

THE STORY SO FAR...

Kaleeba's family is stigmatised by neighbours and when she returns to work, she gets the same treatment from both friends and colleagues...

Fighting in the open:

When I returned home, I found that a lot of things had changed while I was away. The AIDS issue had exploded, as there were increasing numbers of people being diagnosed with HIV infection. At the same time, the issues of denial and stigma had really taken off. AIDS was shrouded in secrecy and gossip was rampant. Those who were diagnosed with the virus were frequently not told of their condition, but were talked about in moralistic and judgmental terms behind their backs. The fact that HIV is sexually transmitted became a reason to view HIV-positive people as sexually promiscuous, dangerous people, whose only aim was to spread the disease to others. Families were abandoning loved ones at the hospital after they were informed of the diagnosis. For me, this was the first time I had witnessed family abandonment by Ugandans. And it was the first time to be personally exposed to AIDS-associated stigma. I soon began to notice that this stigma extended to our children and to my sister, Rose, who was living with us, even though she had not, at that point, been diagnosed with AIDS.

This reaction to affected people was later explained to me by my good friend, Sandra Anderson, under whose mentorship I began my career within UNAIDS, a joint United Nations programme on HIV/AIDS, which took over from World Health Organisation's Global Programme on AIDS (GPA) as the main advocate for global action on the pandemic. Our friendship has continued to be a pillar of my resilience. Sandra described the successive "waves" of community reaction to AIDS as follows:

- First comes the wave of denial, where individuals, families, communities and, sometimes, the whole country, deny the existence of HIV/AIDS. They have elaborate reasons why they believe they cannot be affected by AIDS. They justify the stigmatisation and discrimination of those diagnosed with HIV among them by claiming that they bring shame to their family and community.

- Second comes the wave of fear, which erupts with the realisation that HIV is real, when denial is no longer sustainable. This enhances stigma and isolation of those who are or are perceived to be HIV-infected.

- Third comes the wave of awareness. This follows intensive sensitisation and is often the consequence of personal experiences of self or loved ones being diagnosed with HIV.

- Fourth comes the wave of acceptance, tolerance and community action. This usually happens after intensive awareness programmes, community involvement and model home care,



Kaleeba, the founder and Patron of TASO Uganda, standing near one of the paintings made for her by one of the children who was living positively

which encourage acceptance of the problem.

I began to notice that some of our neighbours were always anxious to move on whenever we would meet them. Some stopped coming to the house. At the same time, I should own up to the fact that I myself, in my resolve to be self-reliant and stand with my head held high, might not have made it easy for them to reach out to us. I now know that in my determination to remain strong and not rely too much on others, I might have gradually lost Chris' family support during this time.

Iwent straight back to work, where I also began to notice that some of my friends were finding it hard to relate with me. I learned that AIDS was being diagnosed more and more in Mulago Hospital. Barrier nursing methods – gloves and

BENT BUT NOT BROKEN
In PART 3, Kaleeba's husband Chris comes back home from the UK...

facial masks were in place on all medical wards. The Ministry of Health had instituted an AIDS control programme with a standard approach to infectious disease prevention. I was not prepared for the reaction of my fellow workers at the physiotherapy school and department. I would walk into the staff room and people would immediately stop chatting; suddenly it was time for everyone to go back to work. I knew that I was not spontaneously included in conversations, or people would talk

to me in excessively kind tones. I was surprised and hurt by this kind of treatment by fellow healthcare workers, who had access to information and were trained to be empathetic to people in vulnerable situations.

Since that time, I have often reflected back on my own attitude and behaviour as a healthcare worker and realised there were a number of times when I fell short of compassion in my approach towards patients before AIDS came to my house. I have deeply regretted these lapses and this regret has been

one of the motives in my taking up leadership on the AIDS care frontline.

As I have indicated, I felt betrayed by the negative attitude of my fellow healthcare workers. But I soon concluded that most of this could be attributed to the fact that there was scanty information on this new disease. The rumours around it were causing panic among the population, including healthcare workers. This panic was amplified by the fact that the disease linked two extremely taboo subjects: sex and death. This was the primary source of stigma among families and communities in Uganda and worldwide.

I realised that there was an urgent need to provide clear basic information. The campaigns launched by the Ministry of Health were inadequate because of their limited geographic reach. Furthermore, the theme of those early campaigns to "love carefully, love faithfully to avoid AIDS" seemed to reinforce stigma by implying that those who had AIDS had somehow loved carelessly and should be isolated and avoided.

It became very clear to me that if I were to fight this disease in an effective way, I would have to fight it in the open. I did not really have a timeframe, a definite plan, or considered strategies for how I was going to fight AIDS. But the one thing I was sure of was that the decision I had made not to retreat from the information I had shared about my husband's illness was right.

In any case, I did not really have a choice. I suppose I could have retracted the information if I had really wanted to. I could have said it had all been a mistake; that Chris had cancer or tuberculosis, both of which carried less stigma. But I decided instinctively to stick to the truth. It helped that Chris and I had discussed this before I left Hull and had agreed that we would remain open. I did not go around continually telling people that Chris had AIDS. But whenever I was asked what the prognosis was – that is, when someone gathered the courage to ask me directly, I would say the prognosis was poor and that because he had AIDS, it was only a question of time before Chris would die.

CHRIS COMES HOME

Idid not really know what to do, but hoped for the best. I was getting information on Chris' condition on a weekly basis from my friend Jan Webster and he was making progress. Just before the end of October, I got another message from Hull. This time it was that Chris was coming home. Panic! Either he had been thrown out of England, which I did not think was possible, or he had reached a stage where he would no longer benefit from further treatment, which meant he was coming home

Confronting AIDS stigma

to die.

I was able to speak with Chris on the phone and he told me he had asked to be discharged; it was his decision. He wanted to come home because he felt he had work to do to give AIDS a human face. He also wanted to come home and be with the family because he felt that life without us was just bare existence.

In those circumstances, I could not persuade him of the need to stay near excellent medical care. Truth be told, we also needed him with us; we were struggling without him and missed him very much. At the same time, I was very worried about how we would manage his medical care and how he would cope with the stigma that I had already experienced. But I knew I could count on his family, his brothers; Henry and William, his sister Margaret and his mother and father, who were all very supportive.

When I told them that he was coming home and his reasons for wanting to do so, they all agreed that it was probably the best option.

I cannot describe the joy in our house after the announcement that daddy was coming home! We decided to do some major cleaning and fumigation, as the need for Chris to be in a bacteria-free environment had been emphasised at Castle Hill Hospital. Every cockroach, every potential source of infection, had to go. We were determined to offer daddy an environment that was super-clean.

Before he boarded the plane from London, Jan had arranged for Chris to have two nights of rest at the London Lighthouse, a care centre that had recently opened as a half-way home for AIDS patients being discharged from hospital.

During those two days, Jan worked with Castle Hill Hospital and London Lighthouse to put together a big consignment of medicines and nursing care materials which they shipped to Uganda to support Chris' ongoing care. These came in extremely useful during Chris' final days and whatever was left over after he died was used in the early days of TASO's homecare programme. The medical supplies were intended to provide palliative care, because, of course, antiretroviral drugs (ARVs) had not yet been developed.

The day came when Chris finally reached home, accompanied on the journey by our friend Jan Webster, who, as well as being the British Council's welfare officer, was also a qualified nurse.

My sister-in-law, Betty Nalwanga Njuki, who had a job at the airport, had arranged for an ambulance to be available on the tarmac at the arrival gate to receive him. Nobody imagined that he would



TASO clients who live with HIV/AIDS performing at Bomah Hotel during an experience-sharing workshop organised by Civil Society Fund for 46 civil society organisations in northern Uganda a few years back

be able to walk after such a long flight, so when he did walk off the plane leaning on Jan's arm, it was a tremendous boost for me and for the whole family who were at the airport.

Among those at the airport was a large group of people who I did not even know at the time. Word had already spread, largely from people around me, who I had informed about Chris' intention to come home. Many came to the airport to see with their own eyes what an "AIDS victim" looked like.

Chris handled the situation brilliantly; he was very happy to be home. The children were excited, but also puzzled that their daddy did not want to hug them — he was still unsure about whether or not he might be contagious. We stopped at Chris' family home, where a large meal had been prepared.

Chris ate more food than he had eaten in months. Amazingly, he did not throw up! After this, he was always able to eat and retain small amounts of his favourite local foods. He would subsequently refer to that day and the experience of being with family as "getting a new lease on life".

Before Chris came home, I had

held many discussions with God. I constantly prayed for a miracle; Chris coming home that day was the first miracle I can recall in my entire life. I was later to record another miracle — my own continued good health and the opportunities I have had to make a difference in the lives of my family and other people affected by HIV/AIDS. But the first miracle was definitely when Chris came home — a miracle of nearly two whole months living as a family again in our third floor flat at Buganda road.

From the airport, we had arranged for Chris to be admitted for a few days in Mulago Hospital. We expected he would be tired and would need time to rest and recover from his flight, under medical observation. He was in hospital for only two days, but during that short stay, we were exposed to the full force of what it meant to be known as an AIDS patient in Mulago Hospital at that time.

Despite being admitted in a private room, on the private wing with the best facilities, we were



Kaleeba displays some of the awards she received for her campaigns against HIV/AIDS awareness

exposed to subtle stigma and made aware that healthcare workers had no time to waste on us. Only Dr Edward Kigonya, the then medical director of Mulago, to whom Chris had been directly referred from the UK's Castle Hill Hospital in Hull, checked on us while we were there. The nurses were most

unwilling to go anywhere near our room. My friend Mary and I did all the necessary hands-on caring. Fortunately, he only needed to rest and after two days, we left the hospital. I made a mental note never to bring him back and resolved to give him whatever care he needed myself in the future.

DON'T MISS PART 4 TOMORROW in Sunday Vision