

FROM VICTIM TO SURVIVOR

By Irene Nkosi

Good evening ladies and gentlemen. My name is Irene Nkosi. I am an HIV positive mother, breadwinner and wife.

I am employed as a Mentor Mother at mothers2mothers, an NGO committed to ending paediatric AIDS and improving the health of mothers and their families.

That is where my life has brought me. To a good place. But it did not begin well.

I have lived my life in two halves. I need to say that for the first half, it was as bad as a life can be. At five years old when most little girls are loved and play with their friends, I was neglected and emotionally abused.

By the age of 16, not really even a woman yet, I was a parent. I was also the victim of rape and my attacker was never jailed.

When my baby, Lindokuhle was 6 years old, I fell pregnant for the second time. I went to the clinic to verify my pregnancy and here I was given the news I was HIV positive.

Now I was sure. No-one loved me. Not even God.

The clinic just gave me tablets. They didn't educate me about HIV or how to protect my baby from infection.

I was heart broken and frustrated. I feared for my life and the baby I was carrying.

I felt I needed to share my status with my family and neighbours. I was hoping in my heart that they would understand.

Instead, I was isolated, and called names. What a painful chapter that was for me.

Thankfully, my life changed when I was visiting the clinic one day and a counsellor showed me an advert for mothers2mothers in the window. They were hiring a mother living with HIV who was able to speak out. It was then that I decided to educate my community about HIV.

My role as a Mentor Mother is to educate mothers with HIV so that they can have HIV negative children and stay healthy. I encourage men and women to get tested for HIV, stay on

their treatment, and share with them that mothers2mothers is there to support them and their families.

I work with two other Mentor Mothers and together, we are a force to be reckoned with. We are the support system behind the few nurses who work in our clinic. When I meet a new client I always start by introducing myself. I talk about my own HIV status to make them feel comfortable. Then I ask how they are feeling and give them a chance to talk about their HIV status; I find that this is the first step to them accepting their diagnosis.

I then start educating them about what it means to be HIV-positive. My own experiences with HIV come in handy because the clients always ask “why did you disclose and are you taking this treatment?”

My Mentor Mothers and I are seen as role models by the women we work with. They look up to us when they make decisions about their own lives. Some ask if this does not put pressure on us - as Mentor Mothers - to walk on a straight line and my answer is NO. Instead of pressure, this motivates us to live positive lives because we know that hundreds of women look up to us.

When I started working at Dark City Clinic, we used to have many babies testing positive during their 6 week test. I recall once, we had 26 HIV-positive babies in just one year. It was a real tragedy and wake up call to all of us at the clinic. We realised then that the one baby here and one there were becoming part of hundreds of thousands of babies who are unnecessarily born with HIV each year.

Over the years, we have managed to bring those numbers down. Last year we had only two babies who were tested HIV-positive but that is still too many. Both babies were born to mothers who attended other clinics that did not have Mentor Mothers. Their mothers came to our clinic because they were now living in the area. As sad as the news was to all of us, we worked hard to help the mothers accept their babies' status and get them started on treatment. Both babies are responding well to the treatment and we know they have a chance to a full life.

What makes us unique as Mentor Mothers is that we do not talk about HIV only as professionals but we personally relate to our clients' struggles. I also had challenges after disclosing my status, I am also taking ARVs and I also have lain awake at night wondering if

I truly did all I could to save my baby from HIV. This is the kind of understanding doctors and nurses do not have.

This is the reason I believe women living with HIV are the key to ending paediatric HIV. We walk the talk. When women living with HIV support one another, what you end up with is a whole community of women who understand each other in levels no one can imagine.

I once had a client who did not want to take treatment or disclose. After many attempts to help her, the nurses called me to come and talk to her. First thing we spoke about is how she was feeling at that moment. She became engaged in the conversation immediately because we were talking about her and not what she had done wrong. She said she had seen people who were taking treatment but were now dead and she saw no point for her to take ARVs.

I told her my story, showed her my own ARVs and spoke to her about everything I have been through. She soon started asking lots of questions. She asked me how long I have been taking my treatment and why I chose to tell other people about my HIV. We spoke for nearly two hours and from that day, she started taking her ARVs. It took her a bit of time but she ended up disclosing her status to her partner and family. Her baby is now three years old and was tested HIV negative.

Most of my clients are HIV-negative though. And to make sure they remain that way, we educate them on the importance of getting tested regularly, practicing safer sex and encouraging their partners to get tested as well. We disclose our status to them as well so they can understand how challenging life can be once you are diagnosed with HIV. This way they don't only learn how to keep themselves free from HIV but they know that should they ever get infected, there is someone who will support them.

My job at mothers2mothers has given me peace of mind. Being part of their family brought back my self-esteem and self-confidence. Sharing what I have learned at mothers2mothers about HIV with my family has played a massive role in removing the stigma they had placed on me. I am happy to say that my family has come to accept me and my HIV status.

You hear of stories with happy endings. Well after that terrible first half of my life, the second half has been a different story.

Five years ago I stumbled upon a lovely man who is now my husband. He is HIV-positive and supportive of my work.

And to top it off, I got pregnant again. The support and love I received while pregnant at mothers2mothers was so different than my last pregnancy. I knew everything I had to do to protect my baby from infection. My husband and I now share an HIV-negative one-year-old daughter, Nothando, which means love. Finally, the little girls in my family have the love that was missing in my life when I was their age. They have a mother who they can be proud of. I was once a victim but now, I am not only surviving, I am thriving.