

This month SPEAK brings to you the first part of a three part story from the book "We Miss You All: AIDS in the family". This is a true story about the experience of Noerine Kaleeba, a Ugandan woman who lost her husband and many other family members from AIDS

# We Miss You All:



## AIDS in the Family

### The day AIDS came into my house

AIDS came into my house on the afternoon of 6th June 1986 when the British Council sent a telex to tell me that my husband, Chris was seriously ill in a hospital in England. He had gone to Hull University for further training in 1985.

I often wonder what my life would have been like today if that telex hadn't come. I know now Chris was already very ill and dying, long before the telex was sent, but for me that telex was the beginning of my misery and suffering. When I

was given the telex, I was shocked. The message was clear. My husband was critically ill in a British hospital. He had been unconscious for three days. Had he been involved in an accident again? No. He seemed to have meningitis (this is a serious illness in which the covering of the brain swells). He was not in pain, but his condition was critical. The British Council staff were very concerned, offering tea and comforting me. They suggested I return the next day for more news.

I left, walking like a zombie. Fortunately, I had come with my friend Mary, otherwise I would

have been run over on the road. The following day I went back with my friends Margaret and Mary to the same news. His condition was still very serious. Everything which could be done was being done. Everyone was too nice and kind. I began to suspect he had already died. I wanted to go to him. He needed me. The Council people had to ask London first.

I went to a friend in the microbiology laboratory (where they test for germs and viruses) to ask him what he knew about meningitis. He suggested I find out what type of meningitis *Chris had*. I went back to the British Council with the question. The following day the answer came - cryptococcal meningitis (this is a fungal infection of the covering of the brain. It is the type of meningitis which is common among AIDS patients). My friend reacted in a funny way, and asked me if I was quite sure that it was cryptococcal.

I went back to the British Council and asked Debbie Vowels, who worked at the Council, to write it down for me. My friend in the laboratory asked me to find out if they had done an AIDS test. I wondered what the AIDS test had to do with it, but I went back the next day and asked the question. Everybody looked at each other. They said they would find out from the hospital in London, and asked me to come back the next day to talk to the doctor on the phone. I can't quite remember how I got through those days. I remember crying a lot. All I knew was that Chris was dying. When I went back the next day, Dr Symonds told me on the phone the AIDS test had been done and it was positive. I did not accept this news right away. I was already too filled with misery. I did not believe it. There was no reason whatsoever to link my husband with a white homosexual disease, which was what we knew in Uganda then.

I did not know the stigma (bad attitude) associated with AIDS, so I told my friends at work and the neighbours. I told my in-laws, and my parents. I told anyone who came to sympathise with me.

Meanwhile arrangements were made for me to go to Chris. My sisters came to stay with my children who suffered terribly throughout this

time. I was so shocked and sorry for myself that I did not know how to comfort them.

### **My first encounter with AIDS**

My first meeting with a person with AIDS was very short and I quickly forgot about it. Today the experience is very vivid in my mind.

I was working at Mulago Hospital as a physiotherapist (a medical person who helps to heal diseased and injured muscles). One day I wanted to show a group of physiotherapy students how to move a paralysed person from a bed to a wheelchair. I found a young man, about thirty years old, who agreed to be used for the demonstration. His medical notes said he was paralysed due to Immunosuppression Syndrome. I did not know what that was. When I told the ward sister which patient I had chosen for the demonstration, she came closer to me and said: "I wouldn't touch him if I were you. He has AIDS."





We don't touch him, we only show his mother what to do."

I did not use him for the demonstration, neither did I go back to him to explain that I would not be coming. I cancelled the class and arranged for another patient from the orthopaedic ward (the ward for patients who have diseases of the bones or muscles).

I did not think about him again, until AIDS came through my front door. Today there isn't a day which passes when I don't wonder what happened to him. With whom did he carry the burden? With whom did his mother carry the cross? What friends did she have to share her emotions? How much did he know about AIDS? What support did he have: God, children, loved ones? I suppose I will never know. ○



**Noerine Kaleeba at an AIDS conference in Kinshasa, Zaire in December 1990**

In next month's SPEAK we learn how Chris became infected with AIDS and how Noerine nursed him through his final illness.

*Noerine Kaleeba wrote the book "We Miss You All" with the help of two women, Sunanda Ray and Brigid Willmore, from the Women and AIDS Support Network (WASN) in Zimbabwe. The book is published by WASN. Noerine Kaleeba has received many international awards for her work in the fight against AIDS. SPEAK salutes Noerine for her courage and honesty in sharing her story.*

## The HIV virus can lead to AIDS

### You cannot get the HIV virus from:

- Toilets
- Hugging
- Kissing
- Cups, spoons, knives, plates, glasses
- Holding hands
- Sharing a bath
- Telephones, door handles
- Towels
- Sharing food
- Dancing
- Talking to, hugging or playing with someone with the HIV virus
- Crowded rooms
- Insects or mosquito bites

### How you can get the HIV virus:

- By having unprotected sex (sex without a condom) with someone who has the HIV virus;
- By sharing syringes (injections), razor blades or toothbrushes with someone who has the HIV virus;
- Mothers can pass the virus on to their babies during pregnancy;
- You can get the HIV virus through a blood transfusion if the blood is not tested. Hospitals in South Africa now check blood for the HIV virus before they give it to anyone.

### Remember:

Having safe sex by using condoms can help to protect people from getting the virus or passing it on.

Adapted from the booklet 'Love and AIDS' produced by the Johannesburg City Health AIDS Programme, PO Box 1477, Johannesburg, 2000.