



## CHAPTER 1

# HIV is no longer a death sentence

### Lefa's story

Every year since he was 7, Lefa has been too sick to sit for his end-of-school-year exams, so has never been promoted, returning every year to grade 3. Although he is now 10 years old, he is the same size as the 7-year olds in his class.

Lefa has lived with his grandparents since his father, a long-distance truck driver, died of AIDS, and he and his mother Justina came to live with her in-laws. They were glad to turn over the cooking and cleaning to Justina, but soon she too became ill. She started having headaches and seizures, and there were days she could not get up from bed. Before she died, she made Lefa promise that he would take care of his grandparents.

But Lefa did not grow well, and it was more and more difficult for him to clean the yard and help in the garden. Lefa's grandmother knew that something was wrong, but she did not think of HIV. No child his age could have HIV and still be alive. And even if he did have HIV, what could they do? There had been no help for her son and Lefa's mother.



By the time Lefa was 11, he was sick most of the time. He hardly ate anything and was always coughing. As she had many other times, his grandmother took him to the clinic – a four-hour walk, and then an hour in an expensive taxi to get there. Luckily a new doctor had arrived, one who was committed to treating HIV in children. She took blood for a test and told him to return the next week.

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Although it was a hardship, they came back. The journey just about wore Lefa out, not to mention his elderly grandmother. The doctor gave ART medicines to Lefa's grandmother and explained how and when the child should take them. She encouraged them both, saying the treatment should help Lefa recover his health.

When Lefa and his grandmother returned to the clinic 4 weeks later, he had much more energy and had already gained 15 pounds! He ran through the clinic hugging all the nurses, proudly telling them the names of the medicines he takes and when. While Lefa is unlikely to grow much taller, his learning may catch up to his classmates in school, and then: Who knows?



*I could tell he had AIDS. But to be 11 years old and still alive, he must be very strong. With ART, he will thrive!*

Lefa is unusual because most children with HIV who do not get treatment will die before they are 1 or 2 years old. For whatever reasons, he was strong enough to fight HIV for 10 years, although it often made him sick, stunted his growth, and left him weak. But as soon as he started taking antiretroviral medicines, he began to improve. Imagine how different his life could have been if he had started antiretrovirals when he was a baby.

Starting a child on ART as soon as you know she has HIV is best for the child. It is the recommended and increasingly the real practice throughout the world. The sooner a child starts taking ART, the more strength she will have to fight other illnesses, to develop her mind and spirit, to grow physically and to live a full life — she can even have children of her own if she wants to, and then play with her grandchildren!

### **Children have the right to care**

All children, whether they have HIV or not, need healthy food, clean water to drink, loving attention, and a caring community to grow up and be healthy. Providing this can be challenging for all parents, whether or not the family is affected by HIV. If the child has HIV as well, she (and anyone else in the family who has HIV) also needs ART treatment as soon as possible to stay alive and healthy.



## HIV treatment is a second chance

Many people fear HIV, because they remember a time when HIV infection could not be treated. They watched their family members, friends, and neighbors slowly die, often in the prime of life.

But now, antiretroviral therapy (ART) medicines developed in the last 20 to 30 years let people live a long, healthy life with HIV. With care, community, and support, HIV need not make people suffer and die.

*I was pregnant when I found out I had HIV. At first I was scared, but now I'm grateful I found out. I take ART, am well, and care for my baby as she grows.*



If you have HIV, you may have to make changes in your life, habits, and thoughts in order to live a healthy life. Getting enough sleep, reducing stress, eating nutritious foods, and having good times are good for anyone, but especially for a person living with HIV.

Living a healthy life may also mean changing how you think about yourself and your relationships. You may have to learn how to stand up for yourself, say no to unfair demands, and care for yourself as much as you are expected to care for others. Support groups can help you know what you need and find the strength to make changes. See page 286.



I was diagnosed with HIV nearly 20 years ago, soon after HIV was first discovered, and nobody knew much about it. I was very sick and scared, and thought I would never feel hopeful again. One day, I started talking to the virus in my body. I said "OK, virus. Neither of us is going to go away any time soon. We have to learn how to live together." After that day I felt at peace, and was able to hope for the future and fight for my life. My deal with HIV keeps me alive.



When I found out I was pregnant, I married my boyfriend, even though he hit me. After I found out he gave me HIV, I still stayed. Before my second child was born, I realized I wanted my daughter's future to be better than the life I was living. So I left him. I started taking ART and eating healthy food. Now, I counsel other women — and their daughters — on how important it is to be assertive.

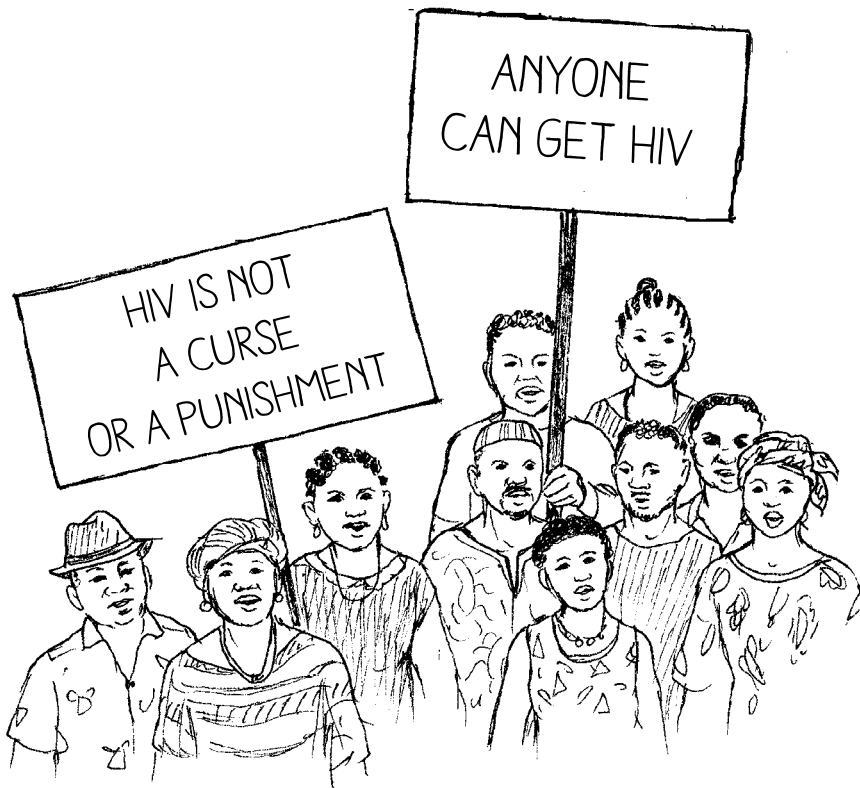
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If you have children who may also have HIV, getting them tested to confirm a diagnosis and then beginning their ART is necessary if they are to survive to live a long, healthy life. This book can help you learn how to do that.

When you and your family learn what HIV is and how to manage it, you can better care for yourselves and others in your community. You can also help eliminate the stigma around HIV often caused by people who are not aware of the advances in HIV treatment. Many still do not know that HIV is something you can live with, and does not easily pass to others.

### **Understanding HIV**

HIV is a virus, which is a very small germ that causes infection or illness. All kinds of people can get HIV – young or old, rich or poor, men or women, people from any profession, race, or religion. Some children are born with HIV.



## What HIV does in the body

HIV stands for Human Immunodeficiency Virus, which means it happens to people (humans) and makes them more easily become ill because the virus makes their immune system weak (deficient).

HIV infection attacks CD4 cells. The CD4 cells in our blood are part of the immune system, which defends us against infections. A healthy person has a lot of CD4 cells that help fight off many diseases. Our skin, our blood, and even our mucus and saliva (spit) are all part of this immune system, which helps prevent diseases from entering our bodies and making us sick.

When a person is infected with HIV, the HIV takes over the CD4 cells and uses them to make more HIV, killing the CD4 cells in the process. Without treatment to strengthen the person's immune system, the HIV takes over more and more CD4 cells, sometimes slowly, sometimes more quickly. As a person's immune system becomes weaker, his body can no longer fight diseases.

You cannot tell if someone has HIV infection by looking at them or watching their behavior. A person with HIV may not know either, and may live with HIV for many years without developing any serious illnesses or looking sick.

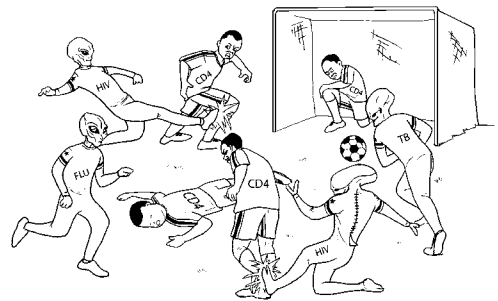
## HIV affects children differently

HIV infection makes babies and children ill faster than it does adults. While adults can take 8 to 10 years to show serious signs of illness from HIV, babies born with HIV often become sickly or die within their first year. Without treatment, many babies with HIV infection die before they reach age 2.

One reason HIV worsens more quickly in children is that, unlike adults, a baby does not have a fully developed immune system. All babies are born with some protection from illness shared from their mothers and they get more from breastfeeding. As children grow bigger and more able to do things, their immune systems develop too, partly in response to fighting illnesses.



**When you first get HIV, the body stays strong...**



**...but after a while, HIV attacks and weakens your defenses against sickness.**

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But babies infected with HIV do not get the chance for their immune systems to develop fully because HIV takes over their CD4 cells too quickly. Without treatment, babies cannot fight illnesses and most will die.

Another difference for children is that HIV infection can harm how children grow during their first few years of life, which is the time they learn and grow the most. Moving, speaking, understanding — all the abilities that change so much during the first 5 years — depend on the healthy growth of a child's brain and nervous system (the parts that connect the brain to the whole body). HIV can infect this system and make it harder for children to develop well. So without treatment, HIV causes some children to develop disabilities as they grow.

HIV tests are used differently in children and adults because of babies' less developed immune systems and the protection they get from their mothers. See Chapter 8: How to know if your child has HIV.



### How does HIV spread?

HIV can spread when the body fluids from someone with HIV infection get inside the body of someone else. This most commonly happens through sexual intercourse. It can also happen when sharing or using unsterilized needles or other things that cut the skin, or from a blood transfusion. HIV can also spread when a mother's HIV infection spreads to a baby during pregnancy, birth, or breastfeeding.

People at the very beginning of an HIV infection have a lot of HIV in their blood for just a few weeks, even if they do not feel ill. It is very easy to infect others during this time through sex or any of the other ways of sharing fluids. Unfortunately, most people do not know they have HIV right after being infected.

Because sex and childbirth are such common activities, they can spread a lot of HIV. But HIV does not spread casually like many other diseases: you cannot get HIV through the air from someone coughing or sneezing, from touching shared objects such as dishes, clothing, or door handles, or from sharing water or food. It is just not possible to spread HIV through these ways of being together.

There are more than 60 different types of HIV, including the most common types, HIV-1 and HIV-2. It is possible to get more than one type of HIV, so always practicing safer sex, where body fluids do not pass between partners, is important for both you and your partners even if one of you already has HIV. See pages 107 to 109.

## How do you know you are infected with HIV?

When a person is first infected with HIV, he may not even know it. He might have a fever, headache, rash, or upset stomach — problems common with a cold or the flu. Many people do not get sick at all. During this first stage of HIV infection, people have a lot of HIV in their blood and can easily infect others. After a few weeks, the immune system partially controls the HIV, but cannot get rid of it completely.

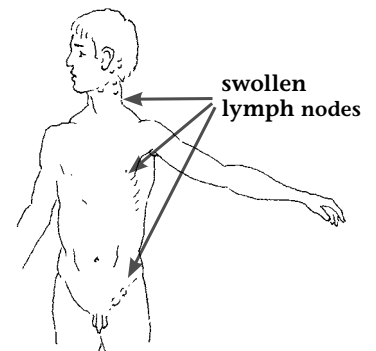
Adults often remain strong and healthy for years after they first get HIV because they still have enough CD4 cells to help fight off colds, diarrhea, and other illnesses. This is why someone can be infected with HIV and not know it — because he feels healthy. But all the while, the HIV is growing in his body, slowly making him less able to fight illness.

Some people may have early signs of HIV infection, such as swollen lymph nodes. The lymph nodes are part of the immune system and are found under your arm, on your neck, and in your groin area. They swell when the immune system is fighting a serious infection.



People with HIV may also get more coughs and sore throats than usual, or lose weight. Because all of these signs can also be caused by other problems, the only way to know for sure if you have been infected with HIV is to get an HIV test (see Chapter 8).

*If we both have HIV, why do I still have to use a condom?*



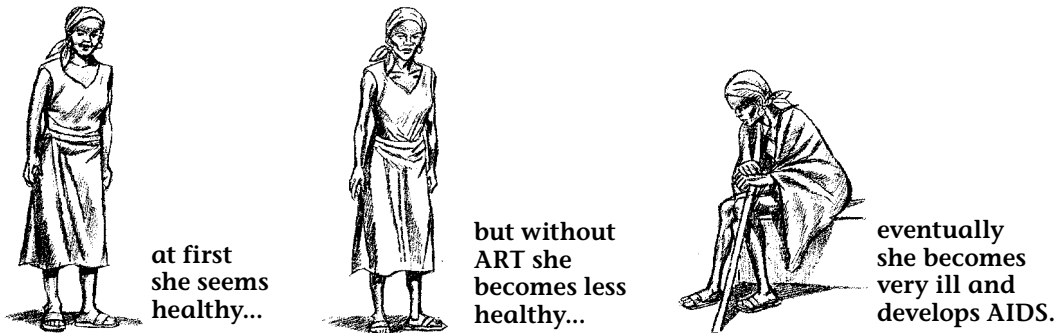
## What is AIDS?

When it is not treated, HIV can cause AIDS, which stands for Acquired Immune Deficiency Syndrome. AIDS is the serious stage of HIV illness that happens when someone does not take ART or if their ART stops working.

AIDS happens when a person's CD4 cells are mostly destroyed and he becomes unable to fight diseases. Usually, someone with AIDS has lost a lot of weight and has a lot of infections and skin problems. His illnesses are worse than usual, more difficult to treat, and keep coming back.

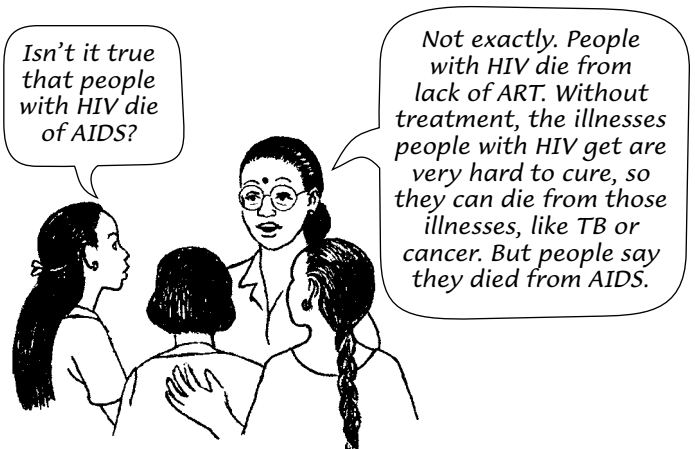
Adults with HIV who do not take ART usually develop AIDS in 5 to 10 years. Children with HIV who do not take ART usually develop AIDS in a few months to 2 years. But anyone with HIV who takes ART rarely develops AIDS now.

When a person has HIV...



If a person is unwell, AIDS can develop more quickly. For example, having tuberculosis (TB) or being malnourished when you have HIV can weaken your immune system more quickly, allowing HIV to kill more CD4 cells. This makes AIDS happen sooner. Because young children have undeveloped immune systems, they develop AIDS more quickly than older children or adults.

Illnesses affecting people with AIDS are sometimes called opportunistic illnesses, because they take advantage of a person's weak immune system to grow in the body. Without ART, children and adults with HIV will eventually die from tuberculosis, malaria, pneumonia, cancer, and other opportunistic illnesses. For more about these and other illnesses, see Chapter 12: Common Health Problems.





## Medicines for HIV

Although there is no cure for HIV, there are many ways to make living with HIV easier. Making sure that everyone has access to medicines, health care, emotional support, and enough food can help people live with HIV and also can help prevent the spread of HIV.

ART is important for everyone in any community affected by HIV. For people who have just been diagnosed, taking it prevents damage to and can even repair the immune system. Taking ART protects other people from HIV as well — if there is less virus in a person's body, it spreads less easily. Anyone can get HIV, so everyone who is sexually active or pregnant should get tested and, if needed, get the medical treatment that will keep them healthy and make them less likely to pass HIV to others.

*When I found out I had HIV, I was afraid of dying — and of making my wife and children sick. Now on ART I have lived to see my grandchildren and no one else has been infected.*

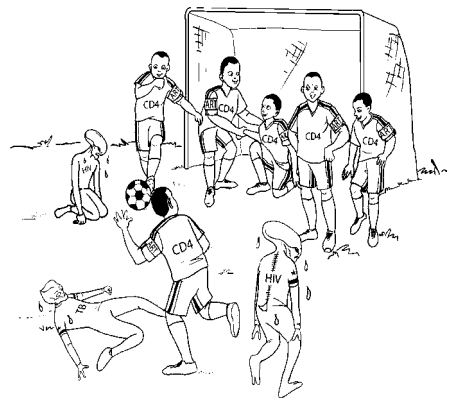


ART can also prevent HIV from infecting a person who comes in contact with the virus. Post-exposure prophylaxis (PEP) can prevent HIV after rape or an accidental exposure to HIV. Pre-exposure prophylaxis (PrEP) can prevent HIV in women or men whose partners have HIV or for those who do not know the HIV status of their sexual partner. For more about these ways to use ART, see pages 112 to 113.

## When should someone with HIV start treatment?

Although people may not feel ill during the first years of HIV infection, this is the best time to begin treatment. Early treatment keeps the immune system strong and the infection weak. Treatment can limit the HIV in someone's blood to such tiny amounts that it can barely be found by a test and will not easily spread to others. To keep HIV under control and stay healthy, people must keep taking ART every day.

Without treatment, or if treatment is stopped or missed too often, HIV will multiply and increase in the blood, making a person get sick more often, stay sick longer, and eventually die.



## When should children start treatment?

Babies and children should start taking ART as soon as you know they have HIV. Children need treatment as soon as possible because they have very little ability to fight illness on their own, since their immune systems are still developing. Without treatment, young children are also more likely to develop disabilities caused by their HIV infection. Treatment helps babies and children grow well.

## Everyone deserves access to ART



ART is necessary for children with HIV. Even a very sick child can take ART and regain her health. And now with ART, these children can grow up to have their own children born without HIV.

Taking ART is also very important for pregnant women, because it can prevent their HIV from passing to their babies during pregnancy and birth (see Chapter 7: Prevention of HIV in children and mothers).

But really, everyone deserves treatment — to stop HIV, and to have healthy families and healthy communities.

All over the world, people have fought together for their governments to recognize the problem of HIV and AIDS, and to provide access to medicines and social services — and we are still fighting. This book includes stories of communities working together, especially in Chapters 14 and 15.



When sufficient resources are not being made available for children and those who care for them, the human rights of people with HIV are being violated, and our communities' right to health is being denied. This is more true now than ever before.



We know now that ART medicines work, but large pharmaceutical companies and governments of wealthy countries are now making it harder for children and poor people to get the medicines they need.

We know now that nutrition is as important as medicine to keep people with HIV healthy, but food access, food sovereignty, and food for poor people are neglected or under attack by large agricultural companies and governments of wealthy countries.

Now that we know how to beat back both the spread and the harm of HIV, we cannot allow those with the power to stop it to turn their backs.

We have seen how food, medicine, and community action have brought a whole generation back to life from the edge of death. As this book shows, we know what must be done to end this epidemic. We must struggle together as individuals, communities, and countries to prevent as many new infections as possible, especially in babies and children, and for our right to live and be healthy with HIV. Because HIV is no longer a death sentence.