



LIVING OPENLY • STORIES AND IMAGES OF HIV POSITIVE SOUTH AFRICANS



## LIVING OPENLY

### Stories and images of HIV positive South Africans

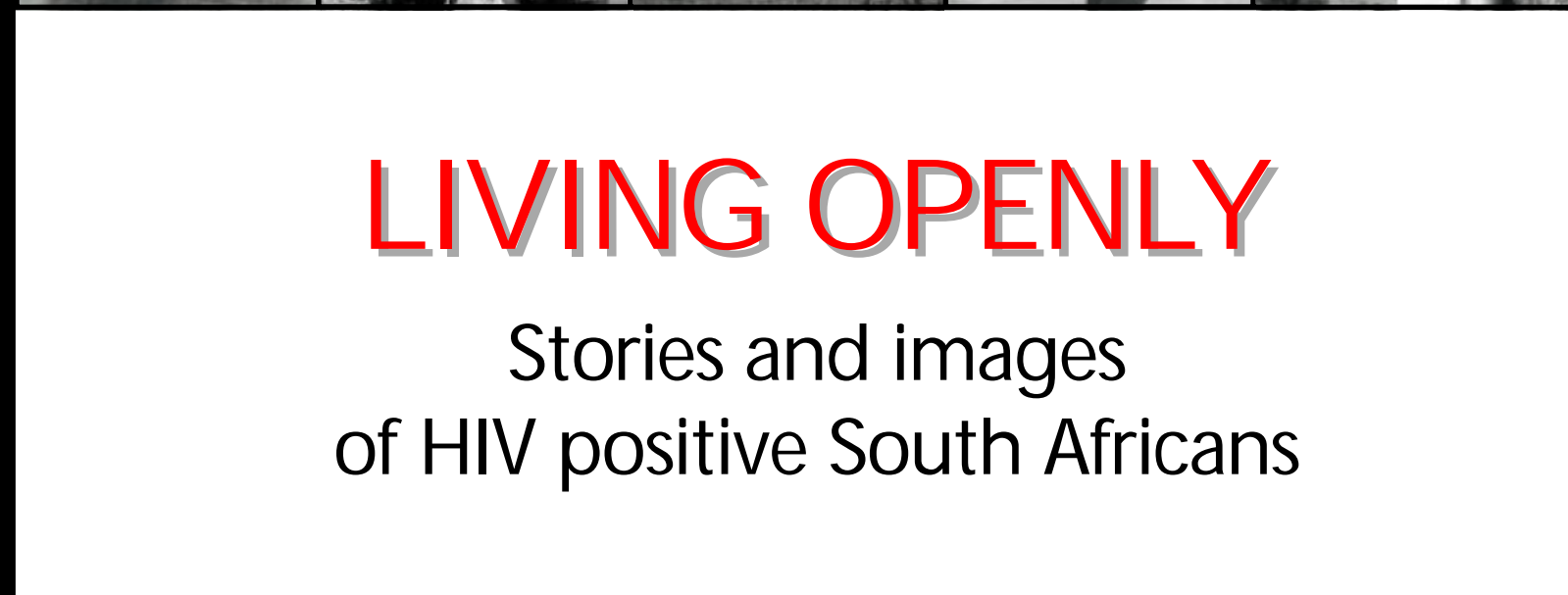
The Living Openly Project is about the experiences of HIV positive South Africans who have publicly declared their HIV status.

The photographs and stories were brought about through the dedicated work of photographer Gisèle Wulfsohn and writer Susan Fox, and this book is one of a number of outcomes of the project.

HIV/AIDS is a disease that is seldom associated with openness, yet these stories, told in the first person, give insight into the courage and strength required when confronting HIV infection. Furthermore, they give insight into the greater courage required to be open about one's infection – open not only to friends and loved ones, but to the general public.

We cannot ignore the fact that many millions of South Africans are infected with HIV, and that most are unaware of their infection. For many of those who know their status, public openness is difficult, for it requires a safe environment and support for being open about HIV. In many instances such support does not exist.

In reading these stories we can begin to understand the complexities of being open about a disease that is, for the most part, hidden. Now we can see the images and hear the voices of those who have chosen openness over silence.



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Stories and images  
of HIV positive South Africans

## COMMISSIONED BY

Beyond Awareness Campaign  
HIV/AIDS and STD Directorate  
Department of Health

FEBRUARY 2000

## PHOTOGRAPHS

Gisèle Wulfsohn

## INTERVIEWS

Susan Fox

## PROJECT CO-ORDINATORS

Warren Parker and Mandisa Mundawarara

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**PHOTOGRAPHS**  
Gisèle Wulfsohn

**INTERVIEWS**  
Susan Fox

**PROJECT CO-ORDINATORS**  
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This book is part of a broader project that focuses on living openly with HIV/AIDS. Other products include a video documentary, poster series and photographic exhibition.

We gratefully acknowledge the energetic contribution of all participants to this project.





# LIVING OPENLY

## HIV positive South Africans tell their stories

The Living Openly Project is about the experiences of HIV positive South Africans who have publicly declared their HIV status.

The project was born out of discussions around media portrayals of people living with HIV/AIDS, and the understanding that so often these images were harsh and stereotyped. Where people were ill, they were portrayed in bed, emaciated and downcast. Where people were healthy, instead of their faces we saw their heads turned away, more often than not, to protect their identities.

There had to be another way to create images around HIV/AIDS, and perhaps the starting point lay in taking photographs of HIV positive people who were living openly with the disease. The photographs and stories were brought about through the dedicated work of photographer Gisèle Wulfsohn and writer Susan Fox, and this book is one of a number of outcomes of the project.

HIV/AIDS is a disease that is seldom associated with openness, yet these stories, told in the first person, give insight into the courage and strength required when confronting HIV infection. Furthermore, they give insight into the greater courage required to be open about one's infection – open not only to friends and loved ones, but to the general public.

We cannot ignore the fact that many millions of South Africans are infected with HIV, and that most are unaware of their infection. For many of those who know their status, public openness is difficult, for it requires a safe environment and support for being open about HIV. In many instances such support does not exist. However, the more we are open about HIV/AIDS, the better equipped we are to tackle the epidemic head on.

In reading these stories we can begin to understand the complexities of being open about a disease that is, for the most part, hidden. Now we can see the images and hear the voices of those who have chosen openness over silence.

The Living Openly Project is one of a number of activities of the Beyond Awareness Campaign of the HIV/AIDS and STD Directorate, Department of Health. The campaign set out to explore alternative approaches to communicating around HIV/AIDS, and has allowed for greater understanding of aspects of the disease that often fall outside of the framework of conventional campaigns. This focus on living openly with HIV forms part of an increasing emphasis on care and support issues that is vital to an expanded response to the epidemic.

This book is dedicated to all of those living with HIV/AIDS.



# Mercy Makhalemele

---

*Diagnosed 1993. Disclosed six months later.*

I decided to keep quiet for some time until I was ready and I had accepted my status. It didn't take too long. It was tough to talk alone to myself, to get the information alone and not have anyone that I could speak to. It was the most difficult thing to keep it inside me. It was the anger that actually drove me to want to say something to someone.

So from that point I did my first interview on TV with Shaun Mellors. My face was hidden. People who knew me, like my family, knew my hands. Usually when I talk I use my hands a lot, so even though my face wasn't clearly visible, people who knew me knew it was me, and that's how my mother and father found out. I did not come home to disclose to my family. They started seeing me on TV. I felt, this is me and this is what I had to do. I cannot face them, but I can face the world. By facing the world maybe they can see.

When my mother saw me and my son said, "Momma, I saw your hands on TV," the whole thing started coming out. From that day I never really stopped. I carried on talking. I was one of the first women in South Africa to disclose. At that time there were only two women who were open about their status amongst a group of gay men, so it took a lot of strength to get to a point of disclosing.

I didn't have courage to tell my mother at that time, because she was very sick. But my concern was, I have brothers, I have sisters, I have cousins. I have a huge extended family and if I don't do anything, I would never live with the guilt of hearing my brother saying he had been diagnosed HIV positive. Maybe, if I had told him three years ago, I could have done something to protect him.

All I could say to my family was that I was doing this because I've got a son who has to grow to become a man. I have to contribute whatever information I have as a parent. I'm a resourceful person in terms of education programmes, I have to ensure that my life does help.

In a way it helped me to be someone I wanted to be and it would contribute to the quality of life of people living with HIV/AIDS. Maybe they can take something the same way that I took from Shaun Mellors, the same way that I took from Peter Busse. Some of these guys started disclosing years

before and I thought if they can do it, so can I.

Thabang faced a lot of complications after my disclosure. After his father died, I told his teacher I was HIV positive. All the teachers at the school said, "Don't touch this child, his mother has AIDS". After that, Thabang said to me, "Don't touch me, mommy, you're going to give me HIV". I asked him who told him that and he said that it was the teachers. The next day I went into school and spoke to them. Thabang never wanted to go to school again so he actually stayed back a year. I had to try and be the teacher in the house with the little time that I had.

One day, I came home and spoke to my brothers and some other guys and said, "You are young, what have you done for your community? The young kids are contracting HIV. They are not going further with their education. You guys have learned so much but you are not sharing with the community." And they said to me, "What do you want us to do?" And I said, "I want to have an AIDS campaign on Human Rights Day because my family has a right to live in society peacefully". I had to accept that I was the one to put them in this position, I'm the one who had to get them out of it.

Then we started getting ready for a huge campaign. That was the first campaign in our township. We invited the people living with HIV that most of them knew already. My father was there. I launched a campaign that was called "disclosure and acceptance" on that day because I wanted my family to be accepted the same way that I was accepted. I was accepted with HIV, whenever I walk around here everyone shows me that I'm accepted. I can't walk from one corner to another corner without anyone coming to me hug me and I could not understand why they would not accept my family the same way.

So in a way, AIDS was an experience for this family and that's how we took it. It's an experience to learn how to be better and deal with it. People always say to me, "What are you doing? Are you strong? Are you taking medication? Why are you so brave?" And I always say, "No, it's love." I believe love heals anything. The love that I received from my family is just too much, it's more than I can imagine. I cannot ask for more.

*Interviewed in Soweto, October 1999. Age 29.*





## Maria Ndlovu

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*Diagnosed 1996. Disclosed 1998.*

The first time I disclosed was to a group of students. There was this film by UNAIDS, "I Can Hardly Wait," and it showed things that the youth do. So we'd watch the movie and then discuss in groups and find out what issues affect them, including AIDS. I came in as the reality and told them my story as somebody living with HIV.

I had made the decision to disclose some time before, but I just had not had the chance to do it. My decision came quickly... two weeks after my diagnosis. My original thought was that I won't talk about it. I'll wait until I get sick and then tell people.

It was when I went to an HIV clinic and it was so silent and quiet. It was like we were sitting in an electric chair waiting to die and we would not talk or greet as we would in other queues, like in the casualty for example, where you would see somebody and you would ask what is happening. It was then that I made up my mind that this needs to be talked about because it is not right to feel as if you are dying when you are not. I wanted to normalise the situation.

For me it's a calling to do this. I feel an urge in me to help other people or to at least help them get through acceptance. I especially feel for the youth that they try to be as preventative as possible.

I am fortunate. My experiences were not negative in the sense that people were harsh on me, but they were negative in the sense that I did not attain what I thought I would attain. Like when you speak to a group there will be people that say, "I don't believe you, you look so fit, it can't be true. They must have given you money to say this." Then there are some men that say, "I would like to taste it on you," like there is any flavor. At least when I was infected I didn't notice any certain flavor.

At the workplace the negative was not directly towards me but a reaction of a people in denial. That's how I see us in South Africa, I see a people in denial. Each time we have something going on around HIV, the response is better than the last one. So I think we are making an impact.

It is important to joke about HIV because it's a positive outlook. It's not like one feels like one is going to die

tomorrow. It puts a bit of life into it. You see it is normal, and it is normal because not everyone who is HIV positive dies of AIDS. Some die of something else, and those that are negative also die of something else. Eventually we all die... it is more about how responsible we are about how we die.

One of the reasons why I wanted to talk about my HIV is because of how I got my virus. Everyone knows that people are being raped in South Africa every day and so they know that is the reality.

When I was raped, I kept quiet for some time. I spoke more of my HIV status than I did of my rape, and then I thought, "Why am I keeping quiet? Am I protecting the rapist, and why should I?" So I started talking about it the way it really is. It's not like I'm blaming because it doesn't help anybody to blame, but it's more about accepting the situation and doing something about it.

There are lots of women who keep quiet about rape. It was really a trauma when I was raped and I didn't get counselled as early as I should have. It is when I talked about it that I got help. If you are silent, people don't know and can't help. For me it was difficult to talk about HIV because I was still dealing with my rape when I knew about my status.

I actually saw the rapist twice after my rape. I think I wasn't the only person this guy raped, I think he raped a few others. He wanted to die with others.

For me, rape and HIV go hand in hand because if you are raped, you are already at risk because a rapist doesn't come to you with a condom. In fact, you are not in a situation where you can negotiate using a condom because you are not in a relationship.

Even in a relationship sometimes it's difficult to negotiate. That is one of the reasons I felt I needed to talk about it, not to talk and say it's a bit better that I didn't get infected any other way because I feel that whatever way one is infected, the fact still stands that one is infected. It is how one deals with it, how one accepts it and lives positively after going through whatever they have gone through.

*Interviewed in Johannesburg, January 2000. Age 42.*



## Brett Anderson-Terry

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*Diagnosed in March, 1999. Disclosed the following week.*

Basically my dad had a hard time with my HIV status and the people at his office. He told his senior colleagues. I had to face it full on and tell everyone else because I knew they would find out anyway.

I was annoyed but my dad was angry – angry at me and at the disease. I think my parents took it a lot worse than I did. I don't think my dad really knew how to handle it. I told him that he was not allowed to go and tell the world. I don't think he realised the serious implications of what it could do. It could have had a negative outcome but it didn't... Instead, it turned out to be positive.

There was a lot of support from everyone at work. Nobody has changed their attitude towards me. I mean I went to the kitchen staff and said, "Okay, this is basically the story, and just wear a condom in the future for yourself." And that was it.

I would say that I was a little more apprehensive than anyone else. I was still in shock the week after and if I cut my finger I'd go through paranoia, thinking, "Oh my God, somebody's going to touch my blood!" Little things like that I had to deal with.

Attitudes haven't changed in the sense that they're not saying, "Oh be careful of Brett," and if they are, they are hiding it very well.

I'll be honest that I haven't bumped into anybody who has been negative about it. I think they are exactly like I was, thinking it wouldn't happen to them. But I would say

that since then, this whole building has changed. A lot is now happening. If anything, I think the people who I work with have woken up to the fact that there is a disease out there and we need to do something about it. I got a whole lot of red ribbons for everyone in the office and I make sure they are more proactive about AIDS.

For me, talking about my status was my saving grace. I'm expecting the day that some ignorant idiot will say something rude to me, but I think South Africa is finally waking up to this disease. As much as I don't believe in notification, I do believe that South Africans do need to get ready for people to start talking. The only way that that is going to happen is for people to realise that disclosure is a healing process. To come out and take control of the disease rather than letting the disease take control of you. Your life doesn't necessarily have to change and you just wait to die. I'm not planning on dying for a long time.

What my father did wasn't right, but in a way it was a good thing for me in the sense that I didn't have to hide it. I didn't have to come out with it myself. Although, if he didn't do it, I would have disclosed anyway. I think talking about it was the best thing that helped me through it and to come to terms with it. I'd still say to anybody else not to hide away. The sooner you start talking and mixing with other people and learning about the disease the better. Empower yourself.

*Interviewed in Cape Town, November 1999. Age 28.*





## Bruce Radebe

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*Diagnosed in 1995. Disclosed in 1998.*

When people think of HIV/AIDS, they think about careless individuals who get infected so they think it's a disgrace and try to hide it. In my mind, the minute you talk about it you are free.

When I disclosed, I did it both for my benefit and for them as well. It was at a high school in northern KwaZulu-Natal. It was at a rural school where there is a lot of ignorance because of the lack of access to information and illiteracy. These were the first people I thought of to disclose to because I thought to myself, "Let me just go out where the world is gloomy".

I spent three days at the school. It was a must for students to attend when I disclosed and there were about 500 kids there. First, I gave them a talk about AIDS to educate them about what it is all about. I fitted myself in with them during the first few days, playing sports and eating with them. On the third day I disclosed as I was about to leave. I was nervous about telling them, but the truth just came out. After I told them, I reminded them about the activities I did with them and I asked them if they thought they were infected now. "Remember where we ate, played sports, shared toilets. Now are you infected?" I asked them.

They showed a lot of interest but questions mushroomed that highlighted the lack of education in the area. I had to show them my results because they didn't believe me. I always carry the piece of paper with my results on it so I can produce it to prove that an individual with HIV can look like me. Most people don't believe me because they say I'm tough and they see my energy. They think AIDS is something that will come and they will be able to see it. They shouldn't confuse healthy or thin with HIV because it has nothing to do with loss of weight.

We as the youth are the pillars of this country's future so we had better start taking things seriously. Kids usually doubt that they can get it. I think we should talk about it. HIV isn't this monster that eats them.

There was a time when I felt like I was drowning, but today I'm back to normal. Telling people has actually brought me back to the real me. Now I tend to see the impact on other people but not on me. I feel like I can conquer this through power and hope. I can overcome obstacles. I flow with the wind but I let it know that I'm resisting.

*Interviewed in Durban, September 1999. Age 22.*



## Faghmeda Miller

*Diagnosed in 1995. Disclosed in 1996.*

Coming back home after the doctor told me I was HIV positive, I asked myself what I was going to do? Could I tell my people because I know that in the Muslim community it's a big sin to have AIDS, so what was I going to do? I told one of my friends and he also told me not to tell my family unless I was prepared for it.

After a few months I built up the courage to tell my family and they were very supportive. They told me not to blame my husband because we believed that this was put out for me from God and I have to make the best of it. But I still felt like I put shame on my family.

After a year I realised that I should come out because even our people, we're not perfect. We all have sins. In my case, I was married to this man when I was 26 so they can't really point the finger at me. But when people hear you are HIV positive there is a stigma attached to it. It was almost a year that had passed and I'd been searching for other Muslims who were positive but I couldn't find any. I was fed up because I belonged to a support group of staunch Christian people who were very supportive – I can say they supported me more than my own people – but I wanted to be with my own people. I couldn't find anyone and it was heartbreaking. The group was talking about how God feels about you and I was asking myself why can't my people accept me like that?

I went public on our local public Islamic radio programme. I didn't tell anybody that I was going to be on the radio but some of my aunts listened to the programme and they came and told me I should have told them. I just told them, "Listen! I myself am not very used to having this disease and I was finding it very difficult telling you people because I know how you are. I know that some of you

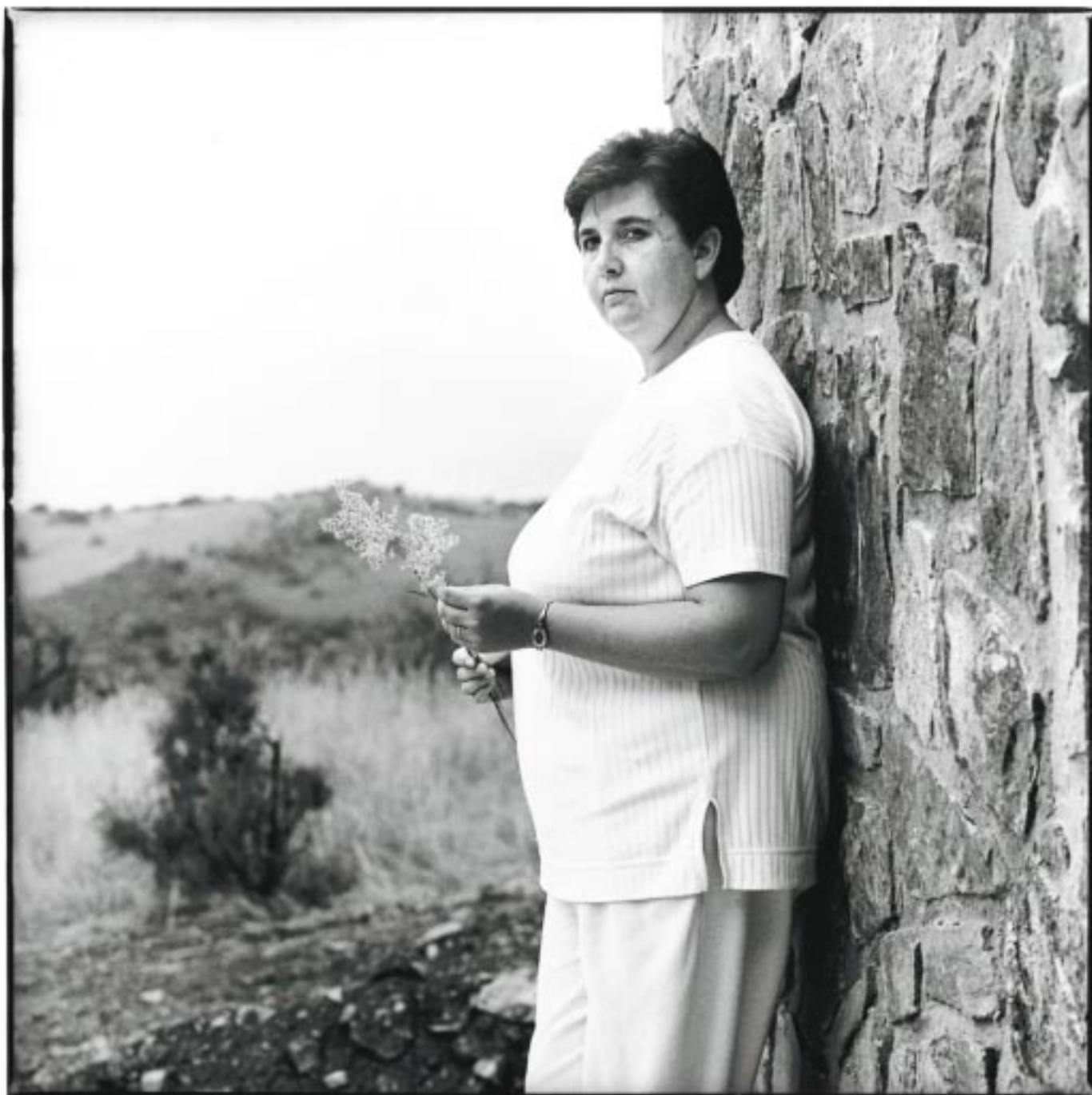
might think badly of me now". They said that they didn't think badly of me because they knew what kind of person I was but I could still feel that things had changed with my family.

Every time the radio station calls me in to give a talk about AIDS and every time someone else in my family criticises me, saying why did I have to go public, I always say, "Why must I keep quiet? I've done nothing wrong!". We people, we always believe that we are superior but we are not superior, we all make mistakes. It's time that someone in our community should come out and be open about this because we are actually endangering the lives of others if we keep quiet about it. There are lots of other Muslims out there who are positive but won't come out about it.

Then again, I can understand why they don't want to come out. I went through a tough time and I'm sure in other communities it's the same thing. But still, today I'm involved with organisations and some of my family doesn't like it. I tell them that I'm the one with the virus and at the end of the day you are on your own. I'm happy with what I'm doing.

Sometimes I do feel down. After I appeared on television I actually expected other people to come forward and when no one actually did, I felt that my time was useless. Then I received a call from another Muslim guy who was diagnosed five months previously. He said to me when he saw my programme he was feeling very down and was afraid to go out in to the community, knowing that they would reject him. He said when he saw my programme, I gave him the courage to live, and without knowing it, by telling me this he also gave me the courage to carry on again.

*Interviewed in Cape Town, November 1999. Age 32.*



## Ame Brown

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*Diagnosed May 1999. Disclosed August 1999.*

My HIV status was disclosed in the *Mail & Guardian* and in *You* magazine in August 1999. Before then I hadn't actually given any thought to going public. It never crossed my mind. I told my family and my very close relatives but that's about it. At that point I was having side effects from the drugs I was taking and it was hard enough just breathing. I literally died for 10 months after I was raped, and all I could really do was breathe. I didn't do very much, I just tried to get my life back together.

I think it's the same as the loss of a loved one. You need that period of time when you stop and you mourn. Eventually you've got to pick up your bag and start again, but you have that period that you have to go through. With the rape, it was a period of 10 months where I had to pick myself up and put myself together again. Then it was five months down the line that I found out that I had HIV and I pick up myself again.

A friend of mine said I have a strong personality to go out and talk to people, and I decided to do that. Somehow *You* magazine got hold of me. I had a lot of time to think about it before I decided to do the interview. I discussed it with my family. We discussed the pros and the cons of going public and we all decided we would bite the bullet and go for it.

In my community, the population is very small. At first, I think their response was one of disbelief... that this could not be happening to a person that they knew. When they heard about it, they heard stories here and stories there. Because it's a small town, they added on their own piece and they deducted their own piece. It all ended up out of proportion.

I was contacted by one of the businesses in Elliot to give a talk, which I did. Basically I did one talk after another in my town. Most of the people came. Initially they may have come with different motives, but after a while I think everybody started opening up and saying, "This woman

needs our love and our encouragement and a backbone to lean on. She doesn't need our pity or sympathy, just a leg to stand on if she doesn't have it already."

I would say just about everyone in my town has stood behind me. That to me is a great success, a sure sign that it was the right thing to do to go public.

My family and especially my husband have been extremely supportive. If I talk with him about going here or there to give a talk, he says, "As long as you help someone." That's all I really want to do, just go out there, be a big mouth if that's what it takes... just to be there for that person who has been through the same thing and doesn't know what to do. I just want to open my mouth, because something like this should have been done a long time ago.

People say to me, "You're so extraordinary, I take my hat off to you," and it goes on and on but my reply is, "I'm not so extraordinary, I'm an ordinary person doing extraordinary things. I'm just doing what should have been done a long time ago."

Sometimes I work as 'Bozo the Clown', so I've always been able to speak to kids, but when you're clowning and you're behind the suit, you sort of hide behind that. But living openly wasn't easy because this isn't just talking, you have to fight. You're fighting for something that's right and that's the difference between clowning and being an activist. I think that since my rape, I take no trouble from no one and I speak up for myself. I wasn't like that before.

Now, it is a shame that I was raped and it is a shame that I have HIV, but I'm not the first person and I'm not the last. You need to turn that negative to a positive. If I can do it, and many others have done it, then so can you. It's not the end of the world.

*Interviewed in Johannesburg, March 2000. Age 31.*





## Nkosi Johnson

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*Born HIV positive.*

I didn't start school until the second term because they didn't know what to do with me. They were worried that if I was to fall and start bleeding, the children would come up to me and say, "Nkosi, can I help you?".

They had somebody come in to talk to the teachers. I don't know who came in, but they also taught the mothers about the responsibility of AIDS. Then the mothers thought about it and decided yes, it's fine for me to go to school, and they let me in.

The first day of school, I was with Gail and we had a nice picture for the newspapers outside the school. I was in my new uniform. It was a nice day. I was a little bit scared because I had no friends at all. It was my first day but everyone else was already at school.

I have a lot of friends now but the first day I didn't know anyone. My teacher was very nice to me and so were the children. She introduced me to all the children and told them "I'm Nkosi".

The first day I didn't tell anybody that I have AIDS but I think they knew. There was one boy that I'm sure doesn't like me. He will greet me but if I go near him he moves away. If I go to touch other boys he says, "Don't go near him, don't touch him!". My friend Aubrey says, "Why not?" and he says, "Because he's got that sickness". Aubrey tells him it's not dangerous. I have lots of other friends though, and I think most of them understand.

One day this one girl was running and I was running and I couldn't keep up. She pushed me and I fell on my chin. She just looked at me and ran away. I had tissues and covered my mouth and the prefect took me to the office. I didn't want that to happen but I have not had an accident after that.

I think schools really know more about AIDS now. Gail says if it wasn't for me, no AIDS child would be allowed in the schools. I think children with HIV also need to learn and look after themselves.

*Interviewed in Johannesburg, January 2000. Age 11.*



## Jeanette Ratonono

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*Diagnosed in 1995. Disclosed six months later.*

I think it was the anger that made me go public. I grew up in a family that was strict about boyfriends. When I came to Welkom, I started having many friends and got involved with a boy. He proposed to me. He was the only one that I slept with. Even if you say you will protect yourself, you don't know what kind of person you are in love with.

I was crying a lot then because he was my first boyfriend. I was so angry at lots of things. Then I started thinking, why should I hide it because I didn't do anything wrong! I didn't sleep around with many boys! If I was sleeping around, people would point a finger at me, but I wasn't. I only had one partner. Why should I hide it? It's something that you can't shake. It just happened, so I had to speak out.

After I found out I was HIV positive, I said to myself, "If I can get HIV with one boyfriend, what happens to girls who have two or three?". I have a younger sister and I had to do something to protect her.

When I disclosed, it was six months after finding out I was HIV positive. I was invited to speak to people at a World AIDS Day event. When they invited me, I didn't feel well and was depressed. I said, "No ways, how can I speak to people? How am I going to live my life after that?". I finally said I would think about it.

About two days ahead of time, I told them, "Yes, I want to come out". There were about 700 people there. It was a huge campaign that day in Welkom. There was the Minister of Health, the Minister of Education, and ministers from many different churches. I felt important because all the people were listening to me – even the ministers. I was nervous at first but as time went on I wasn't nervous. I was crying because I wasn't really sure whether the people would accept me. I had some friends there and I didn't know that if by doing this, they would still accept me afterwards.

I was nervous because I was angry. I was hoping that by speaking, it would get rid of my anger. And it did work. After I heard I had HIV, I think I overloaded on stress. I didn't speak out for an entire six months, so something in me was relieved to speak. After I spoke to the audience, I felt great. I know they listened to me because after I spoke they asked questions.

In 1995, AIDS was not really something people accepted. When they saw me they wanted to see someone with AIDS. So when I spoke to them they were surprised. It was the first time here in Welkom for them to see someone with HIV. Some believed and some didn't believe me when I told them. Some people responded well. They wanted to hug me and tell me things would be OK. "God will be with you," they said. Some people came and wanted to touch me to see how HIV feels.

At the time that I spoke, I was having skin problems. They saw I had skin problems and I was a little bit thinner so it was easy for them to believe. So if someone approached me, they said, "Yeah, you can look at her and see she's HIV positive". Then when I started to get better and got rid of the skin problems, they said, "How can you be HIV positive anymore?".

After I spoke to them I started to gain weight and relax. All the questions I was asking myself... the answers were there. I had been asking myself why God chose me because I was working for Him as a Sunday school teacher. There is a Bible passage in the Scriptures that says "sex without marriage is a sin". As a teacher I knew this, but I didn't take it seriously. I don't know what I was thinking about. After I became sick, I started to ask questions like, "Why didn't I listen to the Scripture or to take some measures to prevent it?".

At church, the minister threw me out when he heard I was HIV positive. Other churches were accepting, but I grew up at that church so I thought they would hear me. If God is with me, he can pull me through this thing. My friends rejected me. They didn't say anything. When I saw somebody passing and I said "Hi", they didn't care that I greeted them. I still have to speak to them about it because I want to know the truth.

It was worth speaking up because some of my friends are dying because people didn't care. They committed suicide just because their relatives didn't show support. Some people are wearing a mask because they don't want to see the truth. Sometimes I feel angry because people don't take AIDS seriously. They say the government has sent me to come out and lie to them and that's not true! We're coming out for the sake of them.

*Interviewed in Welkom, June 1999. Age 25.*





## Kevin Osborne

*Diagnosed in October 1991.*

I was diagnosed HIV positive in October, 1991. At the time I was studying towards my LLB at the University of Cape Town and it was just before the end of the year. Around exam time.

Everybody thinks that it won't happen to them, that in some way and for some or other reason you will be immune to it. So when it happened to me I was really surprised and shocked. I tuned into all the stigma and death and hopelessness. I wouldn't tell anybody because at the time the news around HIV/AIDS was all gloom and doom and I suppose that it was quite natural to believe in the "I'm going to die tomorrow" syndrome.

I do however remember feeling the overwhelming need to tell someone so that it would not be my burden alone. I carefully weighed up all the odds of who I should tell. It was a very calculated and planned process because I knew that if I did not receive the support that I needed, I would never again reach out in search of it. So in telling my closest friend, Sheila, I was guaranteed her unconditional love and care.

I believe that the very first person with whom you voluntarily share your HIV positive diagnosis has to be someone that you are almost "guaranteed" will respond favourably. Because their reaction will pave the way for the future telling (or not) of the next person. And the next...

My friends that I subsequently shared my status with, all of whom responded with loads of care, suggested that I should also tell my family. But that proverbial "right time" does not exist. I suppose that when I decided to tell my family, I had already dealt with my initial feelings of shock and anger, so in this way I could be strong for them as they began their personal journey with HIV.

I suppose I do regret not telling them sooner, as I did myself, and I suppose them, an injustice. Telling about HIV has become a catalyst for measuring the depth of true relationships. Relationships that weather storms, confront hurdles and are real. The deciding factor that made me decide to tell my family was when I developed shingles. I saw this as some sort of physical manifestation of my need to access support and be true... True about myself and about the very nature of our bonds as a family.

I remember the events quite clearly. My parents lived in a little country town at that time and I booked a flight long in advance. In this way I could prepare myself for what I was planning to tell them. It was planned with almost military precision – I was going to go for a week, I was going to tell them on a particular day. It was planned in minute detail.

Telling them was the most difficult because it wasn't something that they had expected to hear. They never thought that HIV/AIDS would knock on their front door. I never ever believed that they would reject me and they haven't.

"What then was the fear? Why all the anxiety?", I ask myself. I think it was the fear that I had let them down, that I didn't want to worry them. But I wanted them to know. For me. And for us, I suppose. I know that they worry unbelievably now if I get the flu, which I know is a natural thing, but suddenly I can see they are wondering if this is the beginning of the end.

There have been times when I can tell they wished that I had never told them, because the burden of responsibility is very great for them as well. They live with the stigma too, perhaps more so than I do at this point in time. It is almost like there is a clash of our two worlds in one universe: their silent pain that never sees the light and my openness and personal journey that has allowed me to find my niche in dealing proactively with living with HIV.

We really have to work with AIDS at an individual level because that's where we will break stigma. And that is where real understanding can grow, where hope can flourish. And this will also go a long way in normalising HIV in our society. PWAs need to be seen as part of the rich fabric of our society. For this to happen, positive people mustn't be defined by their illness or their status. I think being HIV positive gives my work an edge. People often ask, "How do you understand these things?" and I say, "I think its because I'm positive". Yet I don't want to be viewed primarily as "Kevin with HIV" and then, "Oh... this is the work that he does". It must be the other way around. One must include the other. That is after all what life is about the ying and the yang. The infected and the affected. Me and you.

*Interviewed in Cape Town, August 1999. Age 33.*



## Adeline Mangcu

*Diagnosed in 1994. Disclosed 30 minutes later.*

I told everybody I know from Somerset Road to Somerset Hospital, from the Waterfront to the taxi ranks, down the road to my house, my home, and my friends.

I think it was fear that made me tell everyone. Other people have fear and they hide. They purposely keep quiet. Others have fear and they go shopping. Actually that was the reason I didn't go straight home after I was diagnosed, because I felt I needed to buy some stuff. I don't know what I bought because I didn't need anything.

On the way home, people kept asking me why I was crying. I couldn't say I had a toothache... everyone knows I have dentures. I couldn't say I had a headache... my head didn't hurt ever. What was I doing out at the middle of the night? Everyone knew that the baby had been in hospital about four times already. Some people didn't ask me why I was crying. They asked how the baby was and that set me off. I've never been a good liar, let me put it that way.

Later on when I did continue telling people, I just felt that most of my friends, not that they're not professionals, haven't had the privileges that I have had so there is a tendency for them to look up to me. When I was diagnosed it was one of the funniest things to see people coming up to me asking about other terminal diseases, as if I have a glimpse into the afterlife or something.

I felt I needed to tell them, I needed them to know that this is not somebody else's disease. We were lied to. Anyone can get HIV. The way it was presented to us, we thought it was definitely not a black thing. We heard about gay men getting it, but since there are not a lot of gay men in the townships, they were probably not infected. But if you were in America, in a place called San Francisco, then you had a chance of getting it. It was something that was rubbed in before the 1994 elections that is very difficult to rub out.

I felt it was my duty to tell people. I mean I'm a teacher. How could I be so good at being a teacher and be so bad at motivating people on the correct way of doing things and teaching.

I don't know if it helped to tell people that day, but I know it got me a lot of enemies. I was the second black woman to come out and no one wanted to hear about it. I have a friend who said I wish I had been there to hear you that day because I would have killed you myself. I think she felt I had embarrassed everybody.

Somebody told me at the church the other day that she hated my disclosing. But I'm not disclosing all the time, I'm just doing AIDS awareness stuff. I'm doing nutrition, I'm doing things that make their children survive without getting the virus. But I'm getting the feeling they think I'm embarrassing my family by doing this.

In the process of disclosing, some people actually lose their families. Not that they say "don't come to the house anymore", but you lose the support that is really needed.

Sometimes it crosses my mind that I never should have disclosed. I'm not saying people should not disclose, but it takes a personal sacrifice to do it. I mean it's a hell of a job to disclose. But then again, if I don't do it, then who's going to do it?

It has been tough. You apply for a job, you get the job, but because you've disclosed, you get a little letter that says we'll get back to you. Someone else gets the job and bungles it and knows nothing about making HIV/AIDS programmes. That's not what HIV is about, it's about life. It's about, "Hey, she can do this, she can guide us, she's alive". But they always think, "What if?" I get the feeling that we are not economically viable. We cannot let people create a new race-group out of people living with HIV/AIDS.

*Interviewed in Langa, November 1999. Aged 43.*



## Zackie Achmat

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*Disclosed in July, 1998.*

I had two major public disclosures.

One was an open letter to the affiliated members of the Gay and Lesbian Coalition, which dealt with the problems of treatment access and the fact that gay and lesbian people are generally marginalised in the epidemic.

The second was at the hearings on the Employment Equity Bill in Parliament.

Whenever people speak about HIV, they say 90% of transmission is heterosexual. Despite the fact that gay men in particular have played a major role in safe sex promotion for everyone, and in terms of services of legal rights, our role in the epidemic is not acknowledged nor is the fact that we are disproportionately at risk because of gay men's biological susceptibility to the virus.

We've got a brilliant constitution that promises us equal rights, but teenagers don't have the right to know what to do when they are experimenting with sex or how to approach people for condoms.

My disclosure in parliament was in a very safe environment because I am an African National Congress (ANC) member and I've been around a lot of people in the ANC. I was representing the Employment Equity Alliance and I had done a long legal analysis on why protection should be accorded, and why pre-employment testing should be banned and stuff like that.

Because I've worked with the politicians, I knew that no one in the ANC had ever disclosed. I said I didn't want them to misuse it and I didn't want it to be a media event, but it is an issue for me that I have HIV. I told them that it didn't effect my ability to speak to them or to convince them of any argument, whether it was about sentencing or about criminal procedure on anything that effects

human rights. HIV is about human rights, and it affects me personally. So that's why I disclosed.

I love my HIV positive T-shirt. I think it's beautiful. We should start a whole line and get Levi and Calvin Klein and all those people to wear HIV positive clothing because if everybody walks around with an HIV positive T-shirt, there's no stigma to it. You don't know if someone is actually positive. My sister wears it and it confronts people with a reality that a red ribbon doesn't... although in some places a ribbon means "I am positive".

You know, Émile Zola has a very beautiful line that says, "What swine decent people really are". It's marvellous walking into a Rosebank restaurant wearing the T-shirt because if they knew you had HIV and you didn't disclose it to them, they would probably say, "Sorry we're full". But if you go in with a T-shirt like that, they can't kick you out because then it's obvious what they're kicking you out for.

I really got inspired by Nkosi Johnson because there you have a little boy and his mother who decided to put on the school form that he is HIV positive. By being open, they were making themselves vulnerable to a very backward community.

Backwards is not a sign of race, class, gender, or any other of the funny classifications we have. It's only a symptom of wilful ignorance. Nkosi disclosed and was denied entry into a school but because he was open about it, they couldn't touch him. He could rally every thinking person behind him. That's the spirit that told South Africa that sometimes you have to sacrifice a little bit to get something bigger. But I say that and I don't think it's appropriate that one should force anyone at any stage to disclose. I disclosed bit by bit to people and everyone should have the opportunity to disclose to people in that way.

*Interviewed in Cape Town, November 1999. Age 37.*





## Jan de Groot

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*Diagnosed in 1994. Disclosed about a year later.*

It took me about a year before I came to terms with it. During that time only my girlfriend knew. I didn't say anything to anybody.

I thought that if I was going to die, I was going to do what I had always wanted to do – back-packing. So I went to the Far East and became a Buddhist monk for a while. I was away for eight months. I went to a monastery in Northern Thailand. I took a Thai massage course and worked in a hospital with AIDS patients.

I started reading up on the disease and asking myself, "Why me?" Because it's sexually oriented, society thinks you're a sinner and you feel even worse. One's mindset when you're diagnosed is that you will live for one or two years and you don't want any possessions. But now, six year's down the line, I'm still alive and kicking.

When I came back from this meditation holiday, I told my son and his family. They were very sympathetic, but they didn't have a problem with it. About six months before, I was diagnosed with cancer. In my family's mind I was going to die tomorrow. My daughter and grandchildren are still a bit wary of grandpa. They know a lot about medications and the virus, but when we go camping, I don't share the same cup with my grandchildren. It's just a question of ignorance. When I was overseas the same

thing happened. I went with some people from Holland and I had to explain that I couldn't infect them by going on holiday with them.

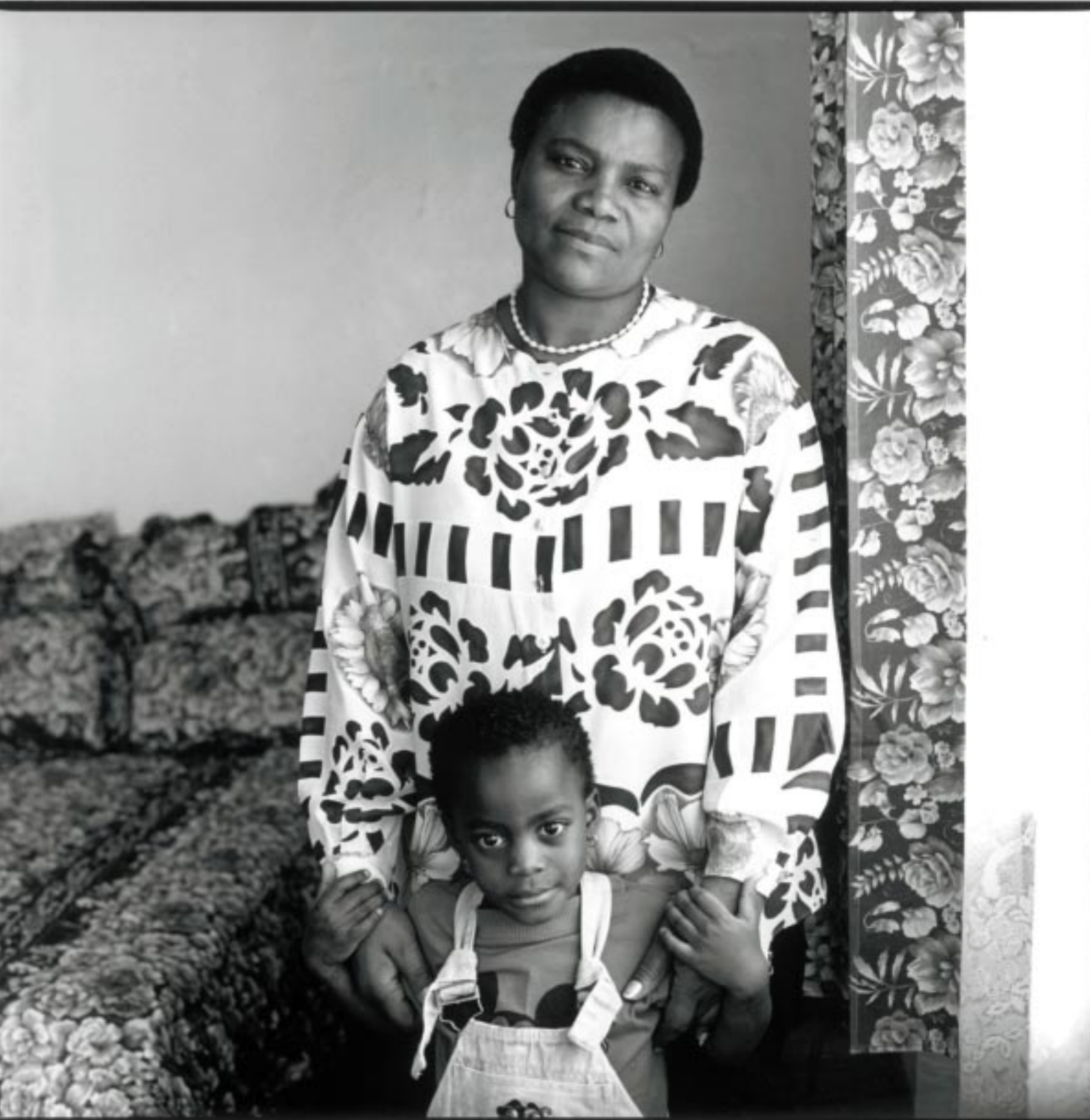
Since I told my family, I have been very open about it. In African society it's very much a question of ignorance and of not wanting to know.

After Thailand, I went to the US and Europe because I thought I should do it while I'm still fit. Next year I'm going to India.

In 1994, I went to a conference in Cape Town with 600 other delegates from around the world. It was my first time to meet other PWAs and they were all normal people. It was a real eye opener. I think it's important for people who are on the brink of disclosure to see other PWAs functioning normally. You have to have a good feeling about yourself and about talking about it.

Back-packing is like life. You sit on the bus and you are planning on going to a particular place, but halfway you meet someone on the bus who invites you to visit his parents in a village and you end up spending two days there instead. Instead of going left, you go right. Every decision you make has the possibility of changing your life.

*Interviewed in Durban, September 1999. Age 73.*



## Elizabeth Chidonza

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*Diagnosed in 1992. Disclosed in 1997.*

In 1996, I separated from my husband. The main reason why I didn't disclose from 1992 to 1996 was he didn't want me to. He didn't want us to talk about it – even when my daughter was born in January of 1994, he didn't want us to tell the doctors that the child could be HIV positive. They had to go through all the tests when all the time we were sure she was positive. He didn't want to come out... Somehow it could have been denial and fear. When I knew about the HIV, I wanted to know what things could help me.

So when I went back to Cape Town in 1996, the first thing I did was go to the doctor and explain my story to her. She quickly gave me a prescription, but I had to go and buy the drugs at a pharmacy and I couldn't pay for them. I heard about a TB clinic where I could get the drugs for free.

I disclosed in 1997. A doctor said that if I wanted to work with HIV/AIDS, then I should go to an organisation called Wola Nani. I started off as a volunteer there for six months. I was just helping the women's programme. I looked after the HIV positive children while the women were at work. I also took training courses at the local AIDS Training, Information and Counselling Centre (ATICC).

Then they employed me as a counsellor on the help line. From 1997 when I started working there, it exposed me to working with people and talking with people. When I went to Wola Nani, I told them my situation. The project manager was a really nice lady who would sit and listen to me. It really opened up the way for me. That's how I started to meet people and attend meetings.

It even opened doors for me. The director at Wola Nani would ask me if I was free to talk on the radio and if I wouldn't mind talking about my status. If I was comfortable with my status, there was always something for me to do. I even spoke at condom bashes where there was a big crowd. In order for the audience to realise the impact of why we were there educating them about HIV/AIDS, I would stand and tell the people that I was HIV positive. Some of them believed me and some didn't. For some people it's only when I mention my child that they really see that I'm HIV positive.

I can't say I was nervous to tell people. I was just sad. I had pains thinking "why me?" because now I had met other mothers and their children. It looked so sad to see the children were so thin. I could see that reality of HIV and this made me angry.

It depends on how you put yourself out to people and what kind of person you are. Where I live, people stand by me, they support me. I think it's how I put my story forward to people. I'm honest and open and people accept me the way I am.

My brother even takes my child to the hospital for treatment. In my family, it's gotten to the point that HIV is just there, it's in my family. And I suppose what makes the difference that I am on a treatment, not that it is a cure, but it's keeping me going. My daughter is also on drug therapy, so I think that for some people, the drugs make a difference. With me at the level that I was, they really made a difference in my life.

*Interviewed in Pretoria, August 1999. Age 35.*



## Martin Vosloo

*Diagnosed in 1990. Disclosed in 1997.*

In 1997, I couldn't care less who knew I was HIV positive. I started through the AIDS Training, Information and Counselling Centre (ATICC) doing little talks with groups and that led to me deciding that it is much better for me to openly speak about it. You're basically living a lie if you don't tell people. Today I could stand in front of the Pick 'n Pay and tell people about it if I wanted to.

One thing that I have really seen is that you have to prepare yourself for all kinds of responses before you can disclose. You have to be comfortable being HIV positive first so you don't care what the next person says.

One time we did an awareness talk for a group of 30 Eskom workers. We started by doing the usual how you can get it and how you can protect yourself, blah, blah, blah. Then when I asked them the question, "What would you do if one of your colleagues confessed to you that he was HIV positive, what would your reaction be?". These guys said straight out that they would kill him. "We don't want him near us," they said, and then I told them, "I'm HIV positive as well, now do you want to kill me?". They said yes, and I had to very quickly excuse myself that day.

The more you speak about it, the more you create an interest for other people. There are a lot of people who don't know very much about HIV. All they know about it is the myths and the totally wrong things.

Most people want to see somebody who is sick. I went for an interview in Secunda, and I went to the front desk and said to the receptionist, "My name is Martin Vosloo and I'm here for so-and-so for an interview". She calls her out, the reporter walks right past me, saying, "Where is he?" I said, "What you looking for," and she said, "I'm looking for that thin guy". I wish I could show you the expression on her face when I told her she was looking for me.

The more that I speak about it, the less I worry about it. If you keep this to yourself, I think it contributes to you dying sooner. From the time that I started speaking openly about it, I really experienced an improvement in my health. I'm not sick. I'm never sick, yet I'm HIV positive.

The other advantage about speaking out about it is that you don't have to worry about what other people think. You eliminate the gossip factor because if they suspect you

are HIV positive, they will gossip about you. You worry all the time about what everybody thinks, whereas if you talk about it, they cannot gossip because you've already told them. To keep it in, you contribute to your own death because you're so worried about what everyone will think.

But there are consequences sometimes, I mean it wasn't nice losing contact with members of my family. I lost a lot of friends. I was very well known in Witbank and when I talked about it, everybody withdrew. You have to make peace with that, you WILL lose people, they WILL reject you. But to me it's not about other people, it's about myself.

You also need to consult with your partner when it comes to disclosure because it is not only you that is subjected to this discrimination but also your family. You sometimes make a decision and come out into the open without really knowing what their feelings are. It was our experience that, especially when my wife would go to Tupperware parties and things like that, people used to discriminate against her. Now she's the one suffering whereas I'm okay.

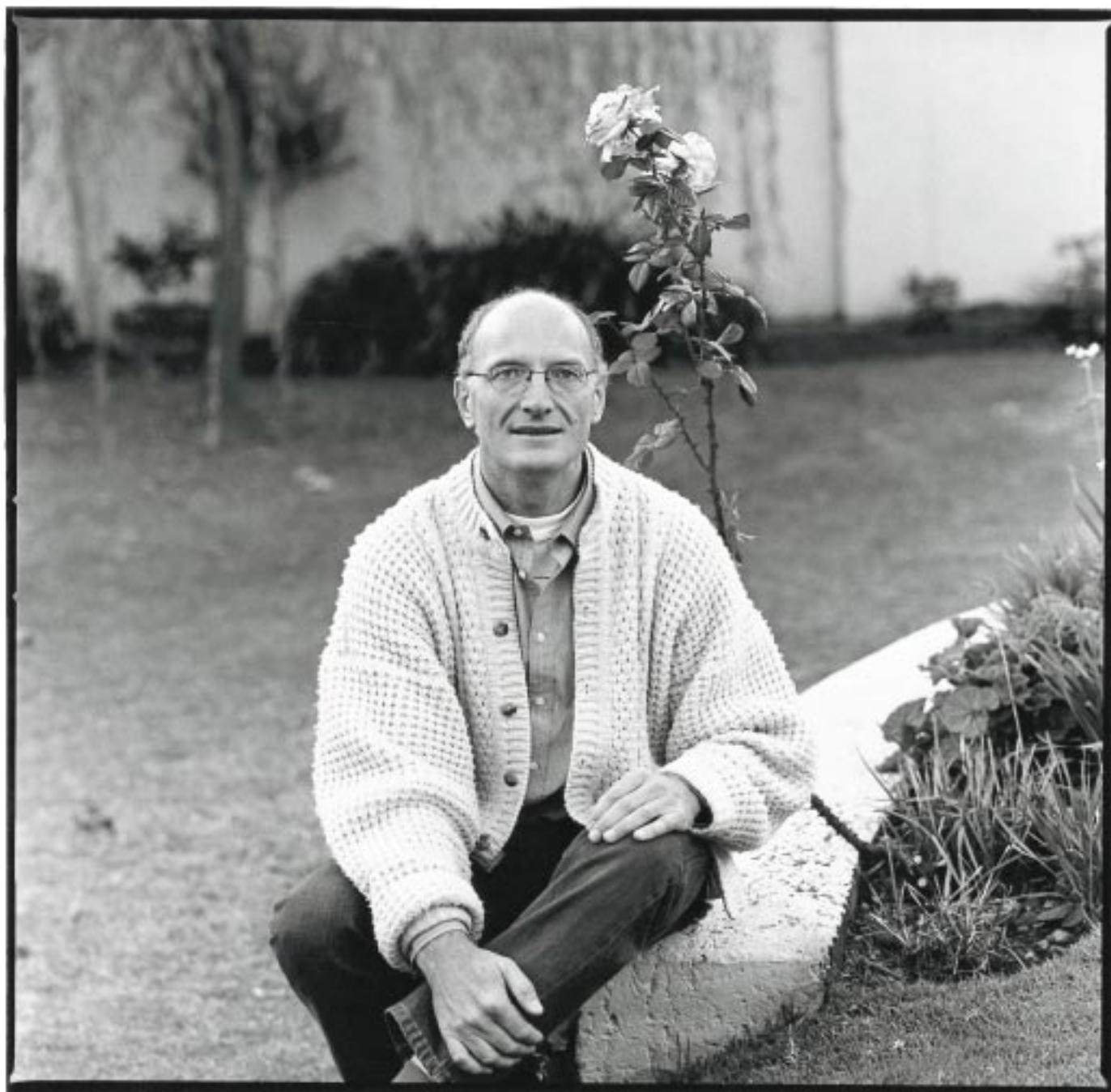
With her it's different because she's not as strong as I am, she's not really ready for this. People are telling her all sorts of stories. By associating her with somebody who is HIV positive, she faces the same discrimination as I do. So that's one of the mistakes I made, I should have rather consulted with her and found out her feelings towards this, if she was comfortable with it.

If there's one thing that I've learned it's that the wrong choices you make in your life are not only obstacles for you but are also obstacles for those closest to you, and that's exactly what happened in our household. We are comfortable with each other, but the way that other people look at you and talk about you is different. Being public has got its advantages for you as the individual, but has its drawbacks for those around you.

The way that I am now is unbelievable. Last night we spoke and said, "We are living a life now as if there is no HIV, because we have spoken about it so much that it's there but you don't think about it."

*Interviewed in Witbank, January 2000. Age 42.*







## Edwin Cameron

*Diagnosed in the 1980s. Disclosed in 1999.*

I disclosed for a combination of personal and political reasons. From a personal point of view, I think it is important that people with HIV or AIDS should be able to feel free... Firstly, to talk to those around one, and secondly, to anyone who has a genuine interest in your status or your well being, to be able to draw on support.

I'd known for a long time that at some time I would make a public declaration that I was living with AIDS. That became particularly urgent after I fell ill with symptoms of AIDS at the end of 1997. Then it became just a question of when it would happen.

I hold public office as a judge in the high court, and now I'm an acting justice of the Constitutional Court, so there is some legitimate public interest in my state of health. The public has a right to know whether their public representatives, their government executives, and the judiciary are in a state of health to carry out their duties.

Until I fell ill with AIDS there was no question about my being unable to do my duties just because I had HIV. When I applied for a vacant position on the Constitutional Court, a senior colleague on the Constitutional Court suggested that it might be appropriate to disclose that I had AIDS. He had heard rumours about my state of health, and he suggested that it might be best simply to state that I have AIDS, that I was on medication and in excellent health. So a combination of the personal and political reasons compelled me to do it.

The broader social and political considerations were that Gugu Dlamini had been killed in a township in 1998. The reason she was killed was ignorance, prejudice, hatred and her own vulnerability. Women in our country, particularly women with HIV, are enormously vulnerable.

By contrast, I have a secure job... in fact a job with constitutionally protected security. I'm surrounded by loving friends and colleagues and family. Many of them at that stage already knew I had HIV and supported me. I'm also able to afford the medication that is keeping me healthy.

So these three aspects are vital – literally vital, because in these three life-saving ways I am different from Gugu

Dlamini. I felt that from my position of relative privilege and protection I should state my position. I had to take at least that limited stand because my privileges enabled me to do so.

Before my statement I felt enormously apprehensive. For one thing, I think the fact that one is living with a deadly virus in one's blood is an intensely personal fact. To make a statement about something that could still claim your life, even if you are on medication, is a very exposing and precarious thing to do. So I felt very vulnerable.

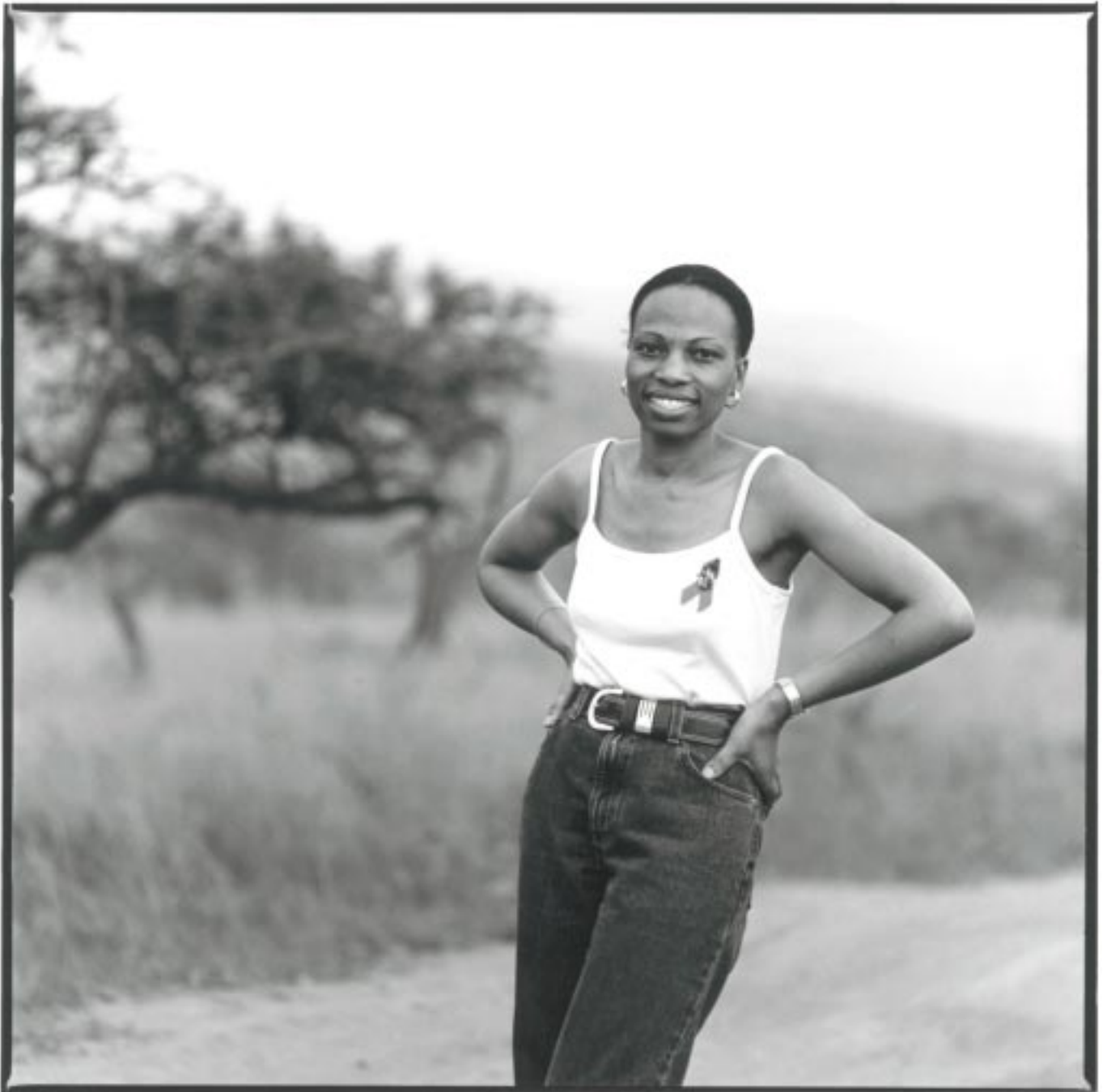
There is a great deal of prejudice and stigma around and I feared that there would be a negative response to my statement. I chose to disclose at a very public forum where the nation's media would be. It was at the public hearing at the judicial service commission, which was interviewing candidates for a vacancy on the Constitutional Court.

I was apprehensive, but deep within myself I knew that it was the right thing to do. I had scrutinised my own motives for doing it. I thought I was doing it for the right motives, so I went forward. My friends and my family really stood behind me. Two friends – Zackie Achmat and Morna Cornell – travelled to Cape Town to be with me. They sat right behind me during the proceedings. I felt very comforted.

The response moved me beyond words. It was almost universally affirmative. I had a deluge of loving responses – letters, cards, faxes, e-mails, telephone calls, and flowers – from many, many hundreds of people.

The size of the response and the extent to which it was positive amazed and moved me. The news was carried on the front page of almost every national newspaper, and on the main national television news. I think that my statement struck a "right note" in the national life at the time. People had at last become concerned about HIV... Perhaps five or ten years too late, which is our nation's tragedy, but the awareness had at last come. People were, I think, waiting for someone to come forward, someone with a public profile, and say "Yes, I have AIDS," and that was my role.

*Interviewed in Johannesburg, July 1999. Age 46.*



## Musa Njoko

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*Diagnosed in 1995. Disclosed a few months later.*

I started by disclosing to my family first. Then I started going out to the community and schools, to church and then I went on to the media. I started giving talks around KwaZulu-Natal, then I went national and I've even disclosed internationally.

The first big crowd that I ever had was at my church. On that day I spoke to more than 100 people. I'm not sure what I was feeling but I wasn't feeling bitter, I wasn't feeling angry, in fact I was very happy. When I went up on stage, I didn't tell anyone, even the pastor, what I was going up there to say. I just told them I had a testimony to give. When I got up there I started sharing with them, they thought I was going to say something else. I don't think there was anyone who thought I was going to talk about HIV.

You should have seen their faces. If they were not black people, they would have gone pink. But they had all kinds of expressions. Some of them were saying, "You're lying," some were shocked. I don't know exactly what they were thinking but I saw a whole lot of expressions on their faces. Afterwards they prayed for me.

Since I disclosed, we have started an AIDS programme at my church. It wasn't very easy because churches are very conservative. Because when we talk about HIV we have to talk about sex. We sat down with my pastor and structured it in a way that was not going to interfere with beliefs of the church but that would get the message across. Time and time again I speak about my HIV status

and people come to me for counselling. I give them whatever information they need so that more people are informed.

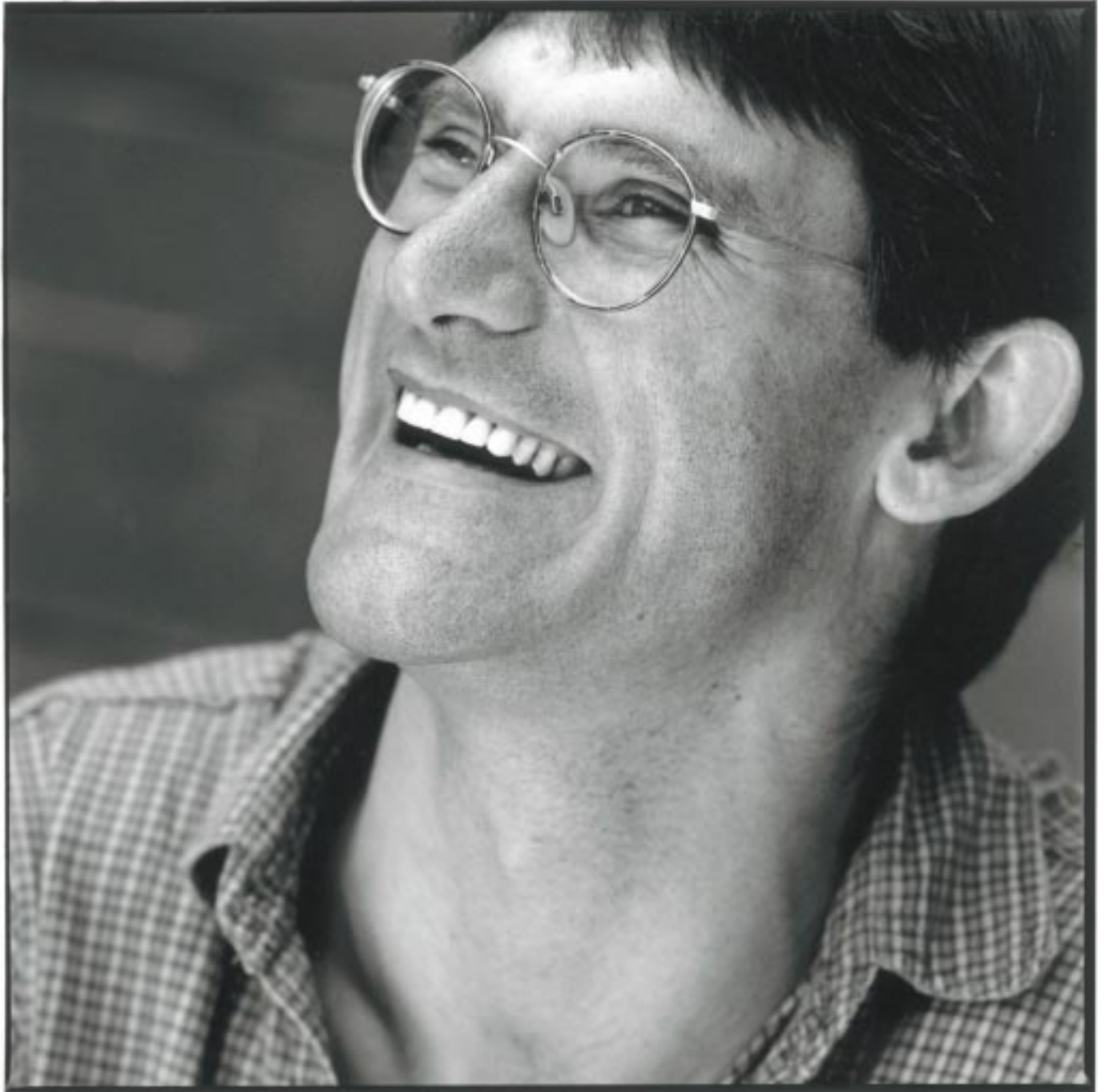
I chose this group because they are the people I spend most of the time with and I wanted them to know who I really am. I felt that I had something to give back to them. They've been a family to me. I believe that HIV can affect everyone... One way or another they are affected. My mission is to make everyone aware to support and care whenever I can.

Today, I get people from the church who tell me about their family members. They would bring them to church to be prayed for but would never say why they were being prayed for. Now people are able to talk about it without fear. Even though they are not pushed to disclose to the congregation, they just do it.

I felt good about disclosing and I have no regrets. I feel more comfortable, and though there were some funny comments from different people or different views, it never made me think I didn't do the right thing. I felt very strongly that I wanted to tell people and that I should do it, so I did.

With the community I've had some strange experiences but because I believe in what I am doing and I know I'm making a difference to one or two people, it helps me. The bad things hurt me, but they never discourage me.

*Interviewed in Durban, September 1999. Age 27.*



# Christo Greyling

*Diagnosed in August, 1987. Disclosed on 10 May, 1992.*

When Liesl and I got married, nobody knew I was HIV positive except our closest friends. Then we went to Namibia. We were in the congregation and it was not a typical situation for a minister of religion to be HIV positive, so we were quite scared about what would happen if we went public.

I always said to Leisl that I wanted to go public at some stage. I wanted to use this negative thing as an opportunity to reach out to people, but Leisl wasn't ready for that sort of thing yet.

Then, I had to go for an operation in Cape Town. They found my white blood cell count was down and everything was just going downwards. I then thought, "Okay, time is getting limited and if I want to make a difference, I must do it now." So I said to her, "I'm ready, I think we must go public with this." Leisl said, "Uh, uh, no ways. I'm not ready for this yet. I don't want to be in the front page of the newspapers," which was what eventually happened.

Before we went public, I had worked with a lot of people and their sorrows. I never told anybody about the fact that I was HIV positive until very close to the time that I went public. There was one woman I was counselling who was really in a difficult situation and she gave me the feeling that, "You're young, what do you know about suffering, how would you understand what I'm going through?". I thought that I would tell her, so I said, "I do understand because I'm HIV positive". A few weeks later, it was communion Sunday so I gave out communion. Afterwards her husband called my colleague and asked how could he allow me, an HIV positive person, to use the same cup and pass it on?

Then, it was a question of who else knows? Working in a congregation situation I trusted those I told, but I knew that those people had told others. Eventually I couldn't control who knew. A lot of people had started to know and I didn't know if they had the real story.

Telling them was difficult. Luckily we had some amazing friends around us that we could chat to about the possibilities. One of my friends said to me, "If you go

public, you can do what you want to do". I always said that I want to spread information about HIV. I want to show people that normal people are living with HIV and I wanted to spread a message of hope in the process. He said that if I could do it at schools, then I could do it anywhere. I didn't really feel ready at that stage, but eventually we decided to go public.

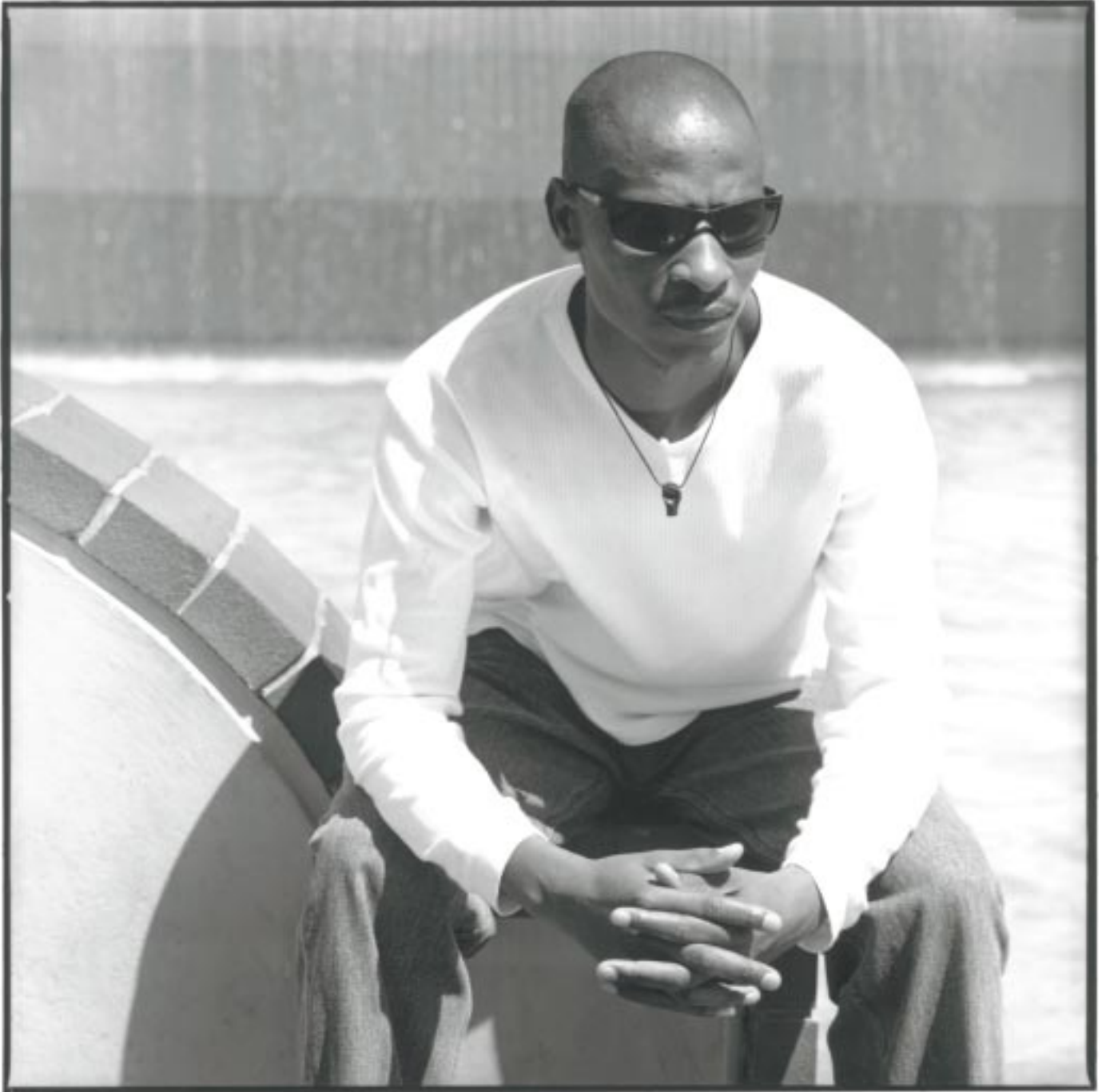
It was Sunday morning in the pulpit. It was difficult to do because I had to say to the congregation, "Listen, I am HIV positive, I feel that I must go and talk to young people about HIV at schools and so on, so I cannot be a minister in the normal sense of the word. I have to be freed a bit to do that". The poor aunties in the congregation were crying their hearts out. Another reason for telling them was that I was thinking at that stage that I might not be alive that much longer, not knowing that I would still be sitting here eight years later.

I thought the best way to do it would be to talk to the congregation first. We knew there would be a media reaction so we pre-empted some of the newspapers and said, "We'll talk to you after the service on Sunday but this is what we're going to say, this is why we're doing it. Don't splash it, don't add, we just want to make a difference." The poor congregation saw these news guys and didn't know what was happening.

We hired a television camera because we expected some negative reactions. I honestly expected people to rush out and be terribly angry with me for not telling them and letting them be part of a lie, but eventually it was only tissues and amazing support. We were flattered with people saying how much they cared for us and were sad about us leaving the congregation.

The moment we told people, we could just relax. It was as if a burden was off our shoulders. It was as if we didn't have to hide anymore. It was as if I had been living a double life. I'd keep up this front of everything is all right, everything is good, but sometimes I was worried but I couldn't say anything about it. After that people knew and they could make of it what they wanted. We didn't care anymore.

*Interviewed in Johannesburg, September 1999. Age 35.*





## Oziel Mdeletshe

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*Diagnosed in April, 1998. Disclosed in 1998.*

I knew I was positive when I lost my daughter. She was tested and the result came back positive, so I assumed that I was HIV positive as well. I didn't get tested until the symptoms developed in 1998. I thought that if I die, I want to know the cause of it.

I got involved with the National Association of People Living with HIV/AIDS (NAPWA), who encouraged me to disclose publicly. I started working with the Beyond Awareness Campaign through DramAidE. I work with the tertiary institutions project and talk to students and run workshops about AIDS and disclosure.

The first time I disclosed was at Ladysmith during an AIDS awareness event. There were about ten people living with HIV/AIDS who disclosed. The response of the community that day was very positive. We were told how to disclose before the event. It was not something where we woke up that morning and then we disclosed.

There are stages... You start from yourself, then you disclose to another person like your partner or your family. If you feel ready, you disclose to your friends next. The public is the last thing that you do because you meet new people and you don't know what their reaction will be after you disclose. So if you disclose to the public, you have to accept anything that might happen afterwards. It could be negative. They might even ask you funny

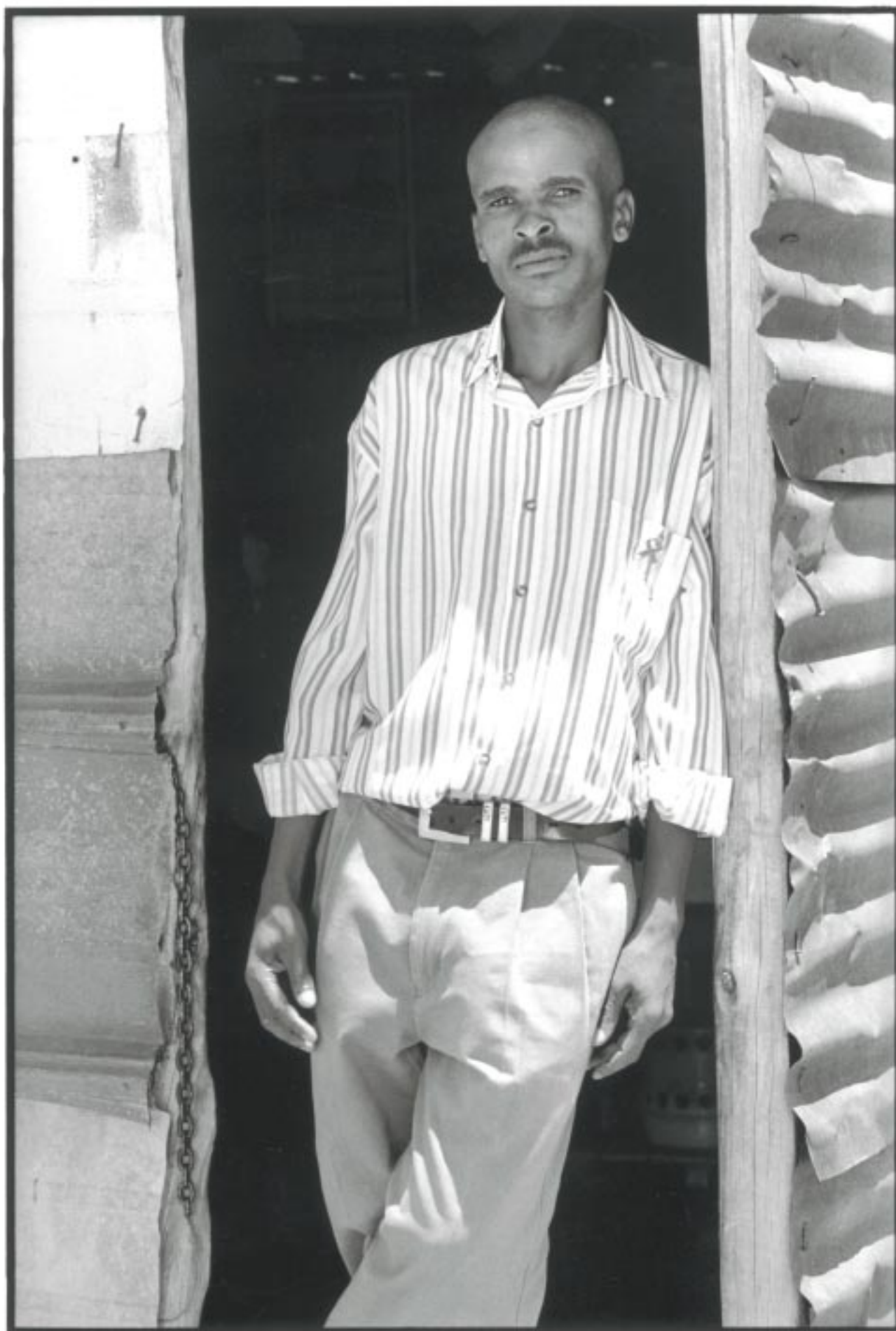
questions. You have to accept any reaction, so you have to understand what you are doing.

I was encouraged after that day because I saw that if you disclose to the public in the right way they won't neglect you, they will support you. After I disclosed, they came to me and talked to me in a positive way. I was very happy in the way that they responded. It showed me that to disclose to the public, it needs to be done, but you need to know what you are doing.

It was something that came from my heart because I was diagnosed without knowing how I got the disease and I felt that I needed to address this issue to the public. And I had to live positively. I think I wanted to do my contribution to serving the nation as well.

When I started my involvement with NAPWA, I got involved in a campaign called Disclosure and Acceptance. This campaign was not about everyone disclosing. It was specifically for those people who wanted to disclose. Disclosure is not about telling the public, it is about disclosing to those around you, telling your partner and your family. You can keep the information within your family without telling the public. We encouraged each and every person who is HIV positive and those who are not positive to talk about it, and to be able to talk to their friends and family when a person is diagnosed.

*Interviewed in Durban, September 1999. Age 31.*



## Jones Mngomezulu

*Diagnosed in November 1996. Disclosed 1999.*

It took me such a long time before I disclosed. I was employed by a company that requested me to take an HIV test. I went for the test and I found out I was HIV positive. Thereafter I felt angry. I even decided to commit suicide. I tried to inform one of my colleagues. After a couple of months, it spread over the company so I decided to leave and join another company. I was lucky because within two weeks I found another job. And there the same thing happened. I tried to inform another colleague after a year and it spread in the company. I decided to leave my job and stay at home. People were discriminating against me.

I disclosed to my family. They too rejected me. After my family rejected me, I was running out of support from the community and my friends. I had only my sister who supported me. Last year, I met a certain lady who was positive too. She's the one who encouraged me to join a group in Orange Farm. That's who I asked to come and visit my family and counsel them. They then later realised that what they did was really wrong. They hadn't accepted me as part of the family.

I was staying with a lady who I called my wife because we were married through lobola. She left when she learned I was HIV positive. I requested that she take a test but instead she left.

What happens with the community as a whole is they point the finger at you, saying you're HIV positive and what not. You're a whore, a prostitute. When you come into contact with such words, really, you feel shy. You feel you don't want to go outside or to meet anybody.

I went to live with a lady who is also HIV positive and we decided to make our own group. HIV positive people in the community were running short of support. As HIV positive people, we decided to keep and support them since we knew that it would be difficult. It's rare that they are accepted in the community. We try to counsel them so they can accept it because even for those who are positive, it's very difficult for them to accept that they've got AIDS.

HIV can come no matter how good you are. It's just an illness which anyone can get. It doesn't only go to people who don't protect themselves. It can still happen.

Most people don't know how to use a condom because they don't have good information on how to use them. I try to talk to most of the people and educate them about AIDS and how a person can prevent it and make people aware of it. Most of the people do accept it and like what I'm doing and some want to join our group.

I was afraid because some people tried to stone me when I told them of this illness. I tried to talk to them. I remember at certain schools I was taken out by the principal when I told them I was HIV positive and the crowd wanted to attack me. I was protected by the principal. They said I was coming to spread the illness and I should go out of town to live. I think they were afraid for themselves. Most people don't know their status. If you tell them to go and take a test, they think maybe their result will be bad, so they don't go.

I'm still going out to tell people because every person should know about this. I also give them protection. When I go up and down in the township, wherever I go, people ask me for condoms. "Brother, where are the condoms?" they say, because they know now that this virus is very serious. It kills a lot of people right in South Africa and overseas and everywhere. If you, as a human being, don't want to protect yourself, really it is going to take you.

We who are infected accept it and protect ourselves from further infection. There are a lot of people who are positive in Orange Farm. They are silent, but some of them want to disclose. I try to show them that even though you talk to her or him about their status, they don't want it.

It isn't easy because some only pretend to support you. They know deep down in their heart that they don't support you. They are angry. They do accept but not wholeheartedly. Even at home, I have my own plate and if I use theirs just once, they won't use it again and put it aside for the next time I come to visit. They still don't understand, even though they say they do.

Sometimes I feel like I want to leave this place and go somewhere that I'm unknown to the community. I do feel angry about my situation but I have to accept it. It wasn't my choice.

*Interviewed in Johannesburg, February 2000. Age 32.*



## Venash Murugan

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*Diagnosed in March, 1985. Disclosed in 1998.*

I waited so long basically because I was still going through a court case for unfair dismissal from my job. The company found out somehow that I had HIV and even though I had everyone, the AIDS Consortium and lawyers, behind me, they were a bit too slow.

It took about two years for this case to come up in court and basically I lost the case on what was the negligence of my lawyers because they were slow in re-submitting things to the court. They said I could re-fight the case, but that would take lots and lots of money and at that time I didn't have it.

In December of 1995, I was destitute, living in a place for destitute HIV positive people. I couldn't get a job. I had done aptitude tests and everything, and the last part was when I disclosed to them. Then they said, "Oh, we'll get in touch with you, we have other interviews". Somehow I thought I had lost everything and there was nothing further to lose and it was about time that I exposed the whole thing.

At this stage, my family didn't know anything about it. I phoned them about five minutes before my status was

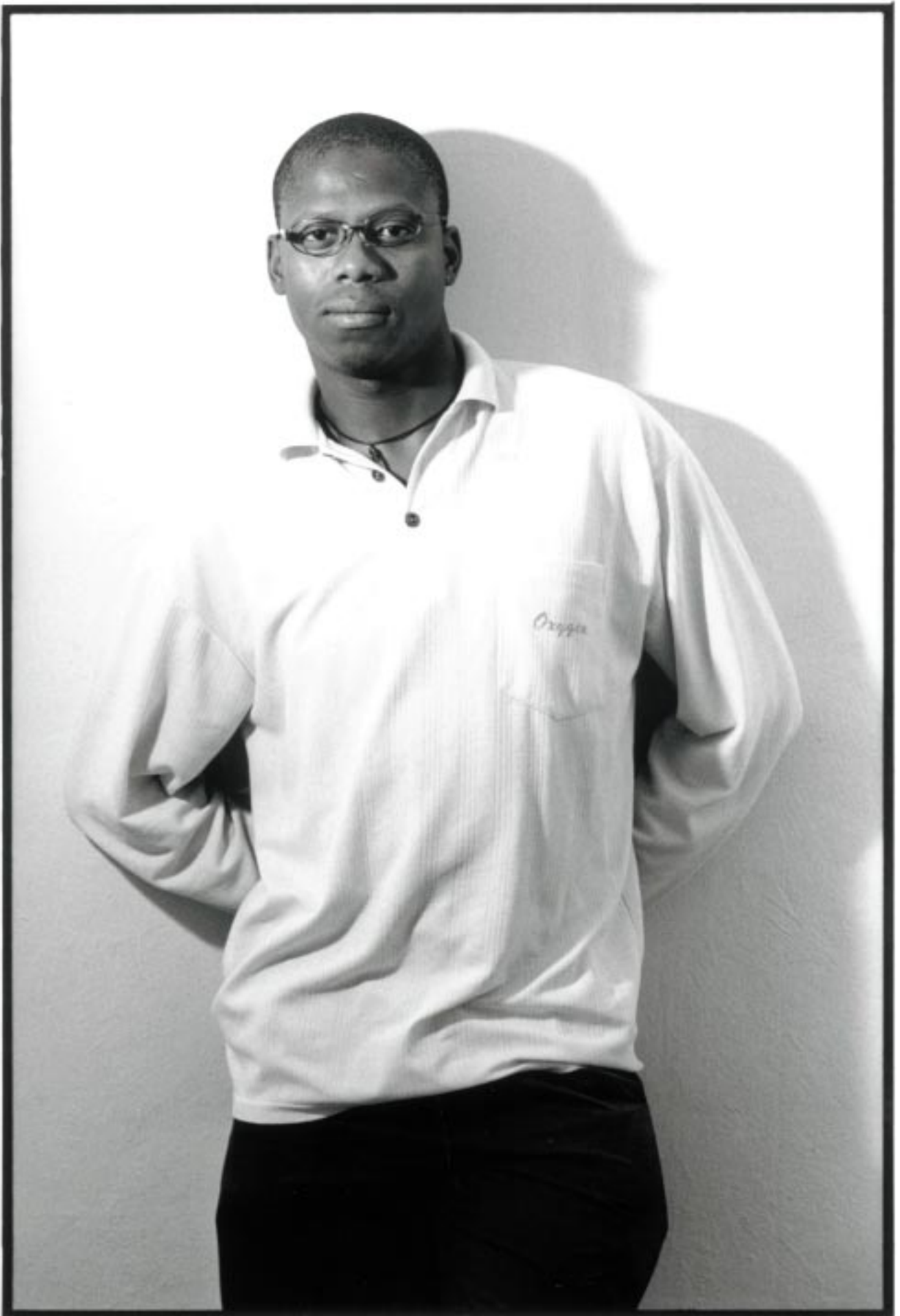
going to be aired on BOP TV. It took them a few months to come to terms with it.

It was on a talk show called "Sister Talk". I felt that by me coming out, I could help others. In counselling, I can understand where people are coming from because it's about paths I have already travelled, and those I talk to are just starting.

When I decided to dedicate all my time to the AIDS field, some HIV negative colleagues of mine felt they were being pushed into corners by HIV positive patients. The first question they asked them was, "How would you ever know how I feel? You are not positive", whereas they could never use that with me.

Once you're out, you're out. What's nice about it is you can never go back. But it has opened lots of doors for me, coming out. I don't have to pretend, or still feel guilty when I walk past an AIDS poster. I carried on and got sponsorship to finish my degree in psychology, then went into all voluntary work. I have sponsors for the car I drive, and the home I live in, and all the work I do is voluntary. I've been a volunteer for the past seven years.

*Interviewed in Johannesburg, January 2000. Age 32.*





## Paddy Nhlapo

*Diagnosed in 1994. Disclosed in March, 1999.*

I waited so long to disclose because basically it's lack of understanding of HIV and not having the right information that kept me in the closet for a long time. I didn't undergo any counselling, I was just diagnosed and was told to go. I went to a clinic for an STD and my blood was taken so they could find out what I had. When I went back the nurse just said, "It's bad news, you have HIV." And that was it... no pre- or post-test counselling. I went for the results of the STD and it was a shock and that's it.

So I didn't tell anyone, I just kept quiet. During that four years, I was collecting lots of information. I didn't miss anything that happened with HIV/AIDS and I was reading a lot. I started becoming slowly confident. I confided in a friend of mine. She was the first person who knew. That was two and a half years after I was diagnosed. We kept quiet about it, both of us. After people were busy coming out, I talked to quite a few people who were out. I started undergoing counselling, then I decided, "I'm coming out too".

I had various stages of disclosure that I had to go through. I thought I should tell my mom and my dad and the rest of my family. Unfortunately, I couldn't do it, so I started telling people at work first. My then-director, Zackie Achmat, was the first person to know. Then I spoke to my manager and two or three months down the line I spoke to the staff. It went through stages. After they knew, and other closer people started to know, I felt I was ready. It was the right time to disclose at home so that they could start taking care of themselves and I could help them to understand what was going on.

I had very serious problems at home with my dad. Then I got very sick. I think my being sick brought so many things in their minds, like, "It's possible that we may lose him and if we continue fighting about this, it won't help anyone". After that, I started a group counselling session for my family because they didn't want me to go public. That's basically what we fought about... my dad and I. He told me, "You're not going to go public about this because it's an embarrassment to the family". So the counselling sessions took quite a long time.

Already I was telling people in organisations that I am part of, like the African National Congress (ANC), and comrades that are close to me. Finally I told my family that I was doing this TV programme and it was going to be shown to everyone. I told them, "I've already started doing it, so you will have to get over your fears and problems". My dad just kept quiet and said, "Do what you think is right".

Sometimes you cannot do what parents want you to do. You have to take charge of things. It's advantageous for me to be out and I think I'm playing a certain role in making other people feel comfortable with their status. I'm making other people feel that they are not going to die tomorrow, as people think HIV/AIDS is just a death sentence. You aren't kept from a happy life, a positive life, a productive life for that matter, just because you are HIV positive.

I came out for a few reasons. One was a political reason and the other is a personal thing. Personally I wanted to be free and do what I wanted to do. There were times that I was with my friends and they would be having Coca Cola and I'd be asking for juice. People came to my house and asked why I bought filtered water, why did I like 100% juice? People see the difference in you, even if you might not notice it, they will see. They will keep on asking questions and it's better that people know and you are free with them.

Also they can confide in you. You don't know how many young people have come to me and said, "I want to go have a test. I had a partner who died of AIDS and we were careless". People come to me, lots of them. I want people to understand the realities about HIV/AIDS.

Another reason is some of the youth that I grew up with on my street, my neighbours, about three of them passed away and two are very sick. People will have to know that leading a positive life and eating healthy helps people a lot.

It's a small-scale type of achievement, but in the long run it helps people's lives. It enriches people's thinking. I like to lead the way, and give advice. I love to be a part of development and an improved situation.

*Interviewed in Johannesburg, October 1999. Age 29.*



## Andre Mlungisi Mackrill

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*Diagnosed in September, 1994. Disclosed almost immediately.*

*Andre passed away on 28 August 1999. The photograph shows Andre's family with his framed portrait.*

My life has always been an open book.

I disclosed in public one day just shortly after I found out my status. By then I had already decided that if I was going to be infected with HIV/AIDS, I might just as well speak out about my HIV status. It didn't come quite as easily as I had thought because I met with a lot of resistance, especially from my wife.

You'll appreciate that with my political history, there were times when I had difficulty being employed. My wife ran a little vending business, which often enough fed and housed us for the periods of time when I was not employed. A great fear was that no one would come and buy from a house where there was AIDS. Added to this was the risk that I was probably not quite as easily employable.

It wasn't until one of my sexual partners threatened me with press action that I really made a public statement. I think it was more a matter of her reaction to the fact that I had tested HIV positive. So to take the wind out of people's sails... I mean if people were going to make a hullabaloo about my HIV status, then I best just talk about it. I approached my priest of the Anglican Church who, on World AIDS Day of 1996, said to me, "Andre, you are welcome to use the platform".

I was amazed because I didn't realise there was so much goodwill out there. I think this is the fallacy and the fears of most people out there because they are not aware of the goodwill. I was amazed after my address by the amount of people who reached out.

Up until today there are still emotional responses. I personally have not encountered any negative response from anybody. I up until now am a Christian and I just praise my Lord and Master for protecting me through this.

I just want to add what it has done for my family. Whilst

there were the fears right up until the very day I got up to speak, I must say I was very fortunate in that my family came to support me. My mother, my grandmother and everybody made it special because we all attend different churches but they all chose to be there for me on that particular day.

I would almost surely recommend that people speak up, but they have to be careful of the when's, the how's and the who's and whether they've had the necessary counselling.

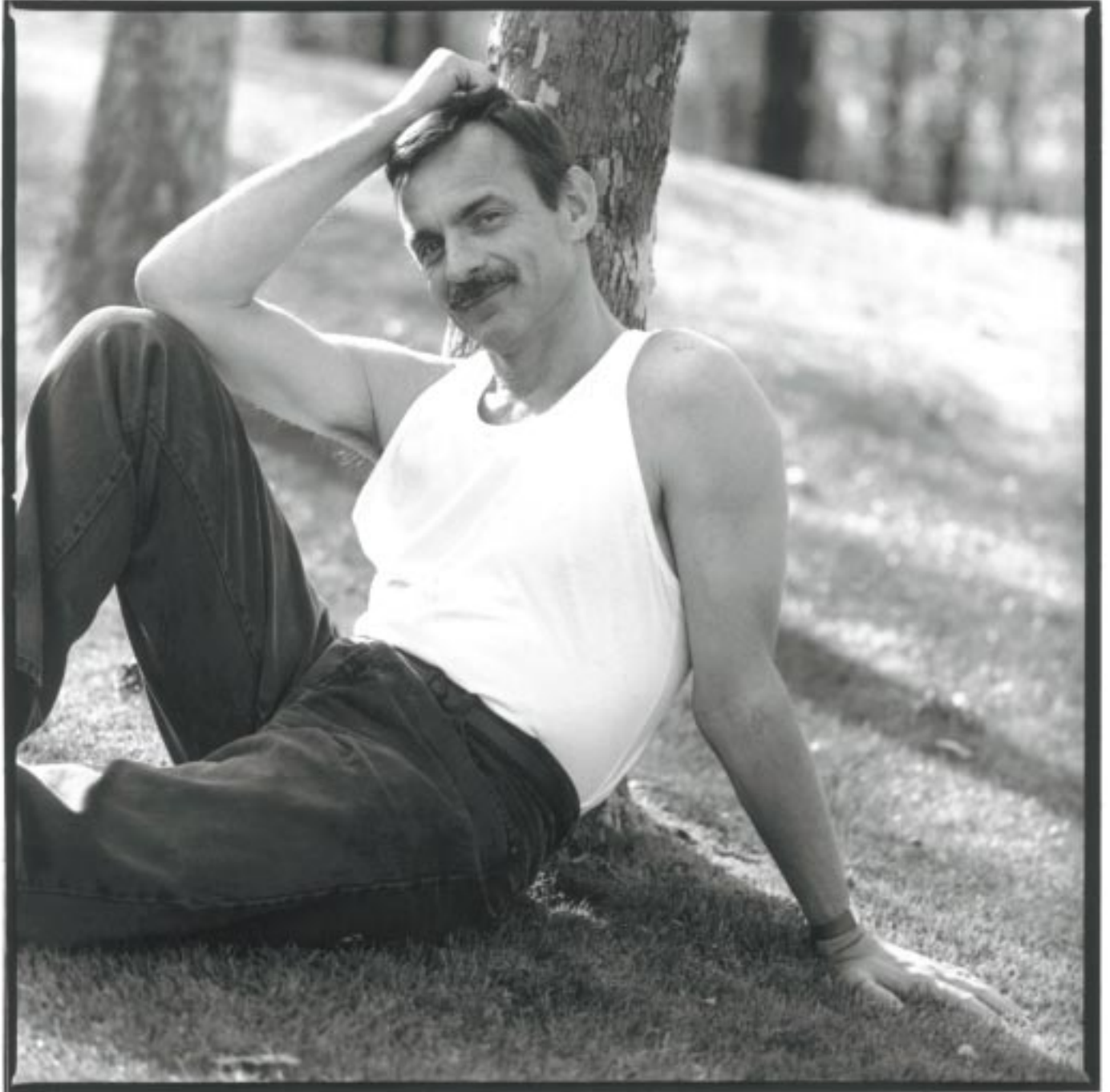
It's done a world of good for my family. It's reduced the talk and our tensions about HIV related things. I remember that immediately afterwards, my family could speak about "dad's HIV status" as opposed to going into a rather harsh tone or a whisper in constant fear that someone would say something out of turn or mention something carelessly. That is all past now. We speak openly about my HIV status and joke about it, speaking very lightly to the extent that as a family there is absolutely no fear. The prejudices have all been broken down.

That essentially is what it's all about. HIV is just another thing and in fact I forget about it most of the time. If it wasn't for my working environment, I would actually forget the fact that I'm HIV positive. I have to remind myself part of the time, "Hey you've got to be careful", and be constantly reminded when I am working in the field not to expose myself and things like that.

But who am I? I get along without those fears or concerns. It's out of my mind, and that's what disclosure would do for a lot of people. Then by talking about it, of course, people would know how to react and how to deal with certain problems that may arise as a person living with AIDS.

Over and above, I'm pretty normal. That's my story.

*Interviewed in Pretoria, August 1999. Age 43.*



## David Patient

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*Diagnosed on 13 March, 1983. Disclosed immediately.*

My disclosure is a weird story because I was disclosed publicly in the United States. I didn't bring myself out, I was brought out. I was dragged out, screaming, I might add.

The long and the short of it was that my partner was in the military and we were diagnosed on the same day. He was a doctor, and somebody in his clinic leaked the news to the media. The media picked up on it, and in those days it was called Gay Related Immune Deficiency Syndrome (GRIDS)... it wasn't called AIDS.

Amazing huh, as gay men we had our own disease, specific to us! So it hit the newspaper and I was brought out by association because I was his partner. Someone spray-painted "fags" on the side of the house, and bricks were thrown at our windows. Somebody poisoned our dogs. The telephone, when it did ring, was usually somebody making some derogatory statement about killing a bunch of faggots and, "This is God's way of killing you".

I was immediately discriminated against at work, as was Bill. He was court martialled. It was an 18-month fight, and the long and the short of it was that we were able to set precedent.

I was working at a travel agency at the time. There was a woman at the travel agency who had seen an article in the newspaper about Bill, made the association with me, reported it to the powers-that-be in the travel agency and, the next thing I knew, I was called in and told I was a shoddy worker and I must please leave.

Then I was discriminated against again about 18 months later when I was working hush-hush in someone's home as a private chef. The news leaked out again. I was no longer living in Vegas at that time and had subsequently moved to Florida. They found out and required me to have an HIV test done, which I did, and they fired me. We then took them to the Constitutional Court of Florida and had precedent changed there.

So as far as coming out is concerned, I came out, I went back in the closet the minute I left Vegas, and it wasn't until I hit Florida when I said, "This is bullshit". The reason I said so was that Bill had won his case with the military and they then tried to screw him on his veteran's pension, and that was absolute crap. So I came back out again and said "This is wrong". I've been out ever since.

I don't have a problem with anyone knowing my status at all. I'm clear on the fact that it's my body that has a disease, not me. I'm not a diseased person. My body has got this thing called HIV and so far I've been able to beat it. I'm looking at 17 years since I was diagnosed and there's no sign of it reactivating.

When I was diagnosed, my first response was, "I'm not going to die from this. This is not how I'm going to die." Based on my reality now, I'm probably going to live until I'm 70. I'm going to be walking around having a great old time and people will be saying, "Oh that smelly old man". Or maybe I'll die of a heart attack from smoking too much. But I don't think it's going to be AIDS, I really don't.

*Interviewed in Johannesburg, January 2000. Age 38.*





## Queenie Qiza

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*Diagnosed in 1997. Disclosed one month later.*

At first I was afraid to tell people. So, I made myself stronger and stronger.

Somebody asked me to disclose at a World AIDS Day event. I stood in front of the crowd and I disclosed. I was afraid because it was the first time I had come out with my status. I told them everything about myself, how I felt and how was it is to be HIV positive. It wasn't so easy to come out. I was crying the whole month, thinking about this illness of mine.

The first time I told people I was nervous but now when I tell people I am open and free. Sometimes when I hear people talking about AIDS, I get in and talk with them and tell them that I'm positive. They don't believe that I'm HIV positive. They say I'm lying. They say they know what a person with AIDS looks like.

There are many, many people in my community who have HIV, others have AIDS. They ask me how I survive and I tell them it's because I'm looking after myself. I go to

treatment every month and I'm telling people. I'm not shy anymore to talk about it. I tell people so that I can help them. Most people are hiding away. I go out and talk to them or talk to their families because some of their families don't care. They don't give them the support and people are killing themselves. Others kill themselves by always drinking. Such people need support and if they get support, they will have a long life.

Things will change for other people because I've come out. I've disclosed on television. People come to my house. Day and night, they are always there. Others see me on the bus and ask me if they hadn't seen me disclosing that I'm HIV positive.

Most of the people are hiding it but not me. I'm doing it for myself and for them, for their long lives. Instead of keeping the secret away, I must tell people. It would only frustrate me to keep it inside.

*Interviewed in Cape Town, November 1999. Age 42.*



# Pat Hlongwane

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*Diagnosed in December 1994. Disclosed in 1996.*

When I was diagnosed the doctors sent me to the ARK, which is a church group, because I could not accept the results that I was HIV positive and I wanted to commit suicide. When I arrived there, the doctors and the pastors explained to me that HIV is a normal disease like any other disease. While I was at the church, they had me attend church and Bible study classes. That is when I experienced the power of God. I told myself, "My body is a temple of God and the virus is in the wrong place, it does not deserve to be here."

That is when I joined the National Association of People Living with HIV/AIDS (NAPWA). In 1997 I went to visit my father in Port Elizabeth and I told him I've got HIV. Unfortunately he is 79 and he doesn't understand about HIV. I explained that it is a killer disease and he asked me if I was taking my medication and told me he would pray for me.

My second challenge was to disclose to the mother of my children. She told me straight away that I have to distance myself from my children. My children love me and they would always play with me but she didn't like that. I had to sit down with her and educate her. Today she is accepting me, and she loves and supports me.

Then I went public, firstly in the media – on the radio and on television. Early in 1997, I said that people had to know that I'm HIV positive. I realised that if I kept this disease a secret, it was going to destroy my immune system. I believe that when I talk about it, that alone heals me and I'm frustrating it. I can live longer if I'm living a positive life. Because with HIV/AIDS, even though it's in your body,

your mind must be liberated. That is the reason I decided to disclose.

People phoned in and wanted to know why I disclosed. They asked "Did I inform my girlfriends that I am HIV positive?" My answer to that was that disclosure and acceptance is nothing other than a healing process. Secondly, I told people that by coming out over the radio I am passing a message to my girlfriends that I am infected.

I was relaxed. I had prepared my mind before I went on the show. Hence, I was not nervous. I expected any question. Fortunately, I am a person who is calm and cool and collected because of my understanding the dynamics of HIV.

I never had any problems with the community. Since 1997, I've been working in the companies and schools and communities, no one has ever challenged me. If people are pointing fingers at me when I walk in the streets that doesn't worry me. I know I am what I am, and HIV/AIDS doesn't choose age, race, colour, or sex.

My commitment is based on education because I am very much aware that people in South Africa are beyond awareness. They know about the transmission of HIV but what I always tell them is about prevention because there is no cure for AIDS. If young people cannot abstain and they have to involve themselves in sexual activity, I tell them to use condoms.

Presently I'm not taking any drug therapy. My belief is that God will bring the cure. That is the only treatment – prayer.

*Interviewed in Durban, September 1999. Age 37.*



## Valencia Mofokeng

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*Diagnosed in February, 1998. Disclosed seven months later.*

When I was diagnosed with HIV I was angry, and for the first time in my life I thought of suicide. I thought maybe if I died, things would be better for my son. After a few weeks, I realised I was making a big mistake because my two older daughters also needed me. So I decided it was better to live and teach people how to live with AIDS. I started seeing social workers to help me get through this.

The first time I disclosed, I was staying in Lenasia and I was working at a Children's Home as a child-care worker.

There were two children there who were HIV positive but the staff were not treating them correctly, it was not like the other kids. They used to swear at them and sometimes they didn't even wash their clothes.

I felt depressed and angry because they didn't invite this disease... it just happened to them. Nobody knows how this disease comes or how it started. I was angry and I had to fight back for those kids because they were small and couldn't fight back for themselves.

The people I was working with started to suspect maybe there was something wrong with me. By that time my husband had just died of AIDS and I thought I had to tell them the truth. They rejected me, they said I'm a loose woman and I sleep around. It was very painful because I

was faithful to my husband and didn't know he was infected until after he died.

I think that by being silent I made myself very ill and depressed. I first got courage after I saw other people soon after they were told they had HIV. These people became very ill and they died because of silence. By that time I was angry because I didn't know about this disease and what it was doing. I used to go to support groups to be with other people to express my feelings. After that I felt better.

Immediately after I told everybody, I was relieved and I began to live a normal life. But it took seven months to tell people. Telling people was the hardest thing to do because you don't know whether they are going to accept you or not. It wasn't easy, believe me.

I think it was the best thing to do because each and every time after I talk with somebody, I feel okay. As long as you accept it, it's like other diseases. As long as you accept yourself, people will also accept you. If you don't accept yourself, you're hiding from yourself. In a way you don't want other people to help you, or to learn more about this virus. So by talking to other people, visiting other people who are HIV positive, talking to each other, discussing your problems, you become relieved.

*Interviewed in Johannesburg, February 2000. Age 35.*





## Peter Busse

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*Diagnosed in 1985. Disclosed in 1992.*

I was diagnosed HIV positive in 1985 in Swaziland. It was very difficult being diagnosed at that time because there was very little counselling support and very little information. There were very few people in the country who even knew about HIV/AIDS. I came back to South Africa in 1987 and then got involved in AIDS work.

The actual issue of disclosure has been a process for me. It hasn't been a sort of one-off big thing of announcing to the world that I was HIV positive. It started off by telling very, very close friends of mine. I spoke to people that I felt I was close to, that I trusted and who would understand. I worked in the HIV/AIDS field and that was also an enabling environment. It was easy to talk to people in that field because people were AIDS literate. They understood about HIV/AIDS, so it was sort of quite easy to be open about my status at work.

In terms of my family, it was a process of first speaking to my two brothers and my father later on. Family, in a way, was the biggest obstacle. It's a much more emotionally loaded issue to talk to a family member because I think one's worry is what is their reaction going to be. If you disclose to somebody that you don't really care about and they reject you it doesn't really matter, but when disclosing to family, their reaction is critical.

Both of my brothers were extremely supportive and my father also very supportive, basically saying that they'd always be there for me and if there was anything I wanted and needed in terms of support, that they'd be there. That was very encouraging.

In terms of public disclosure – and by public disclosure I mean at a national level – that started off for me in the early '90s. I can remember my first public disclosure. It was at a big meeting that was held to draft the NACOSA National AIDS Plan, which was adopted as South Africa's National AIDS Policy in 1994. It was a big meeting for people to discuss the National AIDS Plan. There were about 50 to 60 people there. Everyone was going around the room saying who they were and what they were doing. I suddenly realised that in this entire grouping of people that were writing this National AIDS Plan, there wasn't one person who was HIV positive. I was the second or third last person in the room to introduce myself.

It wasn't a pre-decided thing. As I was introducing myself, I said, "My name is Peter Busse". I said a bit about the work that I was doing, and then I said, "I've also been HIV positive since 1985 and I'm living with HIV. I'd like to bring that perspective into the writing of the National AIDS Plan."

I think the reaction from people who knew me and knew my status was one of shock. Although I had been open to a limited degree, it was my first public disclosure.

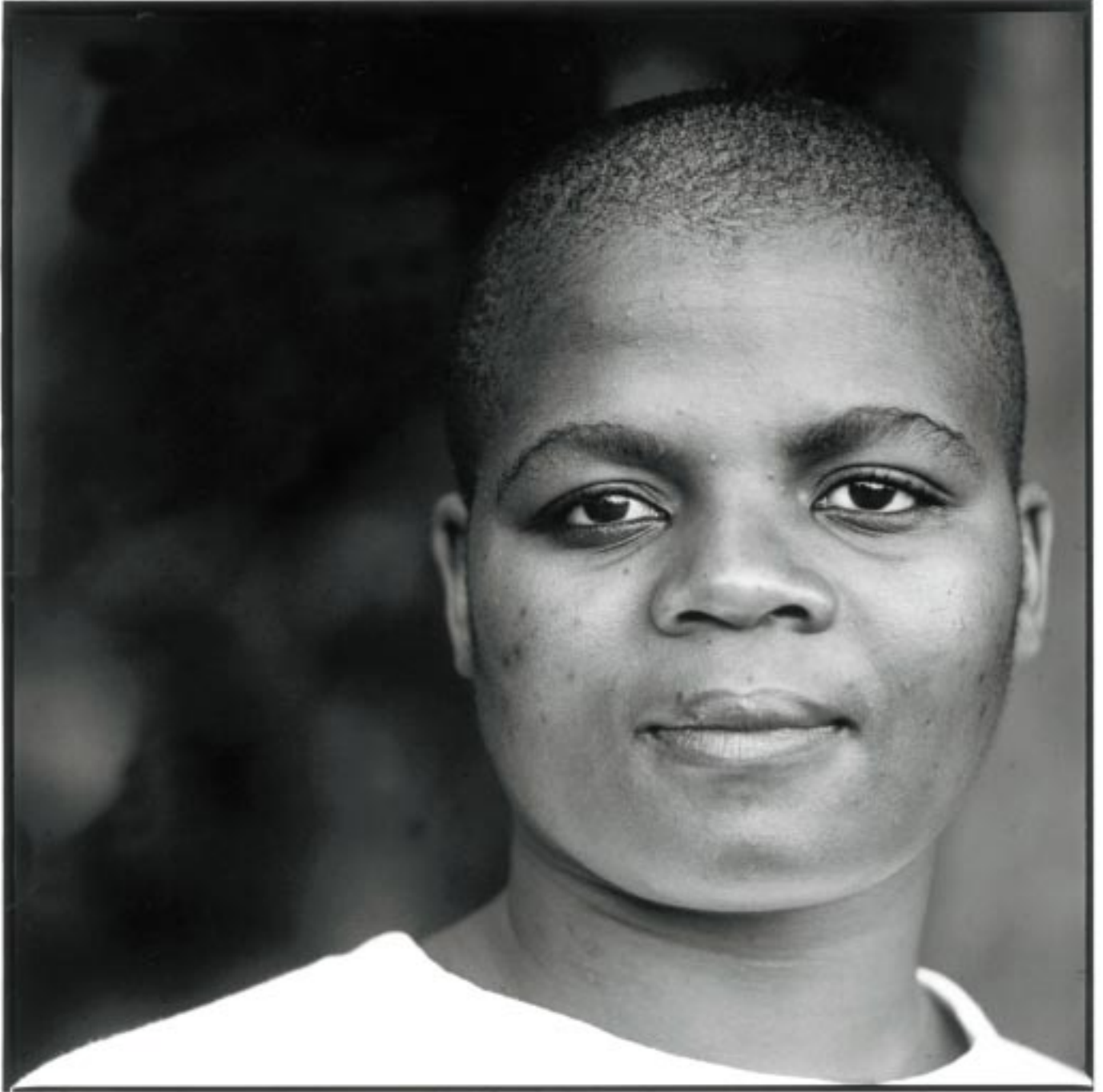
The level of disclosure during those years was quite limited because there were very few people that were open. If I look back, I could count on one or two hands the number of people who were open about their status. It was more difficult because you didn't have a large number of people who were open, whereas in the closing years of the '90s there are far more people who are prepared to be open about their status. There is also a bigger community of support and information that one can tap into.

There is always the worry about personal safety. A lot of people who have disclosed have received threats. I'm aware of people who have been threatened for talking about living with HIV and being open about their status. I think that's also a big consideration in addition to what are people's reactions going to be.

It's vital to have a group of people who are open because it provides a role model for people and also it can break down the viewpoint that AIDS isn't really happening. People cannot "not see" or "not believe" in HIV/AIDS if sufficient numbers of people are standing up and saying, "I'm living with it". So I think that's a very important aspect of it.

The other thing that is critically important on the flip side of the disclosure coin is acceptance. We need to do a lot of work in preparing our society and our communities to accept people once they disclose. This involves working with community leaders, with religious leaders, with police, with social workers, and with members of the community to accept people once they have disclosed. What we need to do in South Africa is to not look at disclosure in a vacuum. It should always be accompanied by acceptance and preparation of the community to accept and support people living with HIV.

*Interviewed in Johannesburg, June 1999. Age 41.*



## Portia Yalezo

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*Diagnosed in 1992. Disclosed in 1997.*

In 1997 I started going out and telling people that I was HIV positive because people don't know that a person with HIV can live for a long time. I thought if I came out as a young person, they will change too and they will learn to tell their parents. They will learn to accept that HIV is not a death sentence.

I first disclosed at ML Sultan Technikon. Some people said I was lying, that the government was paying me. Others believed me. They asked me why I was still so healthy and how many boys I had infected. When I finished, some boys said to me, "Hey! You've got AIDS," and I said, "Don't point fingers at me because four fingers are pointing back at you!". It hurt me but I knew I was doing the right thing.

I used to cry after I spoke. I was crying because people used to ask me stupid questions like, "Now you're seven years with HIV, you're going to die! Have you bought a coffin to prepare yourself?".

I did four talks and after that I was okay because I went through counselling. If they told me that today, I would say, "Have you tested yourself? Do you know where you stand? At least I know where I stand and what to do with

my life. You don't know, you're still infecting others and re-infecting yourself because you think you're not HIV positive. Maybe you are, you don't know. Go and have yourself tested before you talk to me."

Some people I spoke to changed... especially the girls. When I went to Howard College for a week, I went to each and every residence hall to tell them about HIV. Some of them would come to my room and visit me. I think 23 people came and told me they were HIV positive and some of them still phone me. Some of them are my friends now.

I tell the youth that HIV is not a death sentence. Instead I say, "Treat yourselves like you are HIV positive even if you are not because you don't know what will happen in the future".

Today, I'm proud. Before I used to say, "Why did I have to get pregnant, because if I didn't get pregnant, I wouldn't have known that I was HIV." Now I'm thankful that I got pregnant and the doctor told me I'm HIV. If I didn't I would be still infecting others not knowing that I'm HIV. Maybe I would be dead.

*Interviewed in Durban, September 1999. Aged 22.*



## Shaun Mellors

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*Diagnosed on 24 December, 1986. Disclosed in 1988.*

My first public presentations were to small groups at training courses. I saw that I was being used to give personal testimony because I had HIV. I believe people with HIV have more to contribute than just that.

Then I was approached by the former government's AIDS Programme to participate in a national campaign to promote awareness. It was a photo advertisement. I spoke to some of my more politically correct friends and they advised me against it. But I felt that AIDS knows no politics. It's not a line to the government, and I decided I would be doing it for my own reasons and not for the government.

The pictures ended up making me look like an AIDS "victim". I think they chose the worst of the pictures on purpose. But it seemed to be well received, except by my family. I told them I was HIV positive but didn't tell them I was participating in this programme. It created a number of interesting reactions from other family members to my parents but not one of my family members contacted me and I haven't had any contact with them since then. But I don't regret disclosing at all even though I lost my career and my job.

After that I would disclose my status when I was approached to do so, which was about almost every session I did as an AIDS educator. It was the beginning of the end of my personal testimony because I was getting very tired of people inviting me to a conference to share my story but they weren't interested in what I thought about anything else regarding the epidemic. It was like I was only good enough as a person with HIV. It was just emotional wishy-washy.

A turning point was at the International Conference for People Living with HIV/AIDS in London. I was sitting in a room with 500 HIV positive people from all over the world and we all had something in common. The power that experience gave me has been so huge and important in terms of my being involved in HIV/AIDS issues. I came back to South Africa with the determination to bring about change that people with HIV should be treated the same because we have the same dreams and desires.

People who have come out have a huge responsibility to change the environment to allow others to come out and do the same.

*Interviewed in Durban, September 1999. Age 34.*





## Lungisani Biyela

*Diagnosed in April, 1998. Disclosed soon after.*

I started talking about my HIV at schools in KwaMashu. Then I went out to talk at a church and a Christian Centre in KwaMashu. Then I went to other schools in Umlazi.

I was asked many questions. People wanted to know how did I feel when I heard that I had this disease. I told them that it's like I've admitted that I've got this disease. I was in church and people read some verses in the Bible to console me. When they were reading the Bible verses for me, it was painful for everybody. They cried and felt sorry for me.

They asked me about my relationship with my girlfriend. Did I tell her about this and what did she say? I told them I didn't tell her I'm positive because we were separated and I never saw any need go back and tell her to take a test. I was afraid she would say I'm the one who infected her with this disease.

I told my family that I'm infected. At first they made a noise at me, but everything passed. I even told my friends and other people around know and they tell everybody else that I'm positive. I never worry about that because I've already admitted it.

Men listened to me even though some of them didn't like what I was saying. They were always telling me they didn't want to use condoms because they said a person must do 'flesh to flesh'. But they do listen to me. I always carry condoms and give them away so that these men can protect themselves.

My mother was hurt when I told her about the HIV and it was very painful for her. She cried and she tried to chase me away. When I was diagnosed, those same people who diagnosed me told me they wanted to talk to her. She never wanted to go to them because she knew herself that she wasn't treating me right and was afraid about what would be said about her. I didn't want the health people to sit her down and talk to her either. Finally I sat down with her and explained to her about my infection and she admitted and apologised for how she acted, and she cried.

An important thing is that when people know that someone has this disease, they shouldn't go around telling everybody that so-and-so is infected because that makes me, as the person who is infected, feel like I'm not free. It makes me feel like someone who is different from other people when the truth is, there is nothing different, we are the same.

Some people say someone who has HIV should be a skinny person. They want to know why I'm not skinny. They forget there is a difference between HIV and AIDS. I don't have AIDS, I am HIV positive.

I wish people should treat us right because we are the same as them. To say I'm HIV positive, it's just my blood, not my mind. My mind is not HIV positive, it's only my body. Only blood. In my mind I know what is wrong and what is right.

*Interviewed in Durban, September 1999. Age 31.*



## Jaco and Antoinette Fouche

*Jaco diagnosed in 1992. Disclosed a week later.  
Antoinette diagnosed in 1995.*

**Jaco...**

At the stage I was diagnosed it was thought that white people don't get HIV. I think I was the only person at Upington where I was in the army – white obviously – who had HIV. They didn't know how to tell me so they sent me to Bloemfontein for observation. I didn't know what was wrong with me, because I didn't feel sick.

I took it very well. When the doctor told me, I sat on a rock and thought about what I was going to do with my life. I actually didn't feel sad at anytime that I had contracted HIV. I've been through a lot of things, you know. I've been out on the street, hanging out, doing all sorts of things. I probably should have known better. If I only knew the real risk of HIV, because everybody at that stage had heard of HIV but nobody took it seriously. Obviously I didn't take it seriously because I thought all the girls I slept with were "clean" or something like that. That's the whole thing with HIV. You can't see who is HIV positive.

The first people I told were my parents. I went home for a week and after that I told everyone I was working with in the army that I was HIV positive. I told them almost instantly. It took a month. I don't know what came over me, I just didn't like the silence. It was a natural thing. I didn't do it for money, I didn't do it to become popular, I just did it. It's almost a reaction that I had. I think that's how some people cope with problems... by telling other people. By telling others I thought the burden would be a little lighter.

I was a qualified chef so I was preparing their food and it was quite rough for them. I didn't actually explain it to them, I just told them, "I've got AIDS," because I didn't know there was a difference between HIV and AIDS at that stage. I said to them, "I've got AIDS and it shouldn't happen to you, you must be careful," and I ran out. This one medic guy there followed me and said, "Don't worry, it's not too bad," and he supported me.

I finished my service. They still kept me on even though I was HIV positive. Everybody asked me what about the salads, what happens if I cut myself, and I said, "Yes, that's happened. I've cut myself plenty of times cutting salads and probably spilled blood." And it freaked people out.

But I had to tell them that you can't catch HIV like that.

After that, nobody actually turned their backs on me. I was a person that everyone looked at and talked to. I think it's the way that you tell people, if it comes out of your mouth first and people don't find out for themselves, then you've got the advantage. You've got control over what people are going to do with you. When we're talking to a group and we tell them we're HIV positive, we're in control.

For a while, I felt a little bit like a cloud was hanging over me. I didn't do a lot of things, I just hung around waiting for something to happen, which I'm still waiting for. I'm not sick, I don't have a disease. I have a virus in my body. I can't feel it. People should understand that when you contract HIV you don't feel ill.

It depends on your outlook on life when you are diagnosed. If things are going wrong with your life when you find out you are HIV positive, then you're going to take it much more seriously. I never actually took my HIV status very seriously. It's not so serious. Why stop your life? Why stop living? Go for it. It should actually motivate you to go for life even more because you've got a limited life span, which all of us actually have.

It's not to say that because I've got HIV that I don't have a future. People do not take you seriously if you only depend on your HIV status. HIV status shouldn't be the only reason you are here. Don't depend on it for things.

**Antoinette...**

After Jaco told me he was HIV positive, I went for testing as well. We don't know if maybe I contracted it from him. I don't think so because I had other relationships before him. I can't actually remember the first time I actually disclosed in public. For me, because Jaco was already doing it, and he knew what it was like telling other people, it came very naturally and easily for me as well.

I think it's important to disclose. We disclose now as a daily thing for every new group we speak to. Sometimes we feel like we don't want to do it anymore, like we want to have a personal life. Our personal life is everybody else's life. For us it's not a problem to disclose. Maybe it's the way that we do it.

**Jaco...**

It is the way that we do it. We do not make it our total point of everything that we do. Our work is not about being HIV positive. We disclose to make people relate to us because everybody's got a problem in their lives, something that they're struggling with. Like me, I'm not only HIV positive. I have to worry about work and about all the things that everybody else worries about. You can actually cope with anything that comes your way, we are made like that. Its just sometimes its harder to do with HIV.

**Antoinette...**

Both of us think that disclosure shouldn't be done in a radical way. Like walking down the street wearing an HIV positive T-shirt because that stigmatises you from the beginning. You're labelling yourself and creating a separate group. I wouldn't walk around wearing a shirt saying I've got cancer or I've got diabetes or something. We're treating it separately from other diseases and that's causing stigma.

**Jaco...**

I can understand what they're trying to achieve, but that's not the way to do it, especially because people are so scared of it. You need to do it one-on-one in small groups to win the person's trust over before you tell them. It's a need-to-know thing.

**Anoinette...**

And people have to be educated as well before you tell them.

**Jaco...**

We use our disclosures to get other messages through. We want people to make their own decisions and choices. It doesn't help me to tell people they shouldn't smoke or they shouldn't have sex. It is up to you to make your own choice. You decide your own future.

**Antionette...**

Both of us are very happy. People always want to hear the bad, like so how you are suffering, how are you coping? I'm actually managing the disease. It's not a struggle, not a limitation. At the beginning, it might be a coping mechanism, but then you get used to it. People always say it's so difficult and hard, but I know we as humans can adapt to different things, a different lifestyle, so why not adapt to a disease? Why let a disease keep you back? That's our focus.

**Jaco...**

We spend a lot of time at home together, thinking about life and our dreams and our future. We find a lot of motivation in each other. We are both positive about life and the future. I don't see myself doing the same thing forever, I want to do things and explore, go overseas.

**Antionette...**

Nobody sees us as who we really are. They see us as our HIV status and that's it. It seems like people don't really know what to do. They just think we're just HIV positive people and we're just drifting in life. But were constantly finding new things to challenge us.

*Interviewed in Cape Town, November 1999.*

*Jaco age 26, Antoinette age 24.*