

talking point



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Treated like an outcast because of HIV status

Tough life. Folding her legs while seated inside her one-roomed house she rents in the Kampala suburb of Nakulabye's Kiwuunya Zone, Sylvia Nalukwago speaks to Lilian Namagembe about the stigma she has had to put up with, growing up as an HIV-positive child.

Who is Sylvia Nalukwago?
I am a 24-year-old mother of a two-and-a-half year old girl, Miracle Mirembe. I am the second born in a family of two children. I was born with HIV and I have grown up with it for 24 years. My mother died when I was two years in 1996, and I was taken to live with one of my paternal aunts in Kamwokya in Kampala, not far from where my father, who was a plumber, rented. I started school at one of the schools on Mawanda Road in Kamwokya and studied up to Senior Six.

As a person who was born HIV-positive, what are your childhood memories?

All I remember is that I was stigmatised a lot and I didn't know why. At my aunt's place, it was a big family with 11 children, who were much older than us, most of who, were adolescents and a few adults. They could not eat things that I had touched. One day, I wanted to celebrate my birthday and I bought a cake of Shs1,000 to give everyone a piece. Since they already knew that my mother died of HIV, they refused to eat it. It is only my auntie who stood by my side, treated us equally [me, my elder brother and cousin] and did not mind about my illness but I realised later that she had already suspected that we were all HIV-positive.

Did the kind of discrimination continue throughout school?

My schoolmates did not treat me very badly, only that they used to undermine me because I was so small. In Senior One, they used to call me "small atom". So, I hated such names. But I had a friend who could challenge me and one day, he told me: "Sylvia, since you are very small, go back and ask your mother. You could

LAST WORD

Call for help. I have managed to leave a positive life and do handicrafts and knitting, which I learnt from the Internet. I was once a receptionist at the National Organisations of People Living with HIV/Aids in Uganda, but have since left because the maids could not take good care of my daughter. I ask whoever can help me with financial capital to grow my crafts and knitting business. The father of my child no longer has a job and can no longer take care of us. I would ask anyone out there to get him a job so that he can take good care of us.



Enterprising. Ms Sylvia Nalukwago shows off some of her handicrafts that she makes to earn a living. PHOTO BY MICHAEL KARLAIRI

be having a cardiac problem or maybe you were born with HIV." So that always hurt me a lot and I also heard that my mum died of HIV/Aids. I was in a dilemma and when I asked my aunt, she told me my mother was just bewitched. I kept wondering and even became more confused. I didn't understand what was going on.

How did you eventually get to know about your HIV status and how did you manage to live with it thereafter?

When I was in Primary Seven, we went for holidays in the village and the water gave me a rash on the body. One of my cousins even asked whether my other relatives had not told me that I was born with the disease. I became suspicious and it hurt me, but I ignored them. I, however, continued to hear rumours among my cousins. My father would also come home to check on us but I did not tell him because I did not take it serious. My auntie had assured us that our mother had died because of witchcraft. So, I ignored whatever my cousins said. At 13, I went to Kamwokya Christian Caring Community (an ART centre) when I saw a signpost written on "Free HIV testing for children one to 18 months." I went to test. The counsellors were hesitant and insisted on knowing why a 13-year-old would come to test, wondering whether I was sexually active. But I told them I just wanted to know and they accepted. They, however, told me I had to come with an adult to collect the results; my father refused. It is my auntie who went with me the next day. I got the results and I was found to be HIV-positive. I cried, but they counselled me and I became strong after two weeks. My auntie said she already knew, but my father did not want us to

know. They also started me on Septrine.

What strengthened me was the support from my aunt and elder brother. I also got saved [born again] in 2008 thereafter. I joined the Scripture Union at school where we prayed together. So I strengthened myself and said this is not the end of the world.

So how have you since managed to survive?

At one time, I went out with friends to Pablo's [comedy] show and met other young people who are HIV-positive. From there, I got to learn that there are very many young people mistreated because of their HIV status. I resolved to open up and tell everyone to be a hero. Indeed, we have since inspired so many organisations, which have been taking us to young people at school and on radio stations. I was also able to reconcile with my father, as he had disowned me, and I forgave him. I was the one who nursed him at the time of his death in January.

What in your opinion is Uganda's biggest problem in the fight against HIV/Aids?

The biggest challenge is that they have failed to involve young people with HIV/Aids to speak about their problems.

What has been your best moment in the whole struggle with HIV/Aids?

I have managed to come out to speak for those who cannot speak for themselves because it has helped many. I have also got friends and met many people I never expected to meet. I, for example, met the First Lady, Janet Museveni.

I have also since composed a song to encourage mothers living with HIV/Aids to prevent their babies from contracting the disease.

Nalukwago's TOUGHEST MOMENTS

Trouble at school. In 2011 when I was in Senior Five at one of the schools in Gayaza, Wakiso District, the matron checked my suit case on the first day and said: "You came with this medicine to commit abortion. Here, we don't commit abortion." My father came to school to explain. Another time, the headmistress called me to her office and told me to use my status and speak to other students to abstain. But I was not ready to open up because I feared stigma. The headmistress became annoyed and even refused me to go back home for my medicine. She asked me to wait for Visiting Day. I missed my medication for two months and was later diagnosed with pneumonia, which later developed into obstructed pulmonary disease. I would get attacks with breathing difficulties and had to use an inhaler. In my second term in Senior Five, the headmistress found me with another colleague,

who was also HIV-positive, in the dormitory during class time because we were not feeling well. She ordered us to pack our stuff and leave the school, saying she did not have a hospital at the school as we were often sick. We first thought she was joking, but she came back with a cane and threw us out and asked us never to return to her school.

Father disowns her. On going back home, I found my father bedridden. He could not pay my school fees at another school. So I went back to Kamwokya Christian Caring Community, which paid my school fees at a different school where I sat my Senior Six. My father, however, disowned me during my Senior Six vacation, saying he was also tired of taking care of me. He said I should go and look for my uncles to show me my "biological" father until I left home. I was depressed and even withdrew from ARVs for nine months, which I had started in 2011 until I was put on line two of medication.

BUKEDEA DISTRICT SERVICE COMMISSION ADDENDUM NOTICE				
This is in reference to the district service commission advert that appeared in the daily monitor on 06/12/2017				
1. BUKEDEA DISTRICT LOCAL GOVERNMENT				
Department	Position	Reference	Salary Scale	No. of Vacancy (es)
Education	Education Assistants	BDSC/BDLG/EDUC/06/04/2017	U7	15
2. BUKEDEA TOWN COUNCIL ADMINISTRATION				
06	Town Agents	BDSC/BDLG/ETC/011/06/2017	US	02
Secretary, Bukebea District Service Commission				