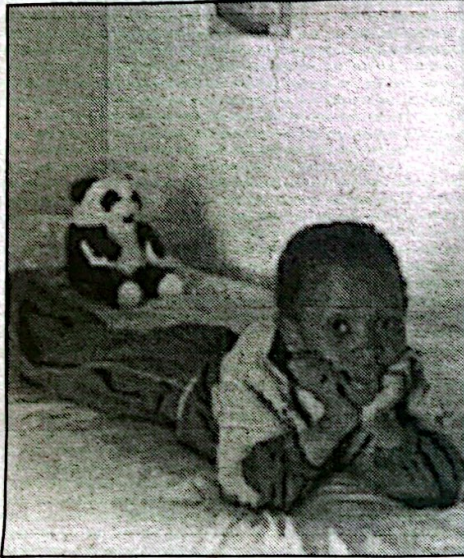
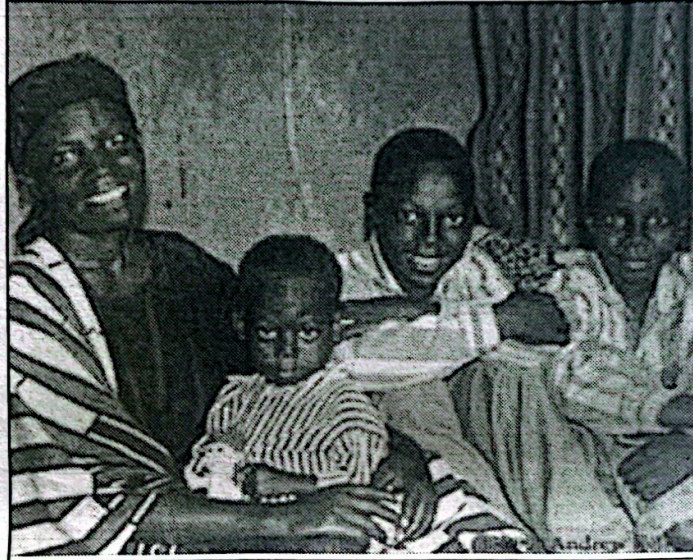


# No good blaming the dead partner forever



The late Nkosi Johnson from South Africa was the world's most famous child patient (File photo).



An HIV positive mother of three abandoned by her husband because of her sero status (File photo).

**JENNIFER BAKYAWA**, a fellow from Makerere University's Institute of Public Health (IPH) attached to *The Monitor* has been speaking to people trying to cope with HIV/AIDS in their personal lives and families. In *The Monitor* yesterday (see: 'You Too Can Defeat AIDS'), she recounted the amazing testimony of Richard Sserunkuma who overcame his own fears and now helps others live more positively. In this second part, Bakyawa brings us the story of Agnes — a family woman who almost went under after both her husband and child died of AIDS:

We had been married for 24 years and were a happy family. We had ten children. In 1991, my husband went to South Africa for seven months. I got a call on December 3, 1991 that he was very sick and had been admitted to hospital. I later received another call that he was arriving on Christmas day. The children were so excited. But I was surprised when I got the last message: I was not to go to the airport with the children. When the flight landed he did not come out immediately. He later emerged from the back of the plane with somebody supporting him. He had lost a lot of weight. As soon as I saw him I knew he had AIDS. He had all the signs. I thought: "Oh my God! AIDS in our family. What are we going to do for the children?" We had a large number of children. My husband had been born alone and he wanted many children. There was nobody to help me look after so many children. But I did not want to show him that I was shocked. When we reached home, every-

body was expecting the dad they saw going away but they saw someone very sick, weak. That was the worst Christmas for the children! Later, I went to talk to him. He told me he had been very sick for three weeks and had been diagnosed with cryptococcal meningitis, a fungal opportunistic infection in AIDS patients. He had been prescribed a drug, which was very scarce here and expensive. I used to buy it from a clinic in Luzira. Each capsule cost Shs 10,000 and he was supposed to take six a day. He had some savings, which we used to buy the drug. He started improving. He could even eat. However, we ran short of money. Friends would buy the drug for four days a week. But we eventually could not buy the drugs anymore. The meningitis returned and he was very sick again. We neither had the drug or an alternative. I had taken him to TASO but TASO (The AIDS Support Organisation) too did not have the drug. We painfully watched him die. After his death on June 27, 1992, I went for an HIV test and it was positive. I tried to cope but it was not easy. TASO counselled me but I had nowhere to start. I did not have any money. My husband had left three friends as caretakers who were very help-

ful. One of them helped me start a canteen that enabled me to feed the children.

I also had two cows that gave us milk. TASO took over my daughter who had just completed her PLEs. After Senior Six, she passed very well and was admitted to Makerere University. She has now completed her degree in Law.

In November, one of my sons became very depressed. He was talking about how he wanted to go to the newspapers and Radio Uganda to tell the public how his father was not such a bad man to have died of AIDS. His parents were very good, how come they got AIDS? I took him to hospital and he improved. However, he insisted that he wanted to go back to school in Fort Portal, where he was in Senior Four. I begged management to be patient with him. I just wanted him to keep at school; hoping at the end of the year, he would have more rest. But the boys started stigmatising him saying: "The other time you were confused. You were talking about your parents having AIDS. Your father died of AIDS. You are going nowhere. You will not even go to Makerere [Uganda's top university] even if you are very bright." He withdrew to his own world and stopped talking to other students for a week.

**'I feel that if the students had been sensitised about not stigmatising people affected by and infected with HIV/AIDS they would not have behaved the way they did. Maybe my son wouldn't have disappeared.'**

On the night of July 5, 1993 he disappeared from the dormitory. The students did not take it seriously at first. They thought he would return. On Monday, the students reported him missing to the school administration, which too thought he would return. It was not until Tuesday, when my brother had gone to check on him that they started looking for him without telling me. My brother came home to see me but it took him the whole day to tell me. First I went to Mulago Hospital to look for him. I was told there had been an accident in which a young boy was involved. I checked the body but it wasn't him. I went to Butabika [mental hospital near Kampala], and several police stations but he was not there. Announcements on radio and newspapers never brought any response. Up to today I have never seen him. I don't know what happened. Maybe if he had died, we would have found his body. I feel that if the students had been sensitised about not stigmatising people affected by and infected with HIV/AIDS they would not have behaved the way they did. Maybe my son wouldn't have disappeared. It really took me time to cope again. I almost went into a depression myself. Sometimes I would board a vehicle and go past my destination. It was as though I was in a trance. I would meet somebody I know but unless he tapped me I would not see him. I consoled myself that maybe God realised that with this boy who already had a problem I would fail to look after the others. Maybe he would have caused a lot of problems. I had to go on with the other children. Unfortunately, in 1994, my youngest son who had not developed any signs of AIDS before

started falling sick. He was five. He developed chest problems and colds. I treated him but he wouldn't improve. I kept on postponing taking him for an HIV test until it occurred to me that he could have TB and needed immediate treatment. When I took him, he too tested positive. I nursed my son for 18 months. It was the worst experience I have had. I was nursing him, well knowing that it is me who infected him. He was so innocent but had to go through the pains of AIDS. He was admitted on and off at Mulago Hospital. The doctors did all they could to save his life but he had had pneumonia and died March 9, 1995. I still live with that guilt knowing that I infected my child. I felt I should share my experience, especially with women. I want them to know that even if you are in marriage you can easily have an HIV positive baby. Once you test positive, it does not help to keep blaming your husband even if you know you have been faithful. Nobody wants to get HIV/AIDS.

**'I nursed my son for 18 months. It was the worst experience I have had. I was nursing him, well knowing that it is me who infected him. He was so innocent but had to go through the pains of AIDS.'**

Everybody has weaknesses even if they are aware of how to prevent themselves from getting HIV.

I don't even know — we could have got it from a dentist's tools. But my husband had two children outside marriage in 1988. And it is the same year I had my son who died of AIDS.

However, it does not help to keep on blaming your partner. It is better to face the problem, try to cope, help each other so that you can live a little bit longer and plan for the children.

Unfortunately, with my husband, because we had to buy the drug we did not have time to plan. I could not work because I kept nursing him.

The money we had, and could have used to plan for the children was spent on treatment. We were also living in a government house and knew that we had to leave anytime.

My husband had a plot where I tried to build a little house. His friends contributed cement and other materials. The iron sheets were already bought because we had earlier planned to build. However, it was also very difficult because I had to take the children to school.

My children also had to go through stigma that was still very high in 1992.

I felt I had to do something to change things for the better. At least, if two people in Uganda read my testimony, they may be more careful about infection, such as mother-to-child transmission or remain faithful to each other.

Editor's note: Agnes requested us not to use her surname name and photograph because her children are still being stigmatised.