy people can normally fight off without any problem. It is when these infections occur that a person is said to have AIDS. The bacteria, viruses and parasites present in the environment that cause these infections take the opportunity given by the weakened immune system to grow unhindered. This is why many of the illnesses that people with AIDS get are called **opportunistic infections**.

This process is described in a cartoon from Uganda shown below.



This may take many years. Remember how much time there was between Mukasa being infected to the time he began to develop the symptoms of AIDS. And also remember that Yulia still had no symptoms when Mukasa died.

For most of the time, people infected with HIV are healthy and usually unaware that there is anything wrong with them. It is not unusual for the period of time between infection with HIV and becoming ill with AIDS to be eight or nine years, and sometimes as long as 15 years. The length of time between infection and the appearance of AIDS can vary widely in different people.

Mukasa did not know he was infected. He felt well and was happy to marry Yulia. Certainly, no one around him thought he was infected. "Not Mukasa", they would have said. **So Mukasa became infected during his visit to the city and, without knowing it, was able to pass the virus to others.**

HIV, the virus that causes AIDS, is passed (transmitted) between people by the ways shown in the box below.

Box 1: Ways in which HIV is transmitted

- through unprotected sexual intercourse with an infected person; that is, intercourse without a condom
- from an infected mother to her unborn or newly-born child
- through contact with infected blood, for example by:
 - the transfusion of infected blood
 - the sharing of skin-piercing instruments, such as injection needles, that are not sterile

HIV infection is most often passed by sexual intercourse. It can be passed from either a man or a woman. A person who is not infected with HIV can take steps to avoid infection just as a person who is infected with HIV can take steps to prevent passing the HIV infection to someone else.

- ◆ **Mukasa passed the virus to Yulia during sex. What could he have done to prevent becoming infected himself or, if he had known he was infected, to protect Yulia from getting this infection?**

How can you avoid AIDS?

Abstinence (not having sexual relations at all) is the most sure way of preventing sexual transmission of HIV infection.

For many people, however, this may not be acceptable or realistic. The use of condoms and other safer sexual practices are the only ways of **decreasing** the risk of becoming infected with HIV or transmitting HIV infection to a sexual partner. Safer sexual practices are described in the box below.

Box 2: What is "safer sex"?

Safer sex is any sexual practice that reduces the risk of passing (transmitting) HIV from one person to another.

The best protection is obtained by choosing sexual activities that do not allow semen, fluid from the vagina, or blood to enter the mouth, anus or vagina of the partner, or to touch the skin of the partner where there is an open cut or sore.

Safer sex practices include:

- staying in a mutually faithful relationship where both partners are uninfected
- masturbation, massage, rubbing, dry kissing, and hugging
- using a condom for all types of sexual intercourse (anal, vaginal and oral)
- avoiding certain practices that increase the possibility of HIV transmission, for example "dry" sex which may lead to breaks in the skin
- avoiding sex when either partner has open sores or any sexually transmitted disease (STD)
- oral sex – this may be an acceptable alternative for some people, but oral sex should be avoided if there are sores present in the mouth or on the genitals

Couples should talk about sex and learn to please each other. This can allow for the negotiation of safer sex and make the intercourse more pleasurable for both and less likely to cause discomfort or minor damage to the genitals.

The use of condoms could have protected this family. Certainly, if Mukasa had used a condom in his relations with the woman before his marriage (or avoided premarital sexual relations altogether) this story might have been very different. Mukasa could not have known whether the woman he had

relations with in the city was infected, and for that reason he should have used a condom.

Condoms are best known as a means of preventing pregnancy. However, they are also the most effective means of protection against the organisms that cause sexually transmitted diseases, including HIV.

How do you use condoms to prevent pregnancy and HIV transmission?

Condoms are effective if they are used properly every time you have sexual intercourse. Instructions on how to use condoms are given in the box below.

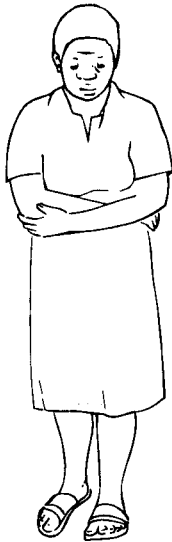
Box 3: How to use a condom

- Be sure you have a condom before you need it.
- Each time you have sex put a new and unused condom on the penis before it enters the vagina or rectum.
- Put the condom on only when the penis is erect.
- If you are not circumcised, pull the foreskin of the penis back before putting on the condom.
- Do not pull the condom tightly against the tip of the penis but pinch the end when unrolling it – this leaves a small empty space, to hold the semen.
- Unroll the condom all the way to the base of the penis.
- If the condom tears during sex, withdraw the penis immediately and put on a new condom.
- After ejaculation, hold on to the bottom of the condom as you pull the penis out, so that the condom does not slip off, then take off the condom carefully without spilling semen.
- Wrap the condom in paper (such as newspaper) until you can dispose of it in a toilet, a pit latrine or a closed garbage bag, or by burying or burning it.

The following tips will help to prevent condoms breaking or leaking:

- If lubricant is needed use a water-based one (like KY Jelly, or glycerine). Do not use a lubricant made with oil, like Vaseline, which can cause condoms to break more easily.
- Store condoms in a cool, dark, dry place, if possible. Heat, light, and humidity can damage condoms.
- If you have a choice, choose pre-lubricated condoms that come in square wrappers and are packaged so that light does not reach them.
- Open the wrapper carefully so that the condom does not tear.
- Do not use condoms that are sticky, brittle, discoloured or damaged in any way.

Drawings or teaching models can be very helpful in teaching people how to use condoms correctly. The types of instructions, drawings and models available for this purpose vary from country to country. You can use the written instructions provided in Box 3 to accompany any pictures or models you are using.



Unfortunately, because neither Mukasa nor Yulia knew what was going on, Yulia became infected during their sexual activities.

Now Yulia can pass HIV to others by the ways shown in Box 1. However, a test for HIV in the first 12 weeks after HIV entered the body could be **negative** because the test looks for antibodies to the virus, not the virus itself (see Box 4).

The mild illness that Yulia experienced at that time could have been caused by her initial infection with HIV. Most people experience a mild flu-like illness a few weeks after they become infected.

Shortly after her initial infection with HIV Yulia's body responded to the virus by making antibodies against it.

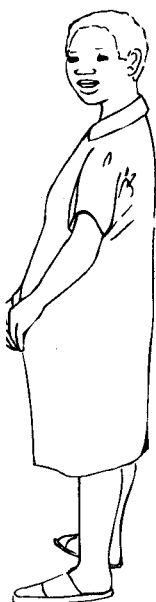
Now her test for HIV would be **positive** because she has antibodies to the virus in her blood.



In this picture from the story Yulia is pregnant.

Like most couples, Yulia and Mukasa were very excited about the idea of having children. They did not realize they were infected or that there was any risk of passing this disease on to their children. Unfortunately, just as in the story of Yulia and Mukasa, people often learn they are infected with HIV only when one of their children becomes ill with AIDS.

Couples who know that one or both partners are infected with HIV will need information about pregnancy. You can be helpful in discussing the issues surrounding pregnancy and HIV infection, and can help them come to a decision that is right for them.



Box 4: HIV Testing

What is an HIV test?

Shortly after infection with HIV, the body starts to respond by making antibodies against the virus. This usually takes 8-12 weeks. An HIV test can find out if these specific antibodies are present in the blood – it does not detect the virus itself.

What do the results mean?

- *A positive test result in a person over 15 months old means that:*
 - The person has antibodies against HIV, and is thus HIV-infected and can transmit the virus to others (see Box 1).
- *A positive test result in a child under 15 months old can mean either that:*
 - the child is infected with HIV, or
 - the child is not infected with HIV, but has received antibodies against HIV from its mother, in the same way as many other antibodies are transferred during pregnancy.

Because of these two possibilities, it is impossible to tell if a baby is HIV-infected until it is at least 15 months old, when the antibodies from the mother are usually no longer present.

- *A negative test result can mean either that:*
 - the person is not infected with HIV, or
 - the person is infected with HIV, but has not yet made antibodies against the virus. (This is sometimes called the "window" period.)
- *The HIV test:*
 - does not provide any information about a person's present state of health
 - does not determine if a person has HIV-related disease
 - cannot tell when or how a person became infected with HIV
 - does not provide any information about whether a person with HIV infection has transmitted the virus to anyone else.

Because the results of an HIV test can have dramatic effects on families, relationships, employment and the individual's own psychological well-being, it is important that people be tested only with their consent, that they be counselled before and after testing, and that the results be kept confidential, that is, shared only with the individual, or others designated by the individual.

Look again at the picture of the family after the birth of Yokaana.

See how happy they are? As a baby Yokaana had antibodies against HIV which were passed to him from his mother's blood during the pregnancy. However, no HIV was passed to Yokaana during the pregnancy. His blood test would be **positive** at this time but it would not mean he had HIV infection. This is why doctors cannot easily diagnose HIV infection in children until they are 15 months of age, when all of the antibodies from the mother are gone from the baby's bloodstream.



Look again at this picture of the happy family, now with a new baby.



What you and the family cannot see, is that this baby was infected during the pregnancy. Just as with Yokaana, the blood test of this baby would be positive because of antibodies he received from his mother, except that this time the baby really is HIV-infected.

You might wonder why this new baby became infected but not Yokaana.

Approximately one-third of babies born to women with HIV infection are infected with HIV themselves. Whether an infected woman passes HIV to a baby appears to be influenced by many factors, which scientists and doctors do not yet understand.

AIDS in children is very much like AIDS in adults. However, in children the disease is more difficult to diagnose correctly, and the blood test cannot be done with certainty until the child is at least 15 months old. Small babies and children with AIDS often have fever, diarrhoea and coughing, and do not gain weight prop-

erly, but these are common symptoms that may also have other causes. This long period of uncertainty is very difficult for families. We shall talk more of this later.



Later, the baby became ill with fevers and diarrhoea.

Babies develop the symptoms of AIDS after infection with HIV more quickly than adults do. This is because their immune systems are less developed and they cannot resist HIV or fight opportunistic infections as effectively.



Look at this picture of the whole family together. This picture is very important. It shows not only the infected child but also Yokaana, the first child. Yokaana remains uninfected even though he has been living with three other members of his family who are infected with HIV.

Think of all the things this child did with his family (all of whom were infected), yet he remains free of the virus.

Clearly you can be very close to someone with AIDS and not catch the virus.

Yokaana's contacts with his own family, the community, and his environment included many of the things listed in Box 5, yet he did not get the virus. Yokaana helps us to see that it is not only important for people to understand how it is spread. It is just as important to understand how it is not spread.

Box 5: Ways in which HIV is not transmitted
Ordinary social contact:
<ul style="list-style-type: none"> • physically close <ul style="list-style-type: none"> – in the same home – breathing the same air; coughs and sneezes – at work – on the bus – at the market – at school – playing together • touching <ul style="list-style-type: none"> – shaking hands – hugging – kissing on the cheeks, hands or forehead
Sharing:
<ul style="list-style-type: none"> • toilet seats • towels • washing water, bath water • swimming pools • eating and drinking utensils • communion cups • work tools
Being bitten by:
<ul style="list-style-type: none"> • mosquitos • bed bugs • other insects • any other animal

Otherwise, as people begin to see AIDS as a serious problem, they may panic and reject infected people. They may isolate them and their families. These reactions are deeply upsetting for people who are already facing the trauma of AIDS, and they are unhelpful in stopping the transmission of HIV. If people are not encouraged to share the problems they have, then they cannot receive help from their families and enjoy the time they have together.

Another point that came up in the story is told by the two pictures below. Mukasa was treated for his AIDS symptoms at the clinic and became well enough to work again. He had tuberculosis, one of the problems that is common with AIDS. Treatment of this and other HIV-related conditions can make a big difference to how long people with AIDS live and how well they feel. This will be discussed in greater detail later in the handbook.

