

CONVERSATIONS: HIV/AIDS and the Family

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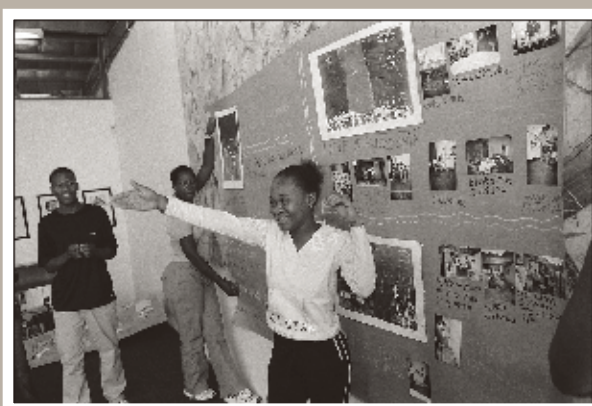
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Introduction

Most South Africans have experienced HIV and AIDS in one way or another – through knowing people living with the disease, through knowing people who have died, or through living with the disease oneself.

Throughout these experiences there is seldom time to reflect on what HIV/AIDS means to our lives, or to come to terms with experiences of how the disease is lived from day to day. Living with HIV/AIDS is glossed over in statistics, in reports and in statements. Seldom do we hear, see, or understand AIDS in the words of those whom it touches most intimately.

This book tells the stories of families living with HIV in words and photographs. What we learn is that in each devastating, painful and heartbreaking aspect of AIDS, there is also an equally heartfelt, caring, compassionate, courageous and life-giving aspect.

In finding and telling these stories we have encountered sadness, and have wept alongside those who have told them. Pain and hope merge in the telling, and from the simple starting point – “tell us how HIV has come into your family” – it has been possible to peel away the layers of what this disease means.

Sadness, fear, comfort, loneliness, intimacy, openness, and secrecy are all part of these stories, but what joins these together is the thread of family and togetherness.

Part of the project included a five-session creative cultural performatory workshop, using a social therapy methodology. The photographs in this introductory section show families sharing their experiences. Through the workshops a sense of caring, bonding, empathy, and acknowledgement of a shared pain prevailed and confidence and friendship grew out of sharing.

Valencia Mofokeng is doing well and continues to build her organisation in Orange Farm. Amos is still active building homes in the community. Valencia's son, Junior, (10 years old and living with HIV) and living with HIV, is on antiretroviral treatment and also doing well. Since giving birth to Junior in 1997, Valencia has had two children, Katlego (age seven) and Mbali (age two). Both children are HIV negative. Sylvia has recently received a bursary to study nursing. Lungile is no longer a volunteer - she has a fulltime job and is no longer living with Valencia and the family.

Jounoos Wippenaar is on antiretroviral treatment and doing well. He is a community worker at Absolute Return for Kids (ARK). He is also a treatment supporter and

teaches antiretroviral treatment literacy.

Christo Greyling is well and still travelling around the world. Liesel has two children, Anneke (four years old) and Mia (two years old).

Regina's father, Ernst (85 years), passed away in February 2007. Thando, Siphos' son, is seven years old and attending school. Regina's granddaughter, Nompumelo, is studying law at Varsity College.

Lungi Mazibuko passed away on the 3rd of May 2007 in Durban. Her two daughters, Zanele and Mandisa, are now living with their grandmother in Durban.

The Mtsi family is well and there are currently eight children living at the Little Angels Life Care Centre in Orange Farm.

Selinah Mashinini is working for the Right to Care organisation in Alexandra. Initially she was a counsellor and now she is training to be a pharmacist's assistant.

Naboe Adams has separated from her common law husband, Jacobus. Naboe's youngest son, Norier, who was born soon after we interviewed her in 2005, is healthy and HIV negative. Naboe is coping well and making some money buying and selling things.

PJ Sabbagha has been living with HIV since 2005. Keith Markland is still on antiretroviral treatment and is doing well. Natalie, Keith's daughter, is now 21 years old and engaged to be married.

Seun Motsoeneng has a part-time job and Portia is at school in Grade 12. Winnie is being sponsored by a family in Cape Town who pay for her education, food and clothing. Jan and Peter are still unemployed and stay at home.

After more than 20 years of living with HIV, Peter Busse passed away in January 2006 after a tiring trip overseas. He died at peace – with himself, his friends and family and with the world.

Momo Mabena gave birth to Reabetshwe in July 2006. Momo and Reabetshwe took Nevirapine and the baby who is now almost a year old is HIV negative. Momo's first child, Thabo, is also doing well.

In April 2005, photographer Gisele Wulfsohn was diagnosed with advanced lung cancer. She says that her strength and positive attitude around her illness is inspired by all the people she has met through her HIV/AIDS work over the years and through this project.

And life goes on...

(Johannesburg, June 2007)



Back from left to right: Valencia Mofokeng (39), Junior Mofokeng (Valencia's son, 7), Amos Ngwenyama (Valencia's husband, 53), Lungile Ngwenyama (Amos' daughter, 26). Seated from left to right: Lerato Selelekela (Valencia's nephew, 5), Sylvia Selelekela (Valencia's daughter, 19), Evelyn Tekela (Valencia's mother, 63), Bridget Mofokeng (Valencia's daughter, 8).

The Mofokeng and Ngwenyama family

Valencia Mofokeng (39) and her family run an AIDS organisation in Orange Farm called Sakhi Sizwe. Valencia was born in Lesotho where her father is a village chief. Her first husband, Ishmael, died in 1996 and his family forced her and their three children out of the house. Ishmael never disclosed his HIV-positive status to his wife, and now both Valencia and her son Junior (7) are living with HIV. Sylvia (20), Bridget (8) and Junior (7) are all children from her first marriage.

Valencia's current husband Amos, has brought five children from two previous marriages with him. The oldest, Sunnyboy (30), helps with the HIV project. Amos and Valencia have two children, Katleo (5) and Palesa (who was born after this interview).

Lungile is a young woman living with HIV who was taken in by Amos and Valencia. Her story is similar to Valencia's. After her husband's funeral she was evicted from her home, together with her son and baby twins. One of the twins died of AIDS soon afterwards. The other was taken away and put into foster care. Her oldest child is still with her in-laws who do not want to give him back.

Valencia's oldest daughter, Sylvia, has already lost her father and her favourite aunt to HIV. Her mother, her brother Junior, and her adopted sister Lungile, all have the disease. She is the primary caregiver to all the children in the house and has had to make many sacrifices.

Evelyn, Valencia's mother, lives with her husband in Lesotho but occasionally she comes to help the family.

Valencia and her family are well known in their community as a household that loves and cares for people dealing with AIDS as well as for those with other difficulties. While their house is bare of furniture and worldly possessions, it is filled with warmth and life.

Sylvia Selelekela (20) – Valencia's oldest daughter

I was 15 when I found out that my mother had HIV. I was upset and angry with her and I didn't understand. My first thought was: "How can I live with someone who is HIV?" I fought with her and decided to move out and live with my relatives. I was thinking that it is better if she dies and I can't see her suffering.

But when I was away I was also always worrying about the little ones and how they were doing without me. So I went back to live with her. It wasn't easy, but I tried. I thought maybe I would get infected. I was angry because I

thought maybe she would die tomorrow and how do you live without a mother? Now I am not afraid or ashamed to talk about my mother's status. I give her all my support. My mom talked to me about it and I joined the project and they have helped me to understand.

One thing that still makes me angry is that I can't study because of lack of funds. But I do enjoy having a big family - I have so many sisters and brothers from different cultures. We are a big, happy family.

At school they were trying to teach us about AIDS but I couldn't understand. I would get upset and not listen because I thought they were talking about my mother. I was scared that the other children would find out. The one person I could tell everything was my

aunt, but she also died of AIDS. I feel painful about losing my aunt and about my mom.

My mother has told me that when she is gone I must be myself and take care of my little brothers and sisters and teach them to stay safe because it is a serious disease. She doesn't want to see any of us infected with HIV.

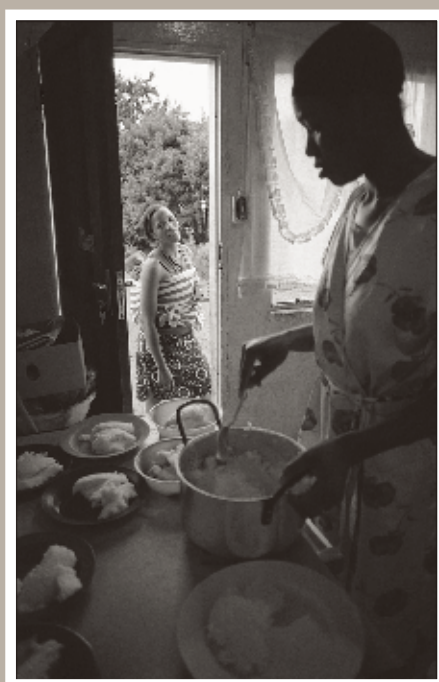
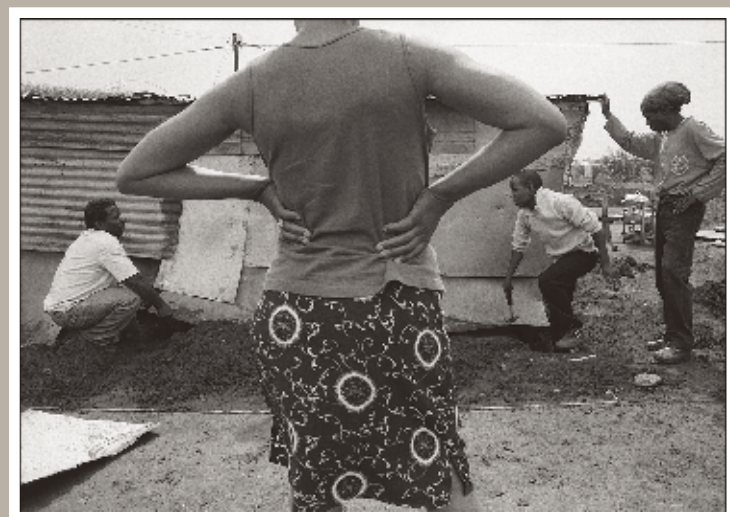
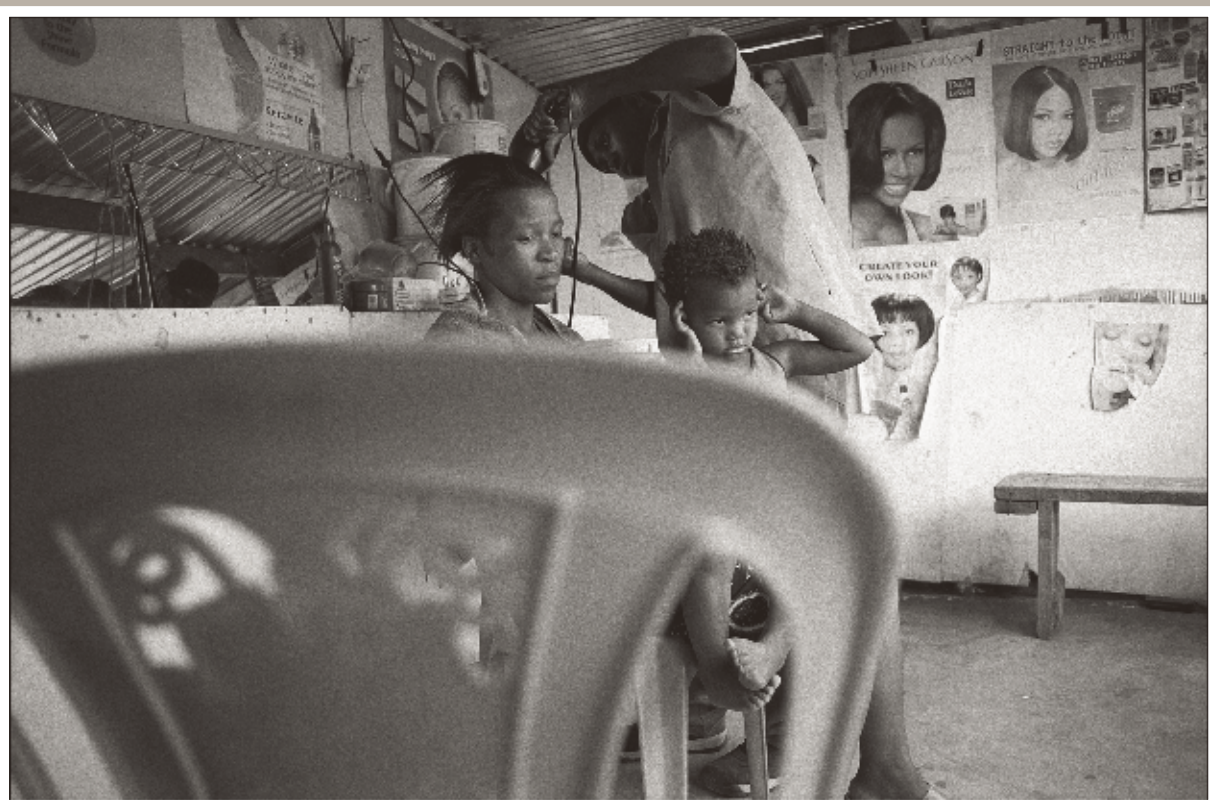
Being strong means getting rid of negative thoughts. It means being confident that I will have my mother tomorrow and to make sure that we talk to each other. I am so proud of my mother. She is a strong lady and a good survivor. I need her guidance and advice. I need to know that there are people who care about me.

Evelyn Tekela (63) – Valencia's mother

If you are not strong you weaken others. When I heard that Valencia was sick I took a deep breath and went to the pastor. He said that Valencia's body is weak but her spirit is strong, it will make the body strong. He said that Valencia was a bridge between God and communities and that God loves her.

Since Valencia has been talking to me about AIDS, I have been reading books and she took me to some people who are counsellors. I have been asking many questions and encourage her not to give up. I learnt that this thing is not about death, but about life.

If somebody's daughter is ill I always make friends with her. I will tell them about my daughter who has AIDS and they can feel free to talk about it and come over to learn more about this. Valencia is my example. I tell people: "There she is, she is still going strong. She is the most active person in this place." They don't believe she has HIV.



Lungile Ngomane (26)

I found out that I was HIV-positive when I was pregnant with my twins. When my husband Dennis died, my in-laws threw me out of the house. They took everything - all the clothes and all the furniture. After his funeral I came back to an empty house. They said I had killed their son.

He had worked for one company for 16 years, but when he died I did not have an ID book. I grew up with my granny and she didn't know I needed an ID book. So I did not get all the money from his company, just enough for the burial. The problem is that we were not legally married, although Dennis had paid all the lobola. Dennis' family said the money must go to them. There is a fight and they are keeping my son Sizwe so that they can get the money. Because of this fight, Dennis' company is waiting for the children to grow up to pay out.

When Dennis died I did not have anywhere to go. I just wanted to die myself. A woman from my hometown recognised me and let me stay with her. That is when I first met Valencia. She found me crying and alone. When she came back with some food and clothes and paraffin we started to talk. I told her my story and she told me that she too was HIV-positive. The woman I was staying with saw that there was someone else who would care for me, so she said I must move out. Maybe she was jealous.

Social Services took the twins away. Siande was sick with AIDS when he was born and I didn't have money for food. I could not fight them because I am not good at English and I do not have a telephone. They put the children in foster care. Siande died in 2002. Now I am fighting to get my children back.

After I lost everything I felt desperate and I asked Amos to take me into his family. Now I have a mother and a father and sisters and brothers. I have what I was dreaming of - a family.

People need to be loved by someone - to have someone who is there to listen. Not to be made to feel that you are different or dangerous. Not separating plates and cups and cutlery. I want to give love and support to those who need it, especially children. They need to see a beautiful life and world.

Amos Ngwenyama (53) - Valencia's husband

My parents both died when I was in Standard 8 and I had to leave school to go and look after the cattle at my uncle's house. If a cow is lost I had to go the whole night looking for it and I had no food. It was very difficult. I never thought I would have a house or a room to sleep in one day.

I moved to Johannesburg from Mpumalanga in 1992 and joined the master builders' corporation. There was a lot of work in those days and I had a wife who supported me.

My first wife died in 1992. Then I married her sister. I met Valencia towards the end of 2000. She had an office at Chris Hani Baragwanath Hospital where people came for counselling. I went there twice or three times a day because I wanted to talk to her. I was listening to her counselling people, telling them: "If you are HIV-positive

that does not mean you are dead, you still have time."

I knew this was the woman for me. I told her: "I want you." She kept saying: "I'm HIV-positive." I said: "You're telling lies." In the end I saw her picture in a book about HIV and I started to believe her. I promised to marry her, HIV or not.

Lungile is 'my child' and what I need from my child is to see her life going on. There was nothing confusing for me about adopting someone with HIV. I want to look after them all and give them love so that they can feel they are still alive.

My biggest problem is that I want to get work. I am a hard worker and I want to work for my kids. Valencia is not working and Sylvia is not at school. People are saying: "No, we can't give this guy the job because he is staying with a wife who is HIV-positive." So I try not to work in Orange Farm because I can't get jobs here. But now my car is broken and I can't get to Johannesburg.

Valencia and I sit down and talk a lot. I tell her that if I die I don't want anyone to come and say anything to her. This is her house and everything is for her. But we don't really know who is going to die first. I just know I was so lucky when I met her.

Valencia Mofokeng (39)

Welcome to the family of HIV! We have learned to joke about it, eat with it, sleep with it - it is a part of our activities, part of our lives. It lives with us. Death is everywhere. In 2000 I was encouraged to start an HIV support group here in Orange Farm and we now have three groups. In those days there were no support groups in Orange Farm and you could see that people were emotionally hungry. They needed to share their experiences so that they could prolong their lives. As well as food, shelter and clothing, children especially need to be responded to on an emotional level.

A big challenge is that when someone dies there are no funds to pay for a funeral. Sometimes four to five people are buried in one plot. This is not good for children because how can you visit the grave if there are so many in one grave? Also, it can take three months to bury someone and the undertakers here in Orange Farm are very expensive.

My sister died, but I only found out much later that it was from AIDS. I was so disappointed. I thought, how can I reach out to other people and I can't even reach my own sister?

Sometimes when I have flu or something I do get very worried about what will happen to my children. I trust that nothing will go wrong, but sometimes it is difficult to deal with death all around. Sometimes I cry a lot, and I speak to the Lord. I go to the park and shout and scream. I do not want the children to see this. But it is okay for Amos, I trust him.

I have my father's heart - I am used to sharing everything. But sometimes I look at them all and I say to Amos: "Aren't you worried that we aren't buying furniture because we keep on feeding people?" He says: "God will provide. We don't need to rush." ○



From left to right: Kashiefa Wippenaar (Jounoos' cousin, 25), Jounoos Wippenaar (48), Mohammed Zaid Wippenaar (Kashiefa's son, 2), Janap Pienaar (Jounoos' sister, 55), Abdul Kader Pienaar (Jounoos' nephew, 35), Abdul Wakeel Pienaar (Abdul Kader's son, 4), Siraj Harrison (Soraya's son, 7), Rudwan Pienaar (Jounoos' nephew, 34), Soraya Harrison (Jounoos' niece, 36), Mohammed Fuaad Pienaar (Jounoos' nephew, 32), Sulailah Wippenaar (Jounoos' sister, 44).

The Wippenaar family

Jounoos Wippenaar (48) lives with his sister, Janap, and her husband in a four-roomed house in the sandy Cape Flats suburb of Steenberg. The neighbourhood exudes a strong sense of community and neighbourliness and their home is a haven to a large extended family, including Janap's daughter, her husband and their children. At the back of the house there are cages full of birds and in the front the cats bask peacefully in the sun.

Janap is the strong but quiet centre of this family. She seems to provide a safe and accepting space for the many ups and downs that life brings. Her arms are always willing to hug and to hold.

Jounoos and his sister are very close. He also has strong relationships with his nieces and nephews and enjoys joining in the children's games.

The family is familiar with illness. Jounoos' mother and aunt both died from lung disease. Two of Janap's children have disabilities, as does her husband and a grandchild. These traumas and experiences seem to have helped the family to deal fearlessly with HIV.

Janap Pienaar (55) – *Jounoos' sister and mother to Soraya and Abdul Kader*

When Joonie Boy told me that he is HIV-positive I told him that I didn't think my husband and I will have a problem. The illness is here and we must just live normally. The biggest challenge is that when he dies I will miss him a lot. We have lived together for many years and I cannot imagine life without him.

Jounoos is everything to me. We understand each other. I will be really lost without him. But he showed me that if he can cope with AIDS, so can I. He makes me very strong. That is why every morning I ask him how he is feeling, how did he sleep last night, check if there is anything that he needs. When he is stressed he comes to me and we sit and talk about it and after that it is fine. I say to him "Don't stress. Take a bakkie and go for a ride to the beach."

Soraya Harrison (36) – *Janap's daughter, Jounoos' niece*
It was a big shock when Jounoos told us he had HIV. This AIDS thing has been happening all over for a long time, but I never thought it would come to our family.

All my children know about their uncle's disease. We often talk with them and they ask questions. I think respect and religion starts within the house. If you do not

talk to your children about these things they will not know. It is your responsibility. Some parents work and have no time for their children; when the child comes out of school there is no mother or father in the house.

We are very emotional people. Jounoos tells us stories about what happens in other families and all of a sudden we all cry.

In our religion there are so many rules and regulations that you have to follow. Even when your husband dies you must mourn three to four months. You must cover

your face and your body. AIDS is also something that must be closed up.

I taught my children openness. They always come to me. A lot of children cannot go to their parents because there is a lack of communication. You sit at the table and you ask: "What happened today?" And the child will say, "Nothing happened

today." They won't tell the truth.

I think I will be able to deal with him being bedridden and all that stuff, but I don't think my mom will cope. It will be heartbreaking for me and my children. He supported us all these years and now I must give him support.

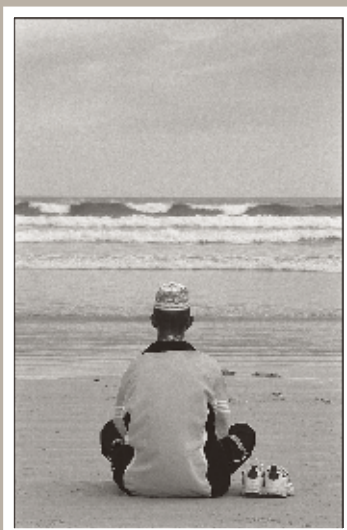
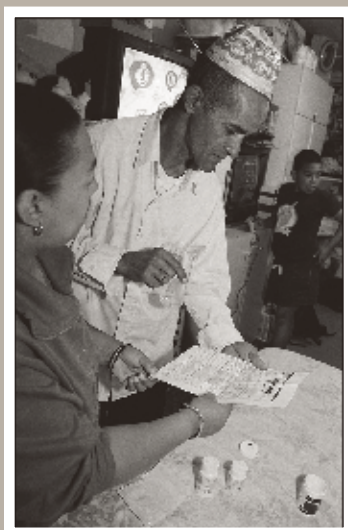
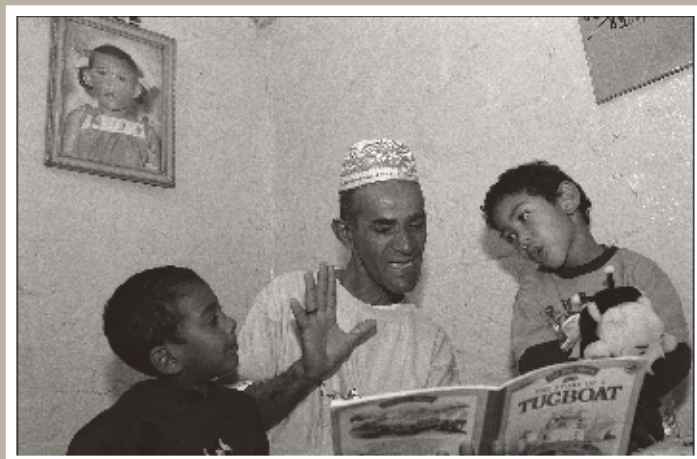
Abdul Kader Pienaar (35) – *Janap's son, Jounoos' nephew*

To be honest it took a bit of time for me to deal with Jounoos' status. But now we know more about the whole thing and how to deal with it and he is also more relaxed and open.

The illness did not change anything. He is still the same person. Obviously we must take precautions with certain things around my uncle. There was a time when he had cuts. We also have to be prepared for what to do when he gets sick so that we will be able to deal with everything that God sends our way. We have to stand together when he needs some things so that we can try and get them.

You always hear people say that our daughters and sons do not come to mosque anymore. The young generation is smoking, drinking and having sex because the fathers and the mothers do not know what the children are doing, because we do not speak to our children, especially about sex. I think the best thing for us as parents is to bond with our children.

My wife and my son do more things for my uncle than before. My son is not scared of him. It is just the challenge that we have to live with. They say the choices that you make and the decisions that you take define the kind of



person you are. I think we as a family are proud of my uncle, because to deal with something like this shows the kind of person he is.

The point that I want to make is that no matter what he contracted, how he got it, if he was naughty - he is still our uncle.

Jounoos Wippenaar (48).

I have stayed with my sister for almost 30 years – from when my mother passed away. When I came here I used to drink, do drugs and things like that. Janap would just say: “Leave the drugs. They are not good.” My family does not like it. They felt vulnerable when I came home all smoked up and drunk.

In 1991 I went for an HIV test at Victoria Hospital. I heard people talking about HIV/AIDS and what it does to people so I never went back for the results. Then in 2000 I contracted TB. The doctor said I would have to be on medication for 13 months. Every morning I went to the clinic for my medication. I told myself: “If I want to get healthy I must stop what I am doing.” So I stopped the smoking and drinking and the drugs, although sometimes I do still need a cigarette to keep me going. It keeps me occupied. I used to take heroine, marijuana and mandrax. After eight months my lungs were healed.

One morning I went to a clinic in 11th Avenue and I saw ‘Free HIV Test’ written in the window. So I went for another HIV test. The counsellor told me: “Jounoos, you are HIV-positive.” It was such a shock. She explained that I won’t die now and called the doctor. I asked them to close their eyes and to pray to God to give strength and courage to my family – because I have a lovely family.

When I came home I told my family that I was HIV positive. They were all sitting here and my sister said to me: “Jounoos, you finished your TB treatment in eight months. We don’t know anything about HIV/AIDS. You have to give us the information so that we can know how to deal with this.”

My doctor gave me the contact details for the Muslim Support Group – Positive Muslims – and I joined. That is where I got all my information. Every second Sunday I go to the group. We get together and talk about the past two weeks, what happened to us – about any problems, how the family was. In the beginning I felt very bad to hear the other people’s stories and how their families treat them. It breaks my heart because my family accepts me and treats me like a normal, healthy person.

The support group encouraged me to be open. I disclosed my status very quickly and my first workshop was at the office of Muslim Youth. I talked about how I contracted HIV/AIDS and it was heartbreaking for them and they asked me: “Jounoos, is there anything that we

can do to help other people?” I told them that peer education is the most important thing.

In 2001 I contacted the Education Department to get involved in schools. I see a lot of young people and wherever I walk people ask me: “How are you? How do you feel?” They take it very seriously. They ask me questions and I tell them to keep on with their life. Drugs and things don’t work with HIV/AIDS, they can make your CD4 count drop and weaken your immune system and that kills you very quickly.

There are many people in the Muslim community who have contracted HIV and they are not open. They will speak to me and I have workshops at the mosque and speak with the family and give them booklets. I tell them that if you have a member of the family who is sitting with the stigma, come to me before it is too late. Deal with the issue now.

For the last couple of years I have been doing meditation and I went to therapy sessions. I have learnt to speak to my inner body and with my God. I talk to my virus and say: “Look I don’t want you to take over.” One day I was sleeping and God gave me the vision so I made a promise that I am going to work with sick people.

Sometimes at night when I am down, I listen to hard music. I also keep my body busy by exercising. The less I think about my sickness the healthier I get. At times I also go to the beach to relax.

My whole family, including Soraya’s children, know exactly how to deal with a sick person, how to take them to the doctors or to the clinic for medication. They also know how to deal with different types of stigma.

My mother had asthma in a very bad way. She had to get a pipe and powder to open her lungs. She passed away after an asthmatic attack. She was 48 then. My family has learnt a lot from that about how to deal with illness and how to speak with people. I learnt to be honest with people and to respect them.

But when the time comes and I have full-blown AIDS there is nothing that the doctor or any member of my family can do. I deal with people with full-blown AIDS all the time who cannot eat, who cannot talk, who cannot bath themselves.

I will be bedridden and I know it will take a couple of weeks or months before I die. At that time I would like a care worker from the outside because I know it will be heartbreaking for my family to see me just lying in that bed.

We are open and happy as a family and are getting closer all the time. So, one day I can say: “Thank you God. I had a family that had courage and gave me support,” and I can pass away peacefully. ○



From left to right: Christo (40), Anneke (2), Liesel (40).

The Greyling family

Christo and Liesel Greyling live in Ruimsig, in a gated community where children ride their bikes on the street. The Walter Sisulu Botanical Gardens, where they go walking, forms part of their backyard.

Christo is the first Dutch Reformed minister to be open about his HIV status. Once he revealed his status in the early 1990s, Christo left his affluent Waterkloof congregation to work full-time in the field of HIV – first with Old Mutual and now with World Vision.

Our interview focussed on their decision to have children and around the risks that are involved. Being finally able to “plant a child” has been a dream come true. They are raising their two-year old daughter Aniki and are expecting their second child.

Christo (40)

I found out that I was HIV-positive on September 12, 1987. It was six months before I got married to Liesel. I was probably infected in 1984 through blood that came from the United States. Liesel and I decided not to tell anyone before the wedding. We were students, away from home and did not want to tell anyone over the phone.

It wasn't until I had to go into the hospital for an operation that my parents found out. I was not going to tell them, but the doctor treating me was a friend of my father and he felt my father should know. So he told him and my father told my mother. They ended up knowing before the wedding.

My father felt that Liesel's family also had the right to know that I was HIV-positive, but we decided not to tell them at that point. We finally told them nine months later. We were all together for two weeks so we had a chance to educate them about the disease. Remember, this was still back in the late 1980's.

They reacted very positively and were very supportive. We asked them not to say anything to anyone else. I think that was a mistake, it was unfair to them. It was only five years later, in 1992 when I went public, that other family members learned of my HIV status.

I decided to go public because I wanted to challenge the assumptions about HIV-positive people. I wanted to challenge the stigma and to give a message of hope. I wanted to share the positive experiences. Initially Liesel's father was opposed to the idea as he was afraid that he would lose his job.

Telling my congregation was the hardest. I did not know

what to expect. There was so much stigma connected to HIV that I was asked to prove that I was infected from a blood transfusion and not from something else. I also had to prepare a press statement for the church. I realised that my congregation was able to accept me, but not 'those others.' So I decided that I wanted to be the voice for the voiceless.

Two months later I left the church to focus on developing an AIDS ministry. That chance came when Old Mutual asked Liesel and I to develop an HIV educational project. They funded it for nine years. It was the 'I Have Hope' project.

From the beginning Liesel was very much a part of the project. While I could do a lot as an HIV-positive person, it was also very important to have someone who knew about the impact of HIV on families. To me and to others, Liesel is a symbol of what

love and commitment is.

Liesel was willing to take risks when we married and again when she got pregnant. I had been HIV-positive for almost 20 years when I first heard about 'discordant' couples – couples where one partner is HIV-positive and the other negative – being able to have children.

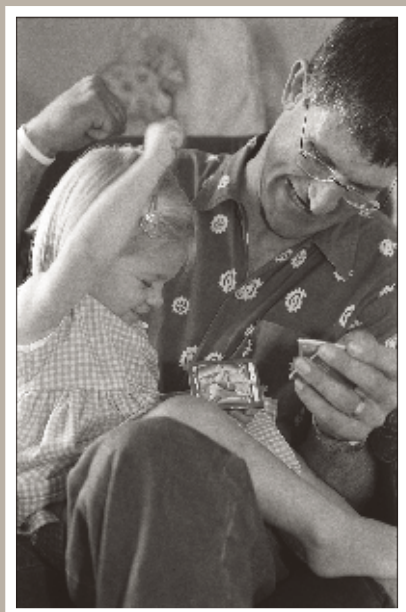
Liesel and I were on a choir tour for our church in 1999 when we met another 'discordant' couple in Boston who had had a baby three months before. They encouraged us and said that it was because of antiretrovirals (ARVs) that they had been able to safely conceive.

We then talked with a number of doctors and found out that if my viral load is less than 400 then the chance of transmission would be 1 in 250 000. But first we went through a lot. We had been married for 14 years and we had to come to terms with the fact that there was a strong likelihood that Liesel would end up a single parent. We decided to talk to only one or two friends about our decision, and we saw that our concerns were no different to theirs.

Still, making this kind of decision was not without risks. So I asked my doctor: "What would you do? What is your gut feeling about this?" And he said: "Go for it."

So we did. I went on ARVs in April 2001. When I started, my viral load was 100 000 and my CD4 count was 300, but within two weeks my viral load was undetectable and my CD4 count had gone up to 800. We still had to wait a bit as the viral load goes down last in semen. We paid attention to the ovulation cycles and made sure that there was plenty of lubrication to minimise any chance of

***“If God leads you
onto a rocky road, he
will give you sturdy
shoes.”***



transmission. Liesel fell pregnant in the first month that we tried.

I have grown spiritually. I have always believed that spirituality is not pie in the sky, but it has now become even more real. I think that God has used HIV to break down barriers between people, to challenge stigma and to challenge churches on what they actually stand for. I always think of this saying: "If God leads you onto a rocky road, he will be sure to give you sturdy shoes."

Liesel Greyling (40) – *Christo's wife*

We found out that Christo was HIV-positive after we had been dating for only about six months. Then the doctors told him that he might have three or six months to live. I was prepared for the worst. Now every anniversary is a bonus. It has made us appreciate life more. We know that we are privileged to be married for 16 years. Our dreams have come true, we have our one child Aniki, and I am pregnant with our second.

I know that I have to face the possibility that I might be a single parent sooner than many of my friends. I have not thought of the details yet, but I know that I will be able to handle it. I have learned a lot in the past 20 years.

I try not to think about the future every day, otherwise I miss the present. I try to handle what comes on my path each day and break things up into smaller pieces. This has made it easier to handle the really hard things. I used to wonder at the slightest sign if this was the 'beginning of the end' for Christo.

But then HIV becomes a part of your life, it becomes normal. Being pregnant with our second child has reminded people again that Christo is HIV-positive, because many friends tend to forget because it has become so normal for us.

The fact that Christo is living with HIV has never been an issue for me. We are very clear about using condoms, so I am not afraid of being infected. Once we did our research and decided to risk a pregnancy the threat of Downs syndrome was scarier to me than the risk of getting HIV. I was so relaxed about the HIV risk that I almost forgot to tell the doctor. When I did tell him he was more anxious that me.

Because of the laws concerning people who are HIV-positive all of the insurance and house policies and mortgages have to be in my name. Christo cannot get life cover, but he does have a pension. ○



Back from left to right: Thando Shange (son of Regina's late son, 4), Noxolo Shange (Regina's granddaughter, 14), Linhle Shange (Regina's granddaughter, 2), Sibusiso Shange (Regina's grandson, 15). Front from left to right: Regina Moloi (Audrey's sister, 58), Audrey Moloi (Regina's sister, 51).

The Shange and Raphasha families

Regina Shange and Audrey Raphasha are sisters who have both lost a son to AIDS. Regina's son, Sipho, died of AIDS in 2001. At that time she decided not to disclose. She used to work as a domestic worker for an AIDS activist but has since retired.

Her garden in Lenasia South has beautifully tended roses, and some of her grandchildren live with her, including Sipho's son, Thando. Regina easily cries as she talks about the loss of her son. She loves her other children and grandchildren dearly, but the loss of her son still hangs heavy on her heart.

Audrey's son, Tebogo, died of AIDS in 2004. The family was very open about it and Audrey, an ex-teacher, used the opportunity to teach people about the disease. Audrey lives in Pimville, Soweto.

Since the death of their sons the sisters have grown much closer and like to visit each other. Their mother Elsie, who is in her late 70's, has been a strong and constant source of support for them.

Elsie Moloi (77) – Audrey and Regina's mother, Sipho and Tebogo's grandmother

An important thing that I have learnt is that once you share with other people you feel better. When somebody says 'funny things' you can help them and tell them that this disease is not so dangerous. It is dangerous but not so that people can hate others when they have this. You can make friends with them. You can help them.

In our church we always visit some people who have this disease and help them. Even some children in our church are already dead.

People must try to do what the AIDS counsellors say. We must tell our children and our grandchildren that they must look after themselves. As a mother you must show concern and love.

Regina Shange (58) – Sipho's mother

The very same day when Sipho phoned me to say he has HIV, I phoned my mother and she came to my work. We did not know exactly what this virus was all about, it was all new to us. What puzzled me was that he was not so thin. That was because he had cancer that caused swelling on his body.

But since Sipho died we have learned a lot about this sickness. I also started to develop a strong friendship with

my sister. When we were young we were not so close, but now I know I have got a sister. She was the one who didn't hide it when her son was sick. She did not do like I did. She just said: "Sister, now we've got the second person in the family sick." That is when I saw that we were getting closer. She didn't hesitate to say: "Come and see Tebogo, sister. Talk to him, he is doing bad things."

When Sipho passed away I was scared so I took his child's mother to the hospital. She was staying with me. We did the test and the results showed that she is HIV-

positive. But she didn't want to listen – she said that it was my son who was HIV-positive, not her.

She phoned her mother who said she must come back. She took baby Thando with her. But after a while they did bring him back to me. I took him to the hospital and had blood

tests done and he is fine.

You know, I cry a lot. I am so stupid – when I am happy I cry. When I hold a baby I cry. When I see something sad on the TV, I cry. Yesterday they showed a teacher who was fired because she was HIV-positive on the TV, and I was crying. I was wondering how she felt when they told her that she can't touch their children; that she can't teach at the school.

Noxolo (14) – Regina's granddaughter

I didn't exactly understand what was going on when my uncle Sipho died. It was a mystery. But now we have learnt about AIDS at school and our granny has talked to us about it. Outside school it is still not something that most of the kids want to talk about. Most people are tired of hearing about AIDS, they just think they have heard everything already.

Nompumelelo (16) – Regina's granddaughter

My uncle Sipho died when I was 12 years old and I wasn't too sure what HIV was all about. Seeing him made me realise what HIV looks like. It affects the person as a whole. It was a shock because we had just moved and then we got a call the following morning that he had passed away. He was in hospital. My family started to realise that it does not only affect the outside world, it can happen to anyone, anywhere.

Audrey (51) – Tebogo's mother, Regina's sister

Tebogo didn't accept that he was HIV-positive. That was very painful. He was somebody who was very quiet. We

***"When I am happy,
I cry and when I hold
a baby, I cry."***



had said when he was sick: "Maybe you should go to the clinic and take blood." He would say: "I'll go tomorrow. Tomorrow is another day."

When he came back from hospital we would ask him about the results, but he always told us they were not there. Maybe he knew but he didn't want to tell us. We don't know, because he is not there so that we can ask him.

People with HIV can live quite some years but with Tebogo we discovered this in August 2003 and in August 2004, he passed away. He got good treatment and I made sure that he ate well and was cared for. I think what killed Tebogo is we discovered too late what was wrong with him. He also wanted us to keep it a secret. He did not come to terms with it. He never wanted to go to any support group.

Sometimes Tebogo would get violent. He broke the doors and was angry. He was always drinking. I tried to talk to him, but he didn't listen. I would cry and scream. My other son was arrested and not at home to help me.

Tebogo was easy come, easy go with money. When he was drunk his friends would come to suck his money and there would be girlfriends too. I am sure he didn't use a condom. I'm saying this because he was getting drunk – so when you are drunk how will you use a condom? He was a target. They all knew that when it is Friday Tebogo would be there. Even if he sat inside the house they would come and knock on the door and look for him. They had no respect.

Tebogo has a son who is 10 years old now. He is living with his mother. They were not married. The child is okay. At first Tebogo did his best but then he started to drink. The drinking caused him and the mother to separate in 1997.

Tebogo's death was so painful, seeing him get weaker and weaker. I was so sure that he would survive. He was taking all the vitamins. He was taking pills for TB for six months. I nursed him at home for one month and then

he could go back to work. His girlfriend also looked after him. But then he carried on drinking and going to parties. I tried not to get angry because I knew he needed my support.

And then he got sick again. He took three weeks sick leave and the people at work started to say things like: "You better go, or die, or leave and get the grant." We did want to call the managers and complain, but we were afraid we would make it worse for Tebogo.

We had an open funeral with red ribbons. My eldest daughter did a speech on HIV and stigma and we gave out photocopies of the booklet on positive living. People were amazed. They said: "You build us." It was a lesson to others about HIV and about drinking and unprotected sex.

What I needed before Tebogo's death was a place where people say: "I've been positive for so many years. I'm still alive." A support group could have helped me to cope and to see role models who can show me that I can also do it.

Even now we need a support group for all of us because my other daughter is having a baby and I can see she thinks because I was taking care of Tebogo, I might have HIV. She is saying I should go for an HIV test. She is a learned somebody but now she has this fear. My daughter is scared of me.

What helped me deal with Tebogo's illness is that I could teach people about AIDS. I started reading about it to find out about it. I think Sipho's death opened my eyes. I talked about AIDS. I was open. I tried to get more information. I think when you try to protect a secret sometimes you create stress. When I am open I can get support. People motivate and encourage me.

What has been most helpful is that Regina and I have been talking about this and giving one another advice. I think the way I am strong in my family has helped my sister. ○



From left to right: Zanele (10), Lungi (35), and Mandisa (8).

The Mazibuko family

Lungi Mazibuko (35) lives with her partner and two daughters, Zanele (10) and Mandisa (8), in a large second floor flat in Woodstock, Cape Town. She moved there from Durban in 2002, leaving her daughters with their grandmother until she had settled in. Her older daughter, Nkulu, 16, still lives with her grandmother in Durban. The atmosphere in the flat is warm and open. The family enjoys playing chess or computer games together or dancing in front of the television.

Lungi works as an HIV and Gender trainer at NACOSA. In learning to live with HIV there have been many times when she believed that she had reached the last stop, that she could not go forward. Yet each time she discovered that she could still grow and develop and that in fact, there are no last stops.

Lungi (35)

I was diagnosed with HIV in August 1996. I was seven and a half months pregnant with Mandisa when I went to the antenatal clinic. I remember there were between 40 and 50 women queuing and then a sister came to talk about sexually transmitted infections and HIV. We were advised to go for a test to check if we had those diseases. So we queued to go through this door. I didn't hear what was happening inside but when I got inside I was given consent forms and had my blood drawn.

There was no pre-test counselling and certainly no post-test counselling. The only thing I was told when I got my results was that I needed to eat a good and balanced diet. That was French to me. I was pregnant and unemployed, with a mother who is unemployed and a sister in college, and I had to worry about where the next plate of food would come from.

When I got back from the clinic that day I immediately disclosed my status to my two sisters. The three of us made a pact that no one else should ever know. Not even my mother.

My sisters really wanted to support me but soon it felt like they were taking over. They did stuff for me and never wanted me to be alone. They would do the washing and cook. I just saw my life ending in front of my eyes. It was like they were saying their goodbyes and wanted to make sure that I should not be alone when I die. They did not give me a chance to be me. It was a crisis that none of us knew how to handle.

At that time on TV there were also Ugandans suffering from HIV/AIDS, who were just skinny, and I saw myself in

them. I thought: "I cannot go through that." I felt that I was at the last stop and that ending my life would save other people embarrassment. I tossed and turned.

But then at some point I realised that being HIV-positive was not the last stop. I wanted to live. Now that I had brought this into the family, the least I could do was to give back the love they have given me.

It was difficult to disclose to my mother. I would think about it all the time. Meeting other people who were HIV-positive helped. But still no one was talking about

how to disclose to your children or how to tell to your parents. Firstly, if you disclose your HIV-positive status it is linked to sex and then you are seen as a whore and the like. This would place my mother in a position

where she would be judged a failure. I did not want to put her through that. My parents got divorced when I was a baby and I thought it would be too much for her to have to deal with this after raising three children on her own. And knowing that she was hoping that I would be working or happily married with my own house, and none of those things were there.

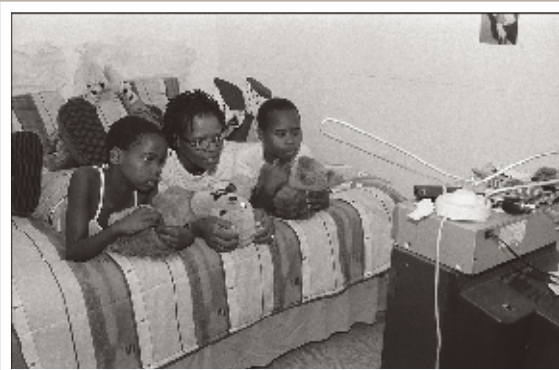
And then in 2000 my sister and I had a fight and my sister let it out that I was HIV-positive. That's how my mother got to know about it. She called about two days later and asked me if it was true. She wanted to know why I had not told her before. I told her that I was afraid to tell her. She said I was her child and I was supposed to tell her when I was going through difficulties. She said she would never throw me out.

I knew this was going to be hard on her and that she would need support, so I took her to some HIV courses in the township. I remember the first home-based care training that she attended. Her face was shining when she came back. She felt so empowered and informed. We began to talk and I told her I thought it would be great for her to meet other parents whose children are HIV-positive.

It was so nice working with my mother, trying to mobilise other women. My mother attended the International AIDS Conference in Durban in 2000 with a group of other mothers. They came together and realised how important it is that parents should meet and talk about issues and about how they are coping with having HIV-positive children.

The support group continued for a little while and then I left. It came to an end because it was difficult co-ordinating and my mother could not keep it running

"There are no last stops..."



mainly because of the lack of resources. But it was a good thing for my mother in the sense that she knew then that she was not alone.

I feel I still need to disclose to my father at some point, even though my parents are not together. I have the same concerns I had about disclosing to my mother – seeing his dreams and hopes shattered.

My children know that I'm HIV-positive and that I might die of AIDS. When Nkulu was only 10 back in 2000, before she knew, she was reading about Mercy Makhalemele. One time she came to me and said, "Ma is she really, really HIV-positive?" I said: "Yes." "But she is so beautiful." I asked how she would feel if that was her mother. She said she would cry every day because I would be dying. "Look at Aunt Mercy and look at how long she has lived with HIV and look how well she looks," I said.

I told my children when we moved to Cape Town in 2002. I thought it was a good opportunity to tell them because Cape Town is not our home and maybe there wouldn't be as much pressure as in Durban.

Coming to the actual disclosure, I want to stress that you don't just throw a bomb at your children. Do it gradually, step by step. Provide loads of information. When I eventually disclosed to them I also wanted them to know who they could go to talk to.

At first the little ones were shocked and thought that it meant that I was dying. But Nkulu told them that mom is not dying. That was reassuring because they heard this from their sister.

My children are dealing with my status surprisingly well. They have suddenly become my parents. They remind me to take my pills. If I'm away on training and I call home in the evenings, they'll ask: "Where are you? Is the room comfortable? Do you have a TV in your room? Who is there with you?" I appreciate it. It's beautiful. But on the other hand it worries me because I see my children growing up so fast. It's not the stuff that I thought about when I was their age.

If I'm stressed and tell them I need to be alone, they respect that. Sometimes they come and offer me some tea. They are very supportive. What I like about it is that they are doing it in their own childlike way. There is no pressure on them to help me.

But I do sometimes get concerned about Nkulu. She does not talk much about her feelings. She doesn't go out

much with her friends at school. All she does at home is watch TV, listen to music and read books. It's so difficult because as an activist, I want her to be an ambassador. I want her to talk to other young girls about HIV and how it has affected her.

It's sad actually, because the school isn't supportive. No one really has time. Teachers only focus on books. During the break the children need to play with other kids so that they can forget a bit about the stuff that is happening at home. I have also noticed that in January when you register your children, kids aged seven or eight are taken to school by a grandmother. And the principal or teachers do not take time to ask where the parents are or what support the class teacher could offer. We need to start with the school governing bodies so that they can understand the impact that HIV/AIDS has on families, especially on children. But they don't think children have issues at that young age.

When the time comes and I get very sick I don't think I want to be around my children. I would rather be far away. I don't want my children caring for me, bathing me and not being able to play freely because all the time they know they are coming to a house with a sick, dying mother. I also don't want them thinking of me all the time and having that ugly memory of their mother's last days.

My youngest sister would probably take up the role of mother. I know that the kids would love to stay with her and she has also expressed that she would like to look after them.

The challenge in a relationship, being an HIV-positive activist with a negative partner, is always being expected to play an understanding, supportive, counselling role. But sometimes I just want to be me – a woman. HIV should come second. All we want is to be a normal family with HIV. To be able to laugh at our situation, to laugh at our HIV and to let HIV teach, build and strengthen us.

But we do give each other space and I appreciate that from my family as well. I think for them, seeing that I have grown, become stronger and know who I am and how I want to be treated, has given them a sense of relief. I do need to remember that I'm not alone on this journey – I have kids, I have a partner, I have parents, I have in-laws. The question is how do I bring these people with me on my journey so that we are all safe from crucifixion, from judgement, from all sorts of discrimination? ○



Back from left to right: Tsidi (Seipati's daughter, 21), Mpho (Seipati's daughter, 13), Itumeleng Makenete (Seipati's granddaughter, 10). Front from left to right: Seipati Mtsi (50), Ivy Makenete (Seipati's mother, 77).