

How families take care of their HIV positive relations

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diseases and they die and leave children behind. There are others who just walk down the street and are knocked down by vehicles. So I have decided to take each day as it comes."

Caring for HIV positive people in the family means constant support. Every morning, Florence Akinyi weaves through the cluster of temporary shelters in Nairobi's Korogocho slums, to her older brother's house. Every day brings its own challenges and surprises.

A few months ago, she had to bathe her brother, turn him in his bed to prevent bedsores, and cook for his family. Her brother suffered from herpes zoster, a painful skin condition, around the waist. His wife was pregnant and sickly. She could not care for him.

The couple is infected with the Aids virus, but it is not a burden they bear alone. Akinyi knows and can care for them whenever they are put down by illness.

Akinyi lives a short distance from the couple's house, and she checks on them often to make sure they have taken their drugs.

Remembering the time she cared for her brother, Akinyi says: "I would wear gloves before bathing him. I explained what I was doing and why: I didn't want to infect him with any disease I may have in case of an open wound."

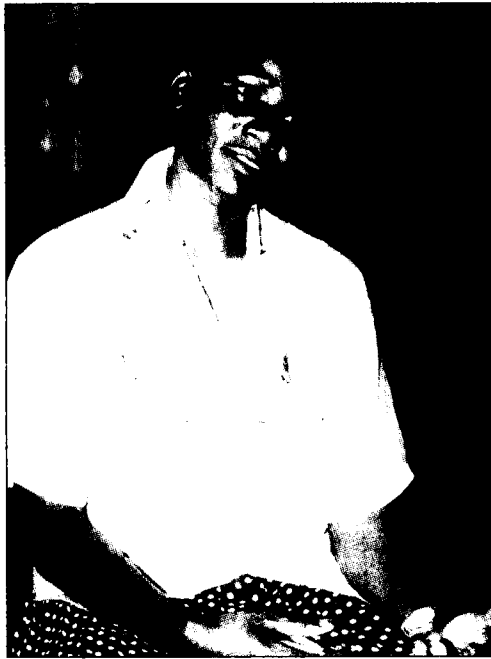
The gloves are to protect her from getting fluid from the patient into any cuts or bruises she may have on her hands. But the bath itself needs to have sugar, which acts as balm for the wounds.

There was a time when her brother looked at her with sad eyes and said, "I am dying now. Will I really come out of this?" Throughout the day, his sad voice hung in the air like a cloud, and Akinyi was afraid of losing her brother.

Akinyi had been through informal training on how to care for HIV/Aids patients, and knew from counselling classes that stress killed faster than the disease itself. Her brother was suffering from stress, and like many newly infected people, thought the ailment was going to kill him.

Sometimes, encouraging an infected person can seem like a lost cause. Although her brother pulled out of each crisis, he would never believe a word of what his sister was telling him.

She, too, was worried because he seemed to be getting worse. He would not hear of going to hospital.



Photos/Chris Omollo

Florence Akinyi: Caring for her brother.

"Why waste money when I am definitely going to die?" he reasoned. More people spoke to him and eventually convinced him to seek treatment. He is now better, but Akinyi still checks on him to make sure everything is alright and that he has taken his medicine. For most infections that HIV positive people suffer from, like tuberculosis, completing the dose can make the difference between complete recovery and recurrence.

Sometimes, all that the family provides for HIV positive people is an environment of confidentiality and trust.

When Margaret Mungai visited her home in Khwisero, Kakamega, and saw her only brother early in 2000, she was concerned. Paul Tito Omukuba looked ill.

He had not seen a doctor. Margaret insisted he get tested for HIV/Aids, and when the results were positive, he was not surprised.

"I asked him not to tell our sickly mother about it, and he promised not to. He also promised to tell his wife, who was then pregnant with their first child."

But Paul broke both promises. He went ahead

and told his mother that he was going to die of Aids, and his wife only knew about it on the day of his burial.

At his Eshirotsa Village home, he gave up on life, took to drinking and became weak. The next time Margaret visited in June that year, she decided to take him back to Nairobi with her to nurse him.

Creating comfort

She put him into her guest house and made sure he ate well and was comfortable. Questions about how he got the disease did not arise. "What he needed was love, not criticism. He was guilty and full of regrets and adding to this would not help anything. He knew he was going to die and as his sister, I helped him to be prepared spiritually."

Tito was sometimes strong, at others extremely weak. Opportunistic diseases assaulted him often, but when he healed, he was up and about.

During one of these instances, he went to watch a football match between Harambee Stars and Morocco at Kasarani early last year. After the game, he was unable to get into a matatu home as there were many people and he was too weak to push himself into one.

He waited until the commotion was over before getting onto a vehicle, and arrived home at 10 pm. By then his sister was frantic. She had feared the worst, and was greatly relieved when she saw him.

All the time he was ill, Margaret remembers, Tito never lost his sense of humour, making those around him reel with laughter.

And he also became close to his creator. When he could no longer get out of his bed, he insisted that his sister bring him a sacrament to take on his deathbed. He died on July 9.

When the announcement of his death was posted in the *Daily Nation*, it bore two red ribbons — the international symbol of compassion for people infected with HIV. His was the first Kenyan family to acknowledge the cause of his death in such a manner.

Taking care of her brother till his death has made Margaret compassionate about people suffering from Aids. "Every time I see an advertisement in the papers with the compassionate symbol, I check the address and visit the home. It is like I know them and I want to be there for them," she says.

So on Tito's first anniversary they held a football tournament, which is always a crowd puller, and took the opportunity to give information on Aids and offer free counselling and testing services.

PERSONAL EXPERIENCES



HOPE: Abel Etyang

Quite some distance to the finish

Death is the furthest thing from Abel Etyang's mind.

Despite the fact that he is HIV positive, Abel, 46, has a dream which he hopes will be realised before he dies. As he watches Aids orphans in his neighbourhood struggle to survive, he has a strong urge to help them. He needs five years, he says, to set up a home for them. Then, he will know he will leave his children and some other orphans with a roof over their heads.

Such a positive attitude did not come easy. When his status was disclosed to him, he was numb with shock.

"It is like a death sentence being handed down to you and you know you can't appeal." Etyang had been suffering from persistent tuberculosis and asthma before he went for the test last year.

"As I sat facing at the doctor, I thought of my two young sons. Fear of death and leaving them helpless shot me like a sharp weapon."

The doctor advised Etyang to visit a counsellor. In Korogocho, where he lives, counselling services are usually offered free.

By December last year, he had pushed thoughts of imminent death from his mind. He was thinking of life and how he would spend his remaining days to make the life of his sons, then aged 11 and seven, more comfortable.

Something else happened to him. He turned to God. "I hold God close to my heart. For the first time in my life I have felt peace."

A positive attitude towards life helped him to go to work every day until a few months ago, when he had to stop to take care of his bed-ridden wife.

Death takes time

Michael Onywere* was shy when it came to women. The fact that he had been crippled by polio when he was a child only compounded his fear of the opposite sex.

When he turned 30, his sister introduced him to a beautiful woman, whom he married early in 2000. She conceived immediately, but by the time she was three months pregnant, she was very sickly, and was given an HIV/Aids test.

When Onywere saw the results, he almost fainted. "I wanted to cry. A dark cloud descended over my life. I blamed my sister for getting me a wife with Aids."

The following day he did not report to work in town, where he was a shop attendant. When he was advised to go for testing, he stubbornly refused. Nor would he agree to use condoms, arguing that he was dying anyway.

He waited for death, but he did not feel any different as the days went by. At least not until the following year, when he suffered a bad rash. The pain was excruciating.

"I just lay there waiting to die. My skin was wasting but I blocked my ears to anyone advising me to go to hospital. What was the point?"

When the pain became unbearable, he was carried to hospital in a push-cart. After three weeks he had healed, and a few counselling sessions brought a change of attitude. He even got a job as a guard.

Since his wife is pregnant again, he has decided that the newborn will not be breast-fed. He knows now that with proper care, he will be able to see his son and daughter grow up.

At 23 and HIV-positive, Jeff's attitude is amazing. He says he stopped focusing on the negativity of his situation and takes his time to appreciate the people he loves, especially his family. "I have not given up on life, but if I were to die today, my affairs are order. Those I love know how I feel about them. I am actually, in a way, ready to die. Meanwhile I try to live a stress-free life."

— Kwamboka Oyaro

ANTI-RETROVIRAL DRUGS

Much-needed help for the weakening body

Although Aids still has no cure, there are a number of drugs that have been developed to help the body delay the complete destruction of the immune system.

These are called anti-retroviral drugs, and come in tablets and syrups. They can reduce the level of the virus in the body and halt the destruction of the immune system, thus putting off Aids and death for quite a while.

Once the virus that causes Aids enters the blood stream, it multiplies rapidly and increases its concentration in the body. The human immunodeficiency virus begins to destroy the body's protective killer T-cells faster than they can be replaced.

Once the immune system detects the virus — usually in the first three months of infection, it starts fighting it. Some infected people develop a rash, fever, fatigue or enlargement of the lymph node at this time. Others show no symptoms.

As the body effectively counter-attacks the virus, a person's killer T-cells, also called CD4s, increase and the load of virus in the blood-stream decreases. One may not have symptoms for up to 12 years, since the immune system becomes very efficient in fighting infection and checking the virus replication and infection of new cells.

After a few years, however, the

body loses its capacity to fight and is unable to replace cells as quickly as they are destroyed. That is when the virus level starts to rise, and the patient moves towards full blown Aids and death. But determining the level of the T-cells in the body will indicate the status of a patient's immune system.

There are about 1,000 T-cells per millilitre of plasma in a healthy person, but this can vary depending on factors like the time the count is done as circulation is different at dif-

ferent times. Those with T-cell counts of below 200 cells per millilitre easily get infections that take advantage of the body's weakness.

Some doctors recommend that one starts anti-retroviral treatment as soon as possible, while others like it delayed until the body starts failing. It is important to take anti-retroviral medication according to instructions, on schedule, and not to skip or reduce doses.

Taking precaution immediately after exposure to possible infection can revert one to HIV negative status. If rape and sodomy victims promptly seek medical attention and

start using anti-retroviral drugs, chances of HIV infection can be greatly reduced.

There are basically two types of anti-retroviral drugs: those that restrain the virus from multiplying, and those that decrease the quantity of the virus. Combinations or cocktails of anti-retroviral agents and protease inhibitors, together with a balanced, high-protein diet, can control lean body mass losses.

When one starts any anti-retroviral treatment, one may have

original virus. Sometimes, the new strains are resistant to drugs. Some mutations can keep multiplying even when one is taking an anti-retroviral drug. That is why doctors recommend a combination of drugs in therapy to prevent development of drug resistant strains.

Before drugs are registered, they undergo rigorous tests to ensure they meet the requirements of a country's drug authority — for example packaging, efficacy and safety.

Many generic drugs available have been certified by World Health Organisation for international tendering but have yet to be registered in Kenya.

The drugs are in the form of tablets, oral solutions, creams (for skin rashes) or capsules. They include didanosine tablets, lamivudine tablets or solution, ciprofloxacin tablets, amprenavir solution or capsules, aciclovir tablets or cream, abacavir tablets or solution, lamivudine, zidovudine capsules, tablets or solution.

In Kenya, many generic drugs are awaiting approval before they can be released into the market.

Even as an infected person takes anti-retroviral drugs, they need to manage the infections that take advantage of the body's weakness, referred to as opportunistic infections.

— Kwamboka Oyaro

Nevirapine makes the liver work faster, and can thus damage it

temporary side effects such as headaches, hypertension, or a general sense of feeling ill. These side effects usually ease or disappear over time.

Nevirapine makes the liver work faster, and can thus damage it. The major side effect of Nevirapine is a skin rash which affects more women than men. Nevertheless, you take Nevirapine with other anti-retroviral drugs, you can reduce your viral load to extremely low levels, and increase your T-cell counts. This should mean staying healthier longer.

Many new copies of HIV are mutations, slightly different from the

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