



World Vision



Champions of Hope

a collection of stories

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Preamble

In 2007, an estimated 33 million people were living with HIV globally.* About 22 million people, or 67 percent of the worldwide total live in Sub-Saharan Africa, where the pandemic is most severe. Almost one third of all new HIV infections and AIDS related deaths occur in this region.

Meanwhile, more than 15 million children are orphans due to AIDS.

In 2001, World Vision launched the Hope Initiative to respond to the HIV pandemic focusing on a community led response.

In Africa, these communities have women, men, girls and boys who are making remarkable contributions in response to HIV and AIDS.

This book honours those people.

Foreword

Hope, in the face of HIV, is the key to unlocking people's potential to respond positively to the pandemic. This book is a celebration of stories about ordinary people, whose experience with HIV would otherwise go unnoticed.

Almost three decades since the discovery of HIV, there has never been a better time for hope. Medical advances are providing essential support to those living with HIV and AIDS while countries continue to make significant strides towards universal access to treatment, care and prevention. Best of all, we have now come to accept that the pandemic affects all of us, a realisation that requires us to make individual and collective contributions towards making the world a better place on the backdrop of HIV.

No person or organisation is too small to respond to HIV and no effort can be too little, as demonstrated by the stories in this book. It is humbling to hear of ordinary people, some scratching the surface for mere survival, giving up whatever little resources they have towards the response to HIV.

This book appeals to people from all walks of life as it contains stories that speak to the heart at an individual level. It mirrors the various situations most of us find ourselves in due to the advent of HIV and AIDS and inspires us to act in response to the challenges arising from the pandemic.

Based on stories documented from different parts of Africa by World Vision International staff, the book highlights stories of hope coming from this continent and encourages individuals, organisations, governments and communities to respond positively to HIV.

I am greatly honoured to be part of this book, by an organisation which tackles HIV through church and faith based responses and community mobilisation to protect and care for orphans and vulnerable children and their households. In addition, the organisation focuses on prevention and advocating for local, national and international changes to mitigate the impact of HIV on those made vulnerable by the crisis.

Indeed, HIV has thrust upon all of us the challenge to take responsibility and act to make things better. The time for waiting for the next person to respond is gone – it is everybody's duty to take action.

God Bless You



Archbishop Emeritus Desmond Tutu

Cape Town

*Archbishop Desmond Tutu is a South African cleric who in 2005 received the Gandhi Peace Prize for his efforts on behalf of people affected by HIV and AIDS. Archbishop Tutu rose to worldwide fame during the 1980s as an opponent of apartheid. In 1984, he became the second South African to be awarded the Nobel Peace Prize and received the Albert Schweitzer Prize for Humanitarianism in 1986. Tutu was the first black South African Anglican Archbishop of Cape Town, South Africa and primate of the Church of the Province of Southern Africa (now the Anglican Church of Southern Africa). He chaired the Truth and Reconciliation Commission of South Africa and is currently the chairman of the Elders, a group of public figures noted as elder statesmen, peace activists and human rights advocates whose goal of the group is to solve global problems, using almost 1,000 years of collective experience to work on solutions for seemingly insurmountable problems like climate change, HIV and AIDS and poverty.



Archbishop Desmond Tutu

Granny Zoe cares for 15 orphans

UGANDA - Zoe Namasinga has spent nearly 60 years bringing children into the world – 12 of her own, and thousands of others as a traditional midwife.

Now, aged around 75, she finds herself looking after 15 grandchildren and great-grandchildren in her home in Kyebe village, in the south Ugandan district of Rakai.

They are the orphans of sons who have died of AIDS related illnesses, and all would probably be living on the streets without her.

Her gait slow but eyes sparkling in her cheerfully lop-sided face, she has already 'graduated' a handful of grandchildren into senior schools and jobs, as she endeavours to keep the family intact in their home community.

Fortunately, she has found a partner in World Vision, which is active in Rakai, and which has found sponsors in the United States of America for five of the 15 children. One of them is Mary.

She provides for the children. "With the help I am getting I am sure I will make it.

"I sell things that I can grow, to raise money. When things were hardest, World Vision came in to assist me. They helped with the tuition fees to keep my grandchildren in school."

For a woman who has spent her life coping with hard times, it can be hard to rely on others for help.

"I got married at 18, and I produced 12 children; six boys and six girls. The eldest was about 25 when my husband died. He got an illness and, although he was treated for it, he passed away when I was 43 years old.

"The children were young, and I had to look for some money to look after them and to buy clothes."

Four of her sons grew up, only to die of AIDS. "One after another, quickly," as she puts it.

"Their wives also died, and they left their offspring behind with me. In all, I have looked after 18 of their children, though I only have 15 now."

When she gets home from school, Mary stays close beside Zoe. When



Zoe's great grand-daughter Flavia helps herself to as many ground nuts as she can shell and eat, while sitting with the woman who cares for the family and her aunt Mary (17)

Zoe wants something, it is the quiet, practical girl that she calls on first, out of the many choices.

"I want to be a nurse, so I can look after my grandmother," says Mary simply.

"I am happy when I can support my gran as she works with these pregnant women. It's a good feeling when you help women who are about to have their baby, and I also help them to give birth."

Mary's attention towards Zoe is far more than dutiful. Every time the grandmother goes to a training for birth attendants, the two spend hours poring over the books and notes afterwards.

"Gran has done so much for me. I would have suffered if she had not been there," says Mary.

“We know that gran went through a lot of hardship and sacrifice for us. Because of what she has done, I see a bright future ahead now.”

There are many orphans in Rakai, the first place to record a case of AIDS in Africa, nearly three decades ago. Many grandparents have found themselves caring for children, at an age when they would normally have expected to be quietly retired. But few have risen to the challenge on such a large scale and as successfully as Zoe.

“There is a hardship that comes from being an orphan,” says Mary.

“Money is short. To get soap is sometimes difficult, for instance, and your friends won’t share with you if you are poor.”

“I see a bright future ahead now”

It is easy to see that Zoe would have little time for such attitudes.

“On the day my father passed away I was already a grandmother,” she recalls.

“I went out and delivered 15 babies. I reasoned that, yes, one person had died, but there were all these new lives coming. I weighed it up and made up my mind to concentrate on the new lives first. I went to my father’s grave later.”

“This has been my life’s work. I started in 1959. I was untrained, but I knew the methods of helping women. Eventually I did get training.”

“I see as many as five expectant mothers in a day and perform deliveries 10 to 15 times a month,” says Zoe.

“I have one son that I trained. He’s 54, and he’s practising now in Kampala.”

Helping women give birth is clearly a joy. However, looking after children in the home has been a harder job. And the numbers who accept her hospitality continue to rise.

“In 2005 I got a great grandson who was brought to me after the grandmother with whom he was staying passed away. His name is Ronald, and he’s five now. His father is in Kampala studying mechanics, but Ronald’s mother is no longer with him.”

The elder grandchildren are starting to have children of their own too. One 21-year-old who, in Zoe’s piquant words, ‘stays around doing nothing’, has a delightful child called Flavia.

The grandmother enjoys the toddler’s company as they sit together happily husking ground nuts for the evening meal, though Flavia eats every nut she manages to open.

Life is made up of such simple chores, in endless succession. At 6am, Zoe is still the first to get up, as soon as the night sky begins to lighten.

“She makes tea for us, and wakes us up. After taking tea, the bigger children get the younger ones ready, and we go to school. Some of us go to collect water first – it’s about a kilometre away,” says Mary.

Zoe says the children are well-behaved and obedient, and she attributes that to the Christian way she has brought them up.

“A grandmother must care for her grandchildren. I don’t think anyone else would have looked after them,” she says.



Some of the children that Zoe looks after are, at rear, Mary Nabakooza, 17, Zoe herself, Agnes Nakuya, 10, Agnes Mayond, 12 and in front, Ronald Kawesi, 5, Beatrice Nakawesi, 15 and three year old Flavia



Sylvia (left) with Nadia on her lap

Making a difference in the lives of children is all that matters to Sylvia

SOUTH AFRICA - It takes a special woman to take children who are not biologically their own into her home. More so, if they have special needs.

That is what makes 36-year-old Sylvia Januarie unique. She is a mother of four children whom, she says, she “so dearly loves and would give my life up for”.

The three younger children all have special needs. One is 10-year-old Nadia who is HIV positive, another is an eight-year-old girl who was

partially deaf when Sylvia took her in, while the two-year-old girl is paralysed on one side. Only the oldest, who is 19 years old, is her biological daughter.

Says Sylvia, “All I want for these children is for them to be happy. I do not care what their conditions or circumstances are, as long as I can make a difference in their lives.”

She has been working very closely with World Vision’s Atlantis programme, on the outskirts of Cape Town, South Africa, since 2005.

She is a home visitor for orphans and vulnerable children, helps out with Bible study for the children and carries out value based life skills training for grade seven pupils, as part of an HIV prevention programme.

Sylvia has been blessed with the gift of giving especially to disadvantaged children, taking those who do not seem to have any hope, into her own home.

She is thrilled at the progress the smaller children are making with the help of her oldest daughter and her husband.

“All I want for these children is for them to be happy”

Her husband has been very supportive, taking time from his job whenever his wife is away so that he can look after the children.

“At first my daughter was concerned about having a little sister who is HIV positive, but after talking to her and giving her information about the virus, she became comfortable. Now she doesn’t even want any of her sisters to go away even for a day,” Sylvia says.

She takes every opportunity to share more about Nadia to ensure that people get as much information as possible about HIV. She says because most people see HIV as a ‘monster’, they understand it less than the disabilities her other children have.

“I am a Christian and I take anything people may associate with HIV in my stride, but I make sure that I talk to my children about the virus as well as tell my daughter’s teachers about her status,” she says.

She described how some teachers are uneasy at first, but explains that being proactive in telling them helps them to accept and treat the child just like all the others.

“At first one of the teachers would not let her play netball or run but I made sure I took reading material to her so that she understood the virus and how to treat those living with it. Now my daughter represents the school in running.”

Although Nadia was sickly when Sylvia first took her in about two years ago, and would sometimes spend days in hospital, she is now on anti-retroviral treatment and looks very healthy and active.

The grade three pupil even knows when to take her treatment without anyone having to follow up on her.

“Initially the whole family had to remind her but now she is in control and knows what to take and when,” says her mother.

Nadia even tells her friends about the virus, including telling them not to touch her blood and supporting other children in situations similar to hers. She enthusiastically takes part in events on HIV.

“Of course at first she had many questions, including wanting to know whether having the virus meant she was going to die soon but I had to give her the facts about HIV and AIDS and explain to her that HIV is not a death sentence,” she says.

Sylvia points out that her children keep her going.

“I could never live without children. My dream has always been to be a social worker and looking after these children is very fulfilling for me. If I had a bigger place, I would take more in,” she says.

“I don’t think I would want to do anything else but look after my children... and God knows why I only had one child... maybe it was to leave space for other needy children out there.”

Meanwhile, her partially deaf child had an operation and is now fine.

The youngest child now spends the day in a special school.

Sylvia has also been assisting many children with food and shelter whenever the need arises.

“Many children got to know me through my community work and they know they can come to me for assistance any time,” she says.

She is also very protective of her children declaring that she will never just leave them with anybody because many girls in Atlantis are harmed by men who abuse drugs and alcohol.

Sylvia acknowledges that working closely with other people and organisations has helped her to understand the plight of children and respond effectively.

“Working with different organisations has helped me to fulfil my desire to work with children,” she says.

Godfrey gives up school to care for his family



Kayemba 'Willy' Wilson, 10, Musabe Godfrey, 12, and Kimera Edward, 7, orphaned grandchildren in the home of widowed Margaret Namuli. Godfrey has been doing most of the work around the house - including building the house - for two years since his grandmother started to get sick and weak



Kimera Edward, 7, Kayemba 'Willy' Wilson, 10, Musabe Godfrey, 12, and their grandmother Margaret Namuli

UGANDA - Godfrey Musabe was 10 years old, when he realised that he must do something radical if his family was to stay intact.

His family – two cousins who were orphans like him and his grandmother Margaret Namuli – were increasingly hungry and destitute in their grass-thatched, termite-ridden home in rural Mwezi parish, Uganda.

So Godfrey, who was in the fourth year of primary education, gave up school, grabbed a hoe and started digging.

“Gran was very weak. She couldn’t do any hard work, she was so sick,” explains Godfrey, now 15.

“I saw she couldn’t cope. I decided to leave school to work. No-one tried to stop me, no teachers came to ask where I was, and no-one compelled me to stop, either. It was my decision.”

While his cousins Kayemba “Willy” Wilson, then 8, Kimera Edward, 5 and Patrick continued to go to Mwezi Primary School, Godfrey now stayed home and tried to work out how families thrive.

“I took on all the major household chores. I take care of the home, I dig,” – he waves his hands at plantations of beans, cassava, maize and savoury matoke bananas – “I take the goats to the field and oversee the chickens and pig. And I built our new house.”

It was obvious to Godfrey and Margaret that the old place was not going to last. So for five months, they gathered poles, sticks and mud for the walls, saved money for some iron sheets and nails, and started building a new home.

“I built the floor and walls, together with gran. At the end we had to pay a man to nail the iron sheets on the roof.”

“All the rest of it, I did. I learned the skills because sometimes people have called me to help build their houses in the village.”

When it was finished in January 2007, the family moved in. One week later, during a storm, their old house collapsed.

“Termites had eaten the main poles,” recalls Margaret. “If we had been in there, I think it would have fallen on us and killed us.”

Margaret, a staunch member of the Catholic Church, retorts, “God is merciful. He loves us. God loves the needy.”

Edward and Willy had the same father, one of Margaret’s sons, a fisherman in Kampala who has not been in touch with his sons or mother for three years.

“I still have four children alive, two male and two female, but I have no real connection with any of them,” she says.

Godfrey’s mother, who was Margaret’s daughter, died of an AIDS related illness when he was still a baby. He stayed with his father for four years, until his father also succumbed to a cocktail of illnesses.

Margaret was the only family member remaining who could take Godfrey in.

“Any time the children got sick I would sell chickens to get money to take them to the health centre in the town, about two miles away.



Godfrey

“I didn’t have enough for treatment, usually, but I did what I could.”

Water comes from a mile away, out of a none-too-clean stream. The children fetch it and boil it before anyone dares drink it. As Margaret grew older and weaker, and the children needed more food and money for school supplies, she often found herself wondering who could help them.

“There has been no help for us. How can someone help you continually? They will get bored.” She starts to get tearful.

Unexpectedly, help arrived. Yussuf Mukasa Kanyadde and Disan Kyajja started visiting, representatives of the Mwezi Parish Community Care Coalition. They are local volunteers, members of one of eight ‘village development committees’ in the coalition.

As home visitors, they are charged with identifying all the vulnerable children in Mwezi Parish and finding ways to help.

“She’s actually lacking everything,” concludes home visitor Yussuf, deeply moved.

“There are five home visitors in the village, each with ten homes to visit. We want to change this area.”

The community care coalition and its development village committees were formed following a community outreach by the humanitarian organisation, World Vision.

“We try to ensure the children go to school and that they have the necessary equipment when they get there – exercise books, pens, pencils. Each visitor tries to work things out with the community to see that they have the money for these things.”

However, Godfrey has no ambition to go back to school, seeing his first loyalty is to Margaret, the house and land.

“Right now I am happy about what I have done. I would like to get a job now. Then I can get money.

“That will enable me to look after the household and keep growing food for gran and the boys. She gets sick almost every week, and I want to take her to hospital every time she gets ill.”

Meanwhile, Godfrey has been supported by Katwe Livelihood project to acquire Building and Carpentry skills.

“God loves the needy”

Every challenge makes Annie stronger

ZAMBIA - "As a pastor, speaking out about my HIV status felt like I was giving others permission to talk about their status," explains Reverend Annie Kaseketi.

Reverend Annie's life has been checkered with losses of her loved ones - her children and her first husband - but in all this she did not even for a single moment think she could be HIV positive.

With these and many other challenges, Reverend Annie has been forging ahead helping to bring hope and wholeness to broken situations.

"I used to think that I couldn't get HIV because I was a Minister of the Gospel, I was faithful and after the death of my first husband, I was abstaining," she recalls.

Reverend Kaseketi first got married in 1986 when she was 23 years old and her husband was 28. She was then working for the government and had been posted to Chilubi Island in Luapula Province of Zambia.

In 1993 Reverend Annie went to Kaniki Bible College in Ndola together with her husband. During that same year, their baby girl, who was one year and ten months old, died.

"It was very difficult for me to lose my baby," she recalls.

The following year she had a son, Shalom followed by Hannah. After completing their training in Biblical Studies, Annie and her husband were allocated a church to pastor in Ndola town.

"I had a strong desire to work with women who were hurting, who couldn't express themselves and had a low esteem."

Her husband died of meningitis in 1999.

"I was really devastated... I was left with two small children. It was really hard."

She decided to move from Ndola to Kabwe town, about 140 kilometres north of Lusaka.

In 2001, she left Zambia for Durban in South Africa where she went to pursue an advanced diploma in Mission Work.

"I went away for a year leaving the children Shalom and Hannah in the

care of some relatives. I wanted to come and launch into full time women's ministry on my return," she explains.

But upon returning home, new challenges awaited Annie. Ten days after her return, Hannah passed away.

"It really dealt me a terrible blow. You can imagine after being away from home, looking forward to being with my children and then my baby is gone!"

She began to work with a group of women in Kabwe.

"Through this group, I managed to work with various women who were in difficult situations, who had given up on life and were hurting," she explains.

"In 2003 my son Shalom was being treated for arthritis and I was being treated for tuberculosis," Annie says.



Reverend Annie Kaseketi (left) at a community meeting

“It was one of the low moments of my life, and I never thought of taking an HIV test.”

Meanwhile, her health kept deteriorating and the need to take an HIV test kept coming up. In the end she gave in to the doctor’s suggestion.

“In August of 2003 I accepted the doctor’s counsel and asked that I undergo an HIV test. The results were not what I expected. I was HIV positive... I was a minister of the Gospel... all kinds of questions came into my mind.”

“What would the other ministers say or think of me when they hear that I am HIV positive? What would the members of my church say?” she asked.

She was put on anti-retroviral therapy and her health began to improve.

“One Sunday, I was asked to preach by the Pastor in-charge of the church that I was attending in Kabwe,” she says.

“While I was preparing my sermon a woman from the same church came to my house and told me that she was HIV positive and that she felt she needed to share that with me. I was at a loss for words. I didn’t know whether I should tell her that I too was HIV positive.”

After the meeting with that lady, Annie struggled within herself as to whether she should tell people about her status or just keep it to herself. She decided she would tell the congregation.

“I give HIV a human face”

“The reaction of the members of the congregation varied. Some treated me like I was going to die there and then, others felt pity for me and then some outrightly condemned me as wayward, while still others avoided me at all cost,” she described.

“I began to ask myself why I had even shared my story.”

A day after sharing about her status, Reverend Annie left for preaching engagements in the Eastern Province of Zambia and Malawi giving her time away from the congregation, as they digested her message.

She also used the opportunity to share about her HIV status as she travelled. There were mixed reactions to her message.



Reverend Annie (right) sharing information about HIV and AIDS

“When I began to work with World Vision and would talk about my story, I usually told it in third person and it would be about a woman called Grace,” she explains.

Once a pastor told her that Grace was a murderer because she caused the death of her husband and children. When Reverend Annie disclosed Grace’s true identity, the pastor felt so bad he later apologised.

World Vision’s Channels of Hope workshops for which Reverend Annie is a trainer, targets pastors and faith leaders. The programme helps to educate many faith leaders on HIV and AIDS.

“I give HIV a human face, which they can relate to. Some feel offended by it, while others feel I need support.”

Some feel that she is an embarrassment to the clergy because her disclosure gives the impression that the clergy are promiscuous.

“God has also been able to use me as a channel, through which He has been able to bring hope to others,” she explains.

In December 2006, Reverend Annie married Danford Mwaba who is also a pastor. He is also living positively with HIV. Her son Shalom is now 14 years old.



Classes are over and the children benefiting from the FOJAIP youth centre run out of the classrooms to take a break for the day

Insert: Taboula Innocent

Taboula has a heart for children

The plight of a young orphaned boy who was selling eggs and cigarettes in a bar to raise money for food, broke the heart of a young graduate. It moved him to form an association to support vulnerable children and provide the youth with vocational training.

He formed the association together with 11 other graduates.

“When I asked him what he was doing in the bar, Michael told me he was selling eggs and cigarettes for the bar owner and receives a small

token at the end of the month for his food,” recalls Taboula Innocent, the Coordinator of the Foyer de jeunes pour l’Animation et l’Insertion Socio-Professionnelle (FOJAIP), a Youth Centre in Moundou, Chad.

Michael was not attending school because both his parents had died and he had no money for school fees.

Most of the graduates are waiting for integration into the civil service and the lucky ones are recruited after three to six years.

“We have started a Youth Skills Training Centre and we are able to provide the industry with 63 community development facilitators after two years in our centre,” explained Innocent.

“We have also launched a small malaria prevention programme and during the sensitization in households we discovered that Moundou has a huge number of vulnerable children who have lost their parents to AIDS related illnesses,” Vincent said.

“We thought of starting a children’s centre with our limited resources and Michael is in the first group of children we are taking care of.”

FOJAIP’s program started in 2004 with 37 children who have lost both parents and now takes care of 123 vulnerable children.

It started off as a day care centre but the management decided to permanently take care of 17 of the children, who had nowhere to stay.

“We have realised that after class, most of the children go into the streets to beg and this is not good for their future. We decided to keep them here and try to provide them with food and shelter out of the association members’ financial contribution,” Innocent says.

Meanwhile, a general medical check up on the 37 children, carried out by the centre revealed that seven are HIV positive. Two of them died a few years ago and the other five are attending the school started by the association. The five live with Innocent’s family.

“My wife is a nurse and we have decided to keep the five children with us at home because they need special care,” says Innocent.

“They live with us like our own children and my wife takes care of them even if they fall sick late in the night.”

The centre, however, needs more financial assistance.

The founding members make contributions to raise money to pay the three teachers.

They also receive contributions from individuals who provide anything from money to a meal for a day. They are grateful to World Vision for its contribution in 2004.

“We would have closed the door if God had not opened the door to allow World Vision to come in,” says Innocent. “We received 34 sows and a year later, we had 157 pigs. We sold 127 of them and that gave us the equivalent of 11,000 US dollars, the largest amount of money the centre has ever had,” he said.

The centre used that money to buy 36 sheep, feed the children and pay teachers’ salaries.

After six months, the number of sheep increased to 100. Forty were sold to raise money for the centre.

WorldVision also provided them with a water point with a pump, 3,500 plants of banana and school uniforms for the children.

Sixty-five of the children at FOJAIP attend the centre’s school, while the remaining study at schools located near their relatives and parents homes.

All of them have medical follow ups through the centre nurse and have at least one meal a day together with those staying at the centre.

Meanwhile, the centre has bought an eight-hectare piece of land in Lolo, a village about 22 kilometres from Moundou.

They have set up a breeding place for the sows and sheep there but also use it to teach children gardening, farming and tree planting skills.

“We want them to learn how to live a normal life and also get skills that will be useful when they become adults.”

In 2008, the centre planted three hectares of banana and cultivated one and a half hectares of maize there.

“It was the first trial and we are satisfied because we have harvested almost 50 bags of an expected 100 kg of maize,” said Innocent.

“We have given six bags to World Vision to donate to other people in need of assistance. We just want to share the blessings we have enjoyed from God with other people in need,” he said.

**“We want them
to learn how to
live a normal life”**



Sumai grows from strength to strength

TANZANIA - “My mother died, so I live with my uncle and my grandmother,” says nine-year-old Sumai Reuben, who has never met her father, and does not know if he is alive.

Sumai’s mother died when she was only three years old. Sumai was born after her mother was separated from her first husband with whom she had five children.

Her uncle, Elia Kingamkono, 27 says nobody knew for sure what killed his sister.

“I only suspected it was AIDS after Sumai was diagnosed with HIV in August last year,” he said.

When Sumai was diagnosed with HIV, her uncle and grandmother, Elizabeth Manene, 70, decided to share her status with neighbours and family members.

“It was important to tell people about her health because she is such a charming child. She plays with anybody and she likes school,” says Elia.

Says Sumai, “Children used to tease me at school and say that I have AIDS.”

Although she was not officially registered at Bukangilija Primary school, she used to go and play with other children. Playful Sumai could not stay at home while she heard joyful noises of her age-mates barely a hundred metres away.

Her grandmother says that before she started using anti-retroviral drugs she used to come home crying sometimes, because some kids refused to play with her.

“Some parents had warned their children to avoid her because of her health. I thank God that the teachers have been very supportive.”

Left: Sumai writing down her name in a notebook

The fungal infection on her scalp that had troubled Sumai healed after she started taking drugs. Now she is more confident at school.

Sumai describes her day and wishes for the future.

“I wake up at six and go to school at seven o’clock. My friend is called Magdalena. I sit with her and another friend at my desk.

“I want to be a tailor. I saw a tailor in Maswa. She made me a nice gown,” she says.

“My grandmother makes me porridge at 12 in the afternoon and in the evening,” she continues.

Elia says Sumai never forgets her anti-retroviral medication. She takes her drugs every morning and evening.

“I take my drugs with water in the morning before school and in the evening before I sleep. I take them by myself,” she says.



“She plays and makes friends easily”

However, even after Sumai started taking treatment, she was still weak because of the low nutrient food she was eating.

Sumai’s uncle approached a development project in the area which gave the family maize flour during last year’s drought.

“We had some food but we needed more so that we could sell what we had produced in order to get a bus fare to take Sumai to hospital. It costs 5,000/- (US\$4) for a trip to Maswa and back.”

Elia is a farmer and during the dry season he runs small businesses, like selling rice to buyers from other towns. They have to make sure Sumai is well fed.

“On Saturdays and Sundays when I don’t go to school I make porridge on my own. I can also make ugali (a thick porridge made of maize meal) for Bibi (grandmother),” says Sumai.

Since her siblings live in different towns, Sumai lives only with her grandmother in a compound that has three houses: one brick house, now being used as a kitchen and two cement block houses. Bibi and Sumai stay in a two-bedroom house. The other is being rented out.

One of Elizabeth’s sons built the cement-block houses.

Elia stays in his own house just a few metres from the main compound. Caring for Sumai is now Elizabeth’s major occupation.

“I have many grandchildren; they stay with their fathers in other cities. I stay with Sumai all the time. If I have to travel I go with her, and make sure that I bring her back in time to go to hospital for her medication,” says Elizabeth.

“What I like about Sumai is that she is a very active child. She plays and makes friends easily at school,” says Elia.

While the grandmother and uncle are talking, Sumai grabs a notebook and grips a ballpoint pen, although she normally uses a pencil at school.

“I know how to write my name,” she boasts and puts the notebook on her knee.

Slowly, she scribes the letters separately ‘Sumai’ and flashes the page with a jubilant smile.

Left: Sumai with her grandmother, 70-year-old Elizabeth Manene

Dan moved from depression to leading a support group



UGANDA - Finding out he was HIV positive sent Dan into a depression but five years later, the 52-year-old widower who is also father and grandfather to several children has a very positive outlook on life.

“Life came to a standstill on getting news that I was HIV positive,” he says.

Coming from a situation of having lost all hope, he now owns a successful garden of pineapples, passion and vanilla fruits and runs a pig project.

It, however, took several sessions of attending a psychosocial support group in Uganda’s Masaka, Kyajjunga village where he lives, to take him to the level where he is now.

In 2003, he was approached and encouraged to join the therapy group by one of the facilitators of World Vision’s Masaka Kyanamukaaka programme.

The facilitator found him alone, lying down in his compound with a blanket over his head.

“He did not want to talk to anybody,” says John Kibuuka, a psychosocial facilitator from Kyanamukaka. After some negotiations he agreed to an interview.

“He had all the nine symptoms of depression and admitted that he had a number of issues contributing to his depression,” adds John.

Being HIV positive, he was very worried about his future. His wife had already succumbed to an AIDS-related illness and he was worried about who would take care of his family after he died.

After explanations to him about depression and how the therapy works, he agreed to join the group and attend the sessions.

The interpersonal psychotherapy group had 11 other men who were also depressed for various reasons including death of loved ones, serious disagreements with other people, social isolation and other changes in their lives.

During the early group sessions, Dan was uncomfortable opening up because he knew everybody there.

“Some of my village mates stigmatised me, so I developed a negative attitude towards everybody,” says Dan.

It took him some time to open up in the group because he did not trust the members and doubted whether confidentiality would be maintained.

He, however, continued to attend the group sessions, listening to other members’ problems and supporting them but did not say anything about his own status and the challenges he was facing.

In line with the advice he got through the therapy, he set up some weekly short-term goals for himself, to keep him occupied.

It was during the seventh group session, that he was able to open up about his own problem after realising that he was not the only one with depression.

He shared with the group that he was HIV positive and that he expected to die soon.

Dan had lost all hope and kept on blaming himself for his status. He also shared that he had lost his wife to an AIDS-related illness.

“I got a big relief on sharing my experience with members of the group,” says Dan.

The group started supporting him and he realised that there was still hope for him.

His weekly goals included growing passion fruits, keeping goats and piglets. This helped him to do some practical work instead of lying down in his compound and thinking about death.

By the time the group disbanded, he was happy and more positive. He began to apply the skills he had acquired from the group.

He spent time doing work in the garden and looking after goats and pigs.

Dan also decided to share his future plans with his family - something he had stopped doing after finding out his status.

His family members said the change in Dan’s attitude was remarkable. He talks and laughs with them now.

He is more practical and spends most of his time working on his projects.

When asked what they thought had happened to him, they said that they could not tell exactly what had brought about the changes, but said they used to see him every Thursday going to meet with other people.

Dan did not share with them what was happening in the group. They were just surprised to see how much his behaviour had changed.

“Most people in the village thought that he would die anytime. However, they are surprised to see that he is still alive and even talks with people, which was not possible before,” says a family member.

Today Dan is strong and free to talk about his HIV status. He has planted more pineapples, vanilla and passion fruits. His piggery project is also doing well. This helps him to support his family.

“I got a big relief on sharing my experience with members of the group”

Dan supports other people in the village who are living with HIV and encourages them to take anti retroviral treatment like he is doing. He gives himself as a reference point.

He comments:“One of the achievements is to see myself back at work and confidently sharing about my status and situation with others. I use every opportunity to counsel and encourage others to take an HIV test and share their experiences.”

The psychotherapy group has formed a Community Based Organisation (CBO) called *Sikyomu*, meaning I am not alone. Dan is the chairman.

The CBO’s main objective is to fight stigma by talking about HIV and AIDS and encouraging people who do not know their status to go for testing.

Through his group, Dan is often invited to different community functions to talk about his experience. Dan has become a leading counsellor in his village and other parts of the district where local leaders always invite him.

Gaspard is committed to fight stigma



Gaspard, addressing a cooperative of 200 people inside a pentecostal church where he is the assistant pastor

RWANDA - Commonly known as ‘pastor’, Gasore Gaspard has become an icon of success in Rukomo sector, Northern Rwanda for the tremendous efforts he has made in responding to HIV and AIDS.

The 45-year-old man, who is married to Josephine Mukamana and has four children, has worked hard against stigma in his home area.

It started out as a personal initiative, but now it has become a full time responsibility for Gaspard.

“It started after a World Vision Channels of Hope training. I decided to go for voluntary counseling and testing. When I tested negative, I imagined how I would feel if I had tested positive. It just strengthened my resolve to fight stigma for it was only by God’s grace that I had

escaped,” said Gaspard.

He says he did not expect to be negative, because he had lived an unsafe life before becoming a Christian.

He was addressing people living with HIV when we visited him. These members are mostly vulnerable and poor women. Some of them do not have anywhere to live while others have big families that they eventually cannot sustain because of the poverty.

“You know how much we care about you with our limited capacity and resources. Personally I will not rest until I see smiles on your faces,” Gaspard comforts a group of 200 people.

Gaspard is an assistant pastor in a pentecostal church of 3,000 members, and he was recently selected to be responsible for the response to HIV and AIDS issues in the church. He felt he had to start with his own church - encouraging people not to discriminate against those living with HIV.

“It wasn’t easy when I first uttered the word AIDS in my church. Many Christians rebuked me, saying it was diabolic,” said Gaspard.

Gaspard advises those living with HIV to go for appropriate treatment and for the communities to take care of those living with HIV. He accompanies the sick to the hospital if they do not have anyone else to help them or when they are too weak to go on their own.

“Pastor has been a real model to us, he has taught us to enjoy work, and also to help those affected by HIV”

He also does advocacy to pull together any possible support from individual groups, NGOs and the Government.

He is the founder of “*Izere Umurimo*” association (meaning ‘trust in work’), which administers all activities in the church including an anti-AIDS club made up of youth in Rukomo sector.

“Pastor has been a real model to us, he has taught us to enjoy work and also to help those affected by HIV. We have grown cabbages, carrots, and Irish potatoes for the most vulnerable. We sometimes sell them so that we can help them buy clothes and medicine,” says 20 year-old Jean Pierre Twajamahoro, leader of Rukomo anti-AIDS club founded by Gaspard.

“I learnt I was HIV positive in 2001, but I didn’t want to reveal my status until I met Pastor Gaspard who convinced me that revealing my identity would make me feel reassured and positive. He told me that I should learn to accept the reality,” says another man who believes Gaspard has changed the way he looks at HIV and AIDS.

He says that he started taking ARVs when he joined Gaspard’s association.

“I would always tell people that there is no salvation in ARVs,” he says.

Gaspard’s commitment has served as an eye opener to the church, community and government officials who sometimes come to him for advice. He also organizes campaigns against stigma, where he involves

the entire community.

The pastor has now started another project of sensitising mothers living with HIV to have their children tested. He recently started with 98 children. Half of them tested positive.

“It is better for the parents to find out about their children’s status early so that treatment will not be delayed,” expressed Gaspard.

Gaspard has previously organized a three-day training for people living with HIV and AIDS and then involved them in community campaigns against stigma.

He has been working on various campaigns and projects, but says he needs more support. He has assisted those without shelter, medical insurance, and seeds to sow in their fields.

Gaspard has submitted various proposals to several organisations for support, and says he is optimistic that God will make a way for these poor and vulnerable women, men and children in Rwanda.



One of the youth who lives in Gaspard’s home area taking a voluntary HIV test after receiving advice from Gaspard

Becky rose from the brink of suicide to providing counselling

GHANA - Who would have thought that the woman who nearly committed suicide when she found out that she is HIV positive would be supporting many people, especially women, to live positively with HIV?

The woman introduced herself simply as Becky. She was healthy and there was no physical sign of the fact that she has HIV.

Becky said about three years back, she started getting sick a lot. Looking for healing, she said she went to spiritual churches where she was told her ill health was due to a curse.

She was asked to provide several items to be used in performing rites to cleanse her and reverse the curse.

“I became very poor because I sold all my belongings to raise money for those things,” she said, “the rites, however, were not successful.”

“Ignorance about how HIV is contracted causes victims to be stigmatised and shunned,” she explains.

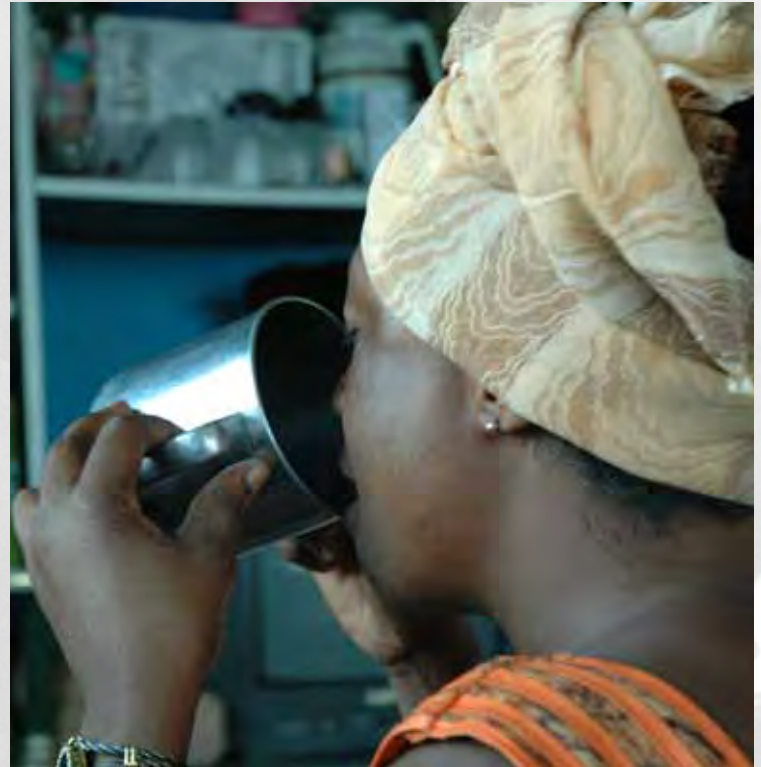
A nurse at a clinic she attended once, shouted at her: “Move away. When you people live carelessly and get AIDS, then you come to disturb us.”

Because she had lost a lot of weight, people suspected that she had HIV and were afraid that they would be infected if they had contact with her. Her own relatives avoided her even though she had not been tested.

“Even my food was pushed into my room. I said to myself that even a dog would not be given food in this manner. So I decided to commit suicide because I realised they wanted me to die,” Becky says.

But even with all her desperate plans, the poison she planned to use to kill herself spilled before she could drink it. She, however, did not know her HIV status then.

That night her husband visited and took her back to his home in Accra and later to the Korle-bu Teaching hospital where she had an HIV test. Becky tested positive.



Becky taking her medication

“The day I was told I had HIV, I wept uncontrollably for a long time,” Becky recalls.

She calmed down when a loving nurse put her arms around her and told her about the Wisdom Association at the Fevers Unit, Korle-bu Teaching Hospital.

“Things did not immediately improve for Becky and her family. After testing positive, the doctor advised that my daughter, who was seven months old, should also be tested. She too tested positive,” she says.

Her daughter currently attends school close to their home.

“My husband also tested positive. Unfortunately he died after trying out a drug that someone claimed was a cure for HIV. Perhaps if it had not been for that drug, he may still be alive.”

“When we counsel them it is more effective because they can identify with us”

The concoction contained highly concentrated bleach, so he and a woman who was also put on the trial died.

Through it all, Becky remembered the nurse’s hug and information about the Wisdom Association.

She is now a very active member of the Association. Members share their stories as part of creating awareness about the pandemic.

The association was formed in 1999 in Accra to bring together people living with HIV and AIDS and to help them cope with the situation.

Their main challenge is to minimise the stigma associated with the pandemic and help people cope with it.

People’s needs are identified through the creation of a congenial atmosphere that allows for discussion of issues affecting those affected by HIV.

Members of the group voluntarily counsel those living with HIV.

“When we counsel them it is more effective because they can identify with us,” Becky says.

Some of their activities include sensitising the general public on HIV and AIDS through outreach in schools, among other places.

“I can not count how many people I have reached because there are so many – in schools, churches, communities. After talks some embrace me, others shake hands, some take my mobile phone number and then phone me later,” she says.

In 2004, the need to have a smaller support group led to the formation of a new group named *Goodwill Aid*. The membership has grown from 30 to 120 people.

“A lot of people want to support groups rather than individuals and there is strength in numbers. You can easily break one broom bristle but it is not so easy to break the whole broom,” Becky explains.

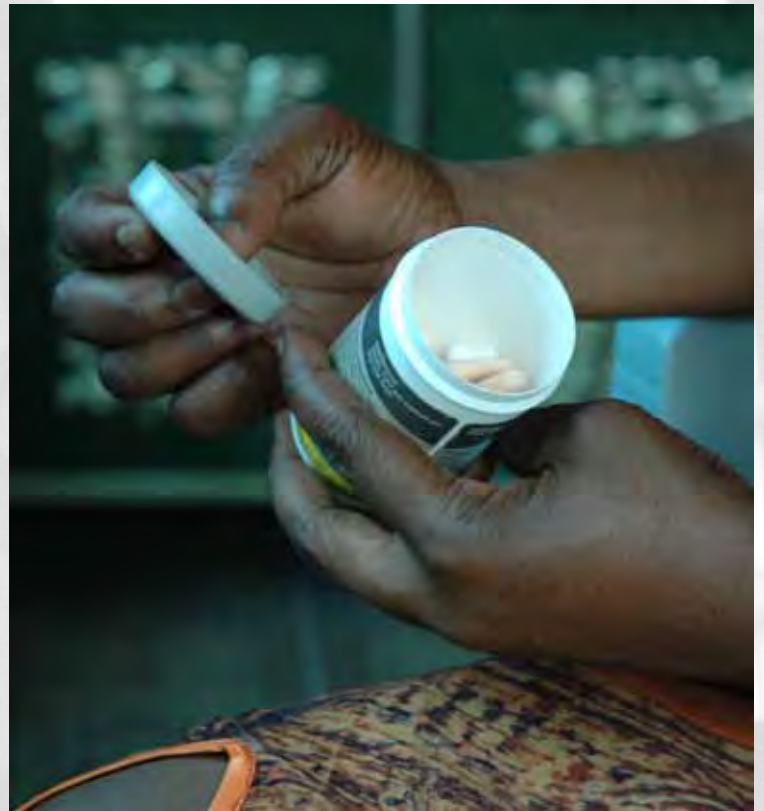
“An individual’s voice may not go far but a group’s word is more difficult to avoid. We have a higher chance of curbing stigmatisation when we go public and declare our status and advise people to live responsible lives.”

“Show love to the victims. If you sack them from work or from their houses, how will they cope?” she asked.

It is more than a decade since Becky first shared her story with World Vision Ghana staff during a World AIDS Day commemoration.

She continues to devote her time and life to reaching out to other people affected by HIV and AIDS.

Below: Becky showing her anti-retroviral medication



Quintin and Kristin stand strong

SOUTH AFRICA - It takes a woman of conviction to defy all odds and marry the love of her life even though he is HIV positive and she is not.

“Twice, we decided to break off the relationship because of all the opposition but we got over it,” said 28-year-old Kristin who is married to Quintin Jonck.

She eventually moved out of her parents’ home so that she could stay alone and make independent decisions about what she really wanted to do.

Says Quintin: “My father-in-law would not hear of it. We had several meetings to try and convince him but he was adamant until the day of the wedding. He came to the wedding and from then on we have become very close.”

Quintin is very grateful to his wife for accepting him just the way he is and standing by him all the way.

He found out his HIV status after going for a routine insurance medical test in 1998.

“The first two years were really tough. It was the accepting stage for me. People reacted in different ways but my family was very understanding. The white community didn’t know what to do, it was as if it only happens to other people and they could not understand how it happened to me,” he said.

Three years after his diagnosis, Quintin met his future wife. He told her about his status through another person as he did not know how to break the news himself. Kristin accepted it but members of her family found it very difficult.

Both Kristin and Quintin recall how Kristin’s father gave them a four-hour lecture about why they could not get married.

“We walked the road with pastor Louis and Lizette. When we told



Quintin and Kristin Jonck at their house

him we wanted to get married, he and his wife advised us to wait for at least six months. So we waited... and eventually got married two years and three months after we got that advice. We prayed a lot for Kristin’s parents and then had a meeting with them together with the pastor,” says Quintin.

He describes the response from Kristin’s parents as showing a slight but not real change, after the meeting.

“That was very hard for us,” he says. They reached a point when they both felt that they could not do much to change Kristin’s father’s mind and it was really up to him whether to come to the wedding or not.

Quintin continues: “This was even harder because the word of God is clear about dishonouring your parents. We believed that by getting married we were doing the right thing to break the stigma.”

Up to the day of the wedding, there was no guarantee that Kristin's father would attend. But on the wedding day, he was there and his attitude began to show real change from then on. Now, all is normal and they have put the past behind them.

For Kristin it was a life changing experience.

Now she has to make sure that she speaks hope into Quintin's life all the time. There is no time for her to be down because when he is stressed, he looks to her for encouragement.

married to someone who is living with the virus. I always remind them about the man I am married to and try to change their attitudes towards those who are HIV positive," she says.

She believes that people need more information about how to live positively. It is also essential, she says, for mothers to be educated on how they can protect their unborn babies from contracting HIV.

Kristin summarises her experiences thus: "My husband and I both realised life is short and we need to live life to the full. In such circumstances you learn to live."

"I use my personal experience to talk to mothers and mothers-to-be at the antenatal clinic, about their attitudes towards HIV"

"I do my best to stay positive. I'm sad that there is still a lot of stigma among many people but my main message is, love abundantly and have compassion. Don't judge what you don't know because there is hope."

"The scripture out of the word of God that I carry with me is 'I send from Zion a rock of offence, a stumbling stone but whoever believes in Him will never be put to shame.'"

Now Kristin is pregnant and the thought of bringing new life into the world has given them new hope. She is still HIV negative.

Her experience has also opened new ways for her to do her professional job. She is a midwife and meets dozens of HIV positive mothers on a weekly basis.

"I use my personal experience to talk to mothers and mothers-to-be at the antenatal clinic, about their attitudes towards HIV and to help them understand that it is not the end of the world if they discover that they have the virus," explains Kristin.

She also points out that the attitude among some medical professionals is very disappointing.

Kristin feels that people are still ignorant and say a lot of negative things about HIV and adds, "I always want to remind them about my situation."

"Some of the comments that colleagues I work with make towards people who are HIV positive are unacceptable and when I listen to them, I wonder whether they say the same things about me who is



Quintin working at his computer

Muse believes in community support

ETHIOPIA - Muse Mamecha, 37, was the first person to disclose that he is HIV-positive in a rural community of nearly 200,000 people.

He is leading an association of people living with HIV and providing care and support to members and promoting prevention to others.

Prior to the formation of the association pioneered by Muse, many preferred to stay home, hide that they are HIV-positive and suffer in silence because they feared being stigmatised.

Now, the members are grateful for the changes they experience in their lives after they disclose their status and join the association.

Muse remembers those who helped him get to where he is today and is grateful to a former Health and HIV and AIDS Response facilitator from a non-governmental organisation.

He says, “The facilitator found out that I was HIV-positive and bed-ridden and started visiting me. At first I resisted the idea of disclosing my status. I did not want to be the first person to do that.

“But he kept on encouraging me to disclose that I am positive and share with others and get support. Had it not been for his persistent encouragement I would not be alive today – I would have continued to hide and thereby hurt myself and others.”

Explaining how the association came into being, Muse recounts: “When I disclosed, World Vision started to support me with nutritious food. And when people saw that I was getting support, they started to join me and also disclose until we established the association.”

“We encourage one another”

The members eventually named their association *Addis Alem*, meaning ‘new world’, to signify the transformation they experienced.

Members of the association are also very grateful for the much needed nutritional support they received.

“Those on antiretroviral drugs need to be well fed. But many of them are very poor. Thanks to the support, many of them are now restored and energetic enough to become productive citizens.”



Muse with his wife, Fantaye and their daughter

They are even involved in income generating schemes now. Muse says they are expecting to make up to 12,000 birr (US\$1,333) from the sale of the root stock of apples they are producing each summer.

The money will be used to further expand the business and start other income generating activities.

“This way we are working on making sure that *Addis Alem* becomes sustainable to support its members,” he adds.

Because of the training and the income generating schemes in place, many of those living with HIV are now encouraged and are more optimistic about their lives.

Due to the impact of the association, many more people are disclosing their HIV-positive status.

“Two years ago, I was the only person who disclosed that I was HIV-positive. Today the number has risen to 118 men and women,” says Muse with pride.

Fantaye, Muse’s wife who is also HIV-positive explains the significance of the association: “We are like one big family. We encourage one another and share what we have with each other.”

Toni makes every day worth living

Toni Zimmermann has been living with HIV for 19 years and her advice to those who do not know their status yet is that it is crucial to be tested because “knowing your status helps you to respond appropriately”.

“I try to make a difference in other people’s lives by sharing my experiences through theatre, addressing gatherings and contributions to my company newsletter and radio station,” she says.

A trainer by profession, her work gives her an opportunity to share information on HIV and AIDS with company employees during training sessions. Her experiences since she discovered she is HIV positive have been very challenging but she is proud to say she now has a very positive outlook on life.

“There is not a word in any language to describe the shock I felt the moment I heard that I was HIV positive,” she describes.

“Talking about my status discourages people from gossiping”

She was 22 when she went for a test after her boyfriend’s insurance medical examination came back HIV positive.

But how she felt then was nothing compared to the devastation she felt when her seven-and-a-half-year-old son died of an AIDS-related illness in 1999. She had stopped working in 1996 so that she could spend more time with him.

Since then, Toni keeps herself busy and hardly has time to sit and worry. She paints, makes clothes, and decorates cakes in addition to her formal employment as a trainer for a large Southern African retailer. She has realised the need to make every day worth living.

Her choice to share her status also helped her to deal with her situation, choosing to go public on World AIDS Day of 1993.

She is very grateful to her family for all the support they give her – her

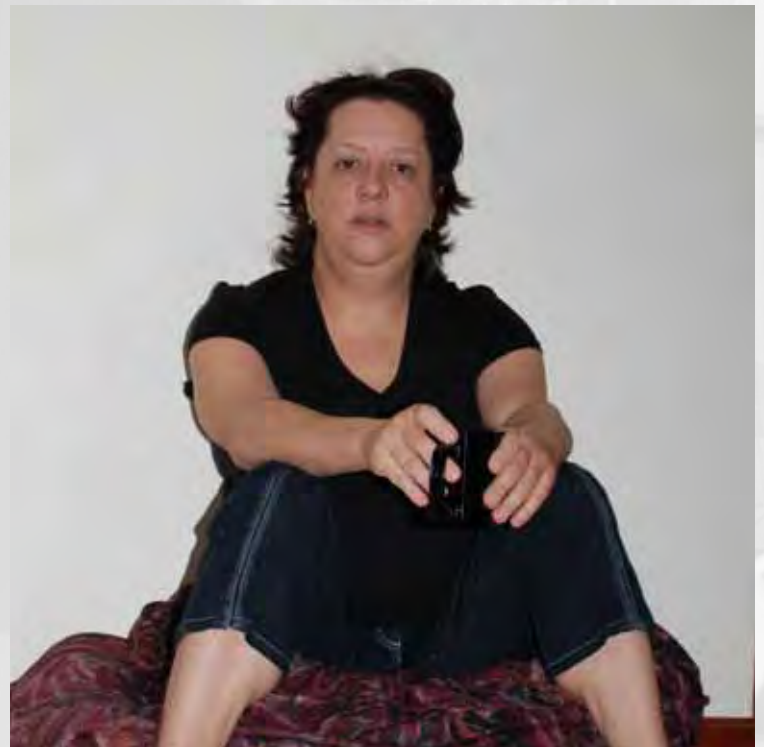
two sisters are in Cape Town while her brother is in Pietermaritzburg. She was only able to tell her father, who is a church reverend, eight months after she found out her status.

“As a preacher, my father was more used to dealing with other people’s issues that did not directly affect him, but this was different, yet he was strong,” says Toni. Her mother was devastated.

“I found talking about my status discourages people from gossiping, so it has worked well for me.”

Since I found out my status, I have decided that I should learn something new every year – from dancing to painting to learning a new language. She loves to paint things that show beauty and the smaller things in life like flowers.

Her key messages when she is training are: “Know your status because when you do you can live a long and healthy life without fear of rejection and discrimination. You focus on dealing with the ignorance about HIV that people still have.”



Toni Zimmerman at home

Emmanuel offers a channel of hope

TANZANIA - Pastor Emmanuel Nambi gets on his bicycle to go and help the sick, the widowed and the orphans in his community.

He is taking food and soap to the hungry and ill, and uniforms and exercise books to children who have lost their parents.

The 36-year-old father of three says he has discovered that helping people whose lives have been affected by HIV, the virus that causes AIDS, is the right thing to do.

He vows that his church will play its part in taking up the cause of vulnerable children.

It was not always this way in the Lutheran Church in Singita village, where he is the evangelist.

“We didn’t know about this ministry, that a church could serve people living with HIV, the widows and the orphans and vulnerable children,” he admits.

“Thanks to World Vision’s Channels of Hope programme, though, I had three days of training and I have learned how to work with people living with HIV in the hospital and at home.”

Channels of Hope is an intensive awareness and training course that has been developed by World Vision.

Its aim is to get religious leaders, of all faiths and denominations to provide an environment in which all aspects of the AIDS pandemic can be practically tackled.

“We have managed to form a ‘hope team’ in our church, which we call *udiakonia*, from the local word for deaconate,” smiles Emmanuel.

“Every Sunday I take five minutes before the sermon to talk about HIV.”

Left: Pastor Emmanuel Nambi ready to leave for his home visits



Church members, recognising that they had a duty to the sick, used to visit people with AIDS-related illnesses in the government hospital in Shinyanga, 30 kilometres away.

However, people needed to understand how to do this properly.

“We used to work without using any kind of protection. We were not careful,” says Emmanuel.

“Now we know how to protect ourselves, and after receiving training we have started working in the community.”

Although the impact of AIDS has not been felt so severely in Samuye as in other parts of Africa, there has been plenty to keep Emmanuel and his colleagues in the 60-member church busy.

“There are seven orphans and similarly disadvantaged children in the church, and we’ve had three of them for three years,” he says.

“We are helping them with school uniforms and school fees, and we give them food. They live with relatives, but are supported by the church.

“We still work with people who are sick with AIDS related illnesses and others infected with HIV. Currently we have just one in this village.

“She was in a very bad condition, but now she is doing much better. I see this as a ministry that is physical, spiritual and psycho-social.”

Emmanuel says pastors in other churches and other villages have also started reaching out to people in need after the training.

“We meet together at evangelists’ committee meetings and discuss how to reach out to people with HIV and to orphans. We see ourselves as one. We have to work together, realising we have different specialties, because we are one community.”

Looking at HIV prevalence statistics, Emmanuel knows there must be many more people in the area who are living with HIV.

“Most people do not know their status, because they have not been tested. Many of those who know they are living with the virus do not know where to turn for help and only a small percent would think of coming to the church with their problem,” explains Emmanuel.

“It’s not enough to know about HIV, people have to change the way they think,” he says.

“This community, perhaps more than others, needs training. People are scared of HIV, they think, ‘what if I am infected, how will I go on living in my community?’

“People who are tested and found positive have a very hard time coming out and saying so. Everyone has to be counselled to accept that this is normal – HIV is there, in the community.”

Emmanuel and his wife Philomena look after their three children, Daudi, 15, John, 9, and Emmanuela, 7.

They are soon going to add one more by taking in one of the church’s orphans. She is four years old and her relatives are no longer prepared to look after her.

**“We didn’t know ...
that a church could
serve people living
with HIV, the widows
and the orphans
and vulnerable children”**

“We’ll take her into our family,” promises Emmanuel.

The cost of looking after the church’s most vulnerable children is spread across the whole congregation.

“We will have a fund-raising in church to help these children. I know the congregation will give; we’ve done it before. Everyone in the church helps by visiting the children as well.

“We used to take it for granted that when someone died they had been cursed.

“We used to dig a hole and throw them in with all their property, and cover them up.

“Now that is in the past. We have been educated about HIV and AIDS.”

Jeanne saves thousands of lives



BURUNDI - It took Jeanne Gapiya's unflagging efforts to ensure there was a continuous supply of anti-retroviral (ARV) drugs into Burundi through a care centre known as *Turiho*; Kirundi for 'we are alive, here we are' which she established in 1999.

With assistance from donors, she provided drugs in the face of an economic embargo in 1996, which resulted in a shortage of several goods including ARVs.

"When I visited a local hospital and noticed that HIV positive people were dying like flies I said, no, no, this is enough, I have to find solutions," she explained.

She would drive 300 kilometres between Kigali and Bujumbura, to buy drugs for people living with HIV who in most cases lay helplessly in hospitals.

Also in 1999, she led a movement of actors that got the government to drop taxes on ARVs and drugs for opportunistic infections.

In order to have better access to HIV drugs, the centre has now established relationships with the national pharmaceutical industry, including manufacturers of generic drugs.

By 2008, about 3,000 patients were benefiting from *Turiho's* antiretroviral treatment programme while 46,000 people have received counselling and testing services from the centre since its formation.

Centre *Turiho* currently employs four permanent doctors, two part-time doctors and 131 other staff members. People line up at the centre daily for testing and to receive drugs.

Before the formation of *Turiho*, Jeanne had already been involved in a lot of work for those affected by HIV and AIDS for several years. In 1993 she formed the *Association Nationale pour Le soutien aux Seropositifs et aux Sidees* (National Association for the Support of those affected by HIV and AIDS - ANSS) with 12 others living positively with HIV.

She was elected president of the association and worked for it on a voluntary basis for more than five years. The association has grown over the years and provides country wide responses to the pandemic.

It runs several programmes, including community mobilisation, testing, counselling, psychosocial support, supplying of drugs and food distribution to vulnerable people affected by HIV.

“Wherever I go, I try to break discrimination against people living with HIV and AIDS and plead for their integration into income generating activities”

Jeanne became the first person to publicly disclose her HIV status through the media in Bujumbura in 1995.

She called upon people to take action to promote HIV prevention and protect the rights of those affected by the virus.

Born in Bujumbura, the capital city of Burundi in 1963, she lost her mother when she was only 14. She grew up with her father and sisters in a small, united family.

During her younger days, she was an athlete and a remarkable basketball player. She later became an accountant and worked in the private

sector before her life took a rather drastic turn.

Five years into her marriage, Jeanne lost her 18-month-old baby in 1989 and her husband in 1990. This eventually led her to go for HIV testing.

She found out she was positive and years of shock, acceptance and positive thinking led to the birth of the association in 1993.

Jeanne obtained funds for HIV monitoring equipment.

She is a tireless advocate for access to treatment and care for people living with HIV.

“Wherever I go, I try to break discrimination against people living with HIV and AIDS and plead for their integration into income generating activities,” she says.

Jeanne is the national co-ordinator of *Paris Sida Project*, a project that provides global support to more than 2,300 Burundian children orphaned due to AIDS, since 2004. The children receive food, clothes, school materials, health care and shelter.

She is also the chairperson and legal representative of a newly created Burundian platform of Civil Society and Faith based Organisations that are active in responding to HIV and AIDS.

Jeanne now lives with her family in Gabon but still visits Burundi regularly.

“On average, I visit Burundi four times a year and communicate daily with the leadership of Centre *Turiho*, ANSS and other associations I lead for regular updates,” she said.

“I may be physically outside of the country but my thoughts are here.”

She married a man who is also HIV positive. Her husband works for a programme on HIV and AIDS based in Gabon.

Jeanne remarried because she believes in life going on. Her husband lost his first wife, with whom he had two sons who are 17 and 16 years old. Jeanne is a caring mother to the boys.

Jabu takes care of the sick

SWAZILAND - Taking care of the sick is part of Jabu Dlamini's life. Nothing gives her more joy than to see an ill person getting better and going back to his or her normal life.

For seven years now, this has been her full time job, even though she is not paid for it.

Dlamini is a home-based caregiver (HBC) in Phonjwane, Gilgal, Swaziland. She volunteered to be a home-based caregiver during a community meeting becoming one of the first caregivers in her community.

"This job comes with a fair share of joy and pain," explains Dlamini.

"Looking after the sick has become part of me. The patients relate with me in a way that makes them part of my family. I can't help but become attached to them."

In some cases, family members isolate their sick relatives once they discover that they have HIV. They will not go close to them, let alone feed them.

Caregivers have to educate people about HIV and AIDS and how to take care of their sick relatives. In some case they refuse to take care of their relatives. When this happens caregivers report them to local leaders.

Says Dlamini: "I find some people very sick when I visit them. During the night, I will be wondering how they are doing. Then early in the morning I go back to check on them and make sure that they have been fed and taken their medication properly."

Some of the ill people will only disclose their HIV status to caregivers and not to their families.

Initially, Dlamini was looking after 18 people. However, it was very difficult for her because the homesteads were far apart. It was also expensive for her as she uses her own money to visit patients. In 2009 Dlamini was looking after 12 patients. However, two have since died.

During the year, new caregivers joined the programme. Dlamini has handed five patients over to another caregiver. She has looked after about 89 patients since 2002. Unfortunately 23 of them have passed away.

"When one of my patients dies, it's like a part of me has been taken away. This is the hardest part of the work," she says.

Jabu says the majority of those who died could not accept that they were HIV positive. This was the case even after professional nurses and doctors tested them. Some abandoned the medication and opted to die because they could not take the pressure of being stigmatized.

However, things are changing. Most people voluntarily go to clinics and hospitals. After proper counseling, they accept their HIV status. Some go an extra mile and publicly share that they are living with HIV. A support group has since been formed in Dlamini's community. WorldVision has also played a major role in this program.

They trained all home-based caregivers and provided them with nutritional supplements, which are useful as they carry out their duties. These include nutritional meals, oral dehydration salts, disposable nappies, bleach and soap, among other things.

The organisation has also provided them with seedlings to give to the families of the sick to start vegetable gardens. Dlamini has her own garden. She shares the vegetables with some of the patients who have nothing.

"Before the training, we used to do things our own way when dealing with patients. We never used gloves but now we use them. The training was an eye-opener for us. Now we know how to look after the sick and ourselves as well," she says.

"This job comes with a fair share of joy and pain"

Dlamini started taking care of the sick in 1994, when her older sister fell ill and she was looking after her. Even though she was not aware of what she was suffering from, Dlamini was not happy about the way her sister was treated in the local hospital. She explains how the nurses were always busy looking after so many patients that they had little time for each patient.

Her sister was finally discharged because there was no room for her in the ward and she was forced to take care of her.

Both of them had small children and because of her sister's condition,

Dlamini was nursing both children, as they were almost the same age. Her sister later died.

In 2004 her younger sister also fell ill immediately after giving birth. She never recovered, and eventually died.

Three months later, the child died too.

“She told me before she died that she had HIV. She had been on ARVs for sometime. But I think falling pregnant affected her negatively. She also told me that after giving birth, the doctor, knowing her condition,

gave her medication for the baby but sadly, she did not use it.”

Dlamini is a mother of four. Her husband has been unemployed since 2004. During her spare time, she goes to the market to join other women to sell her wares.

Two of her children are at school and the other two are still too young to go to school.

She uses the money received from selling at the market to pay school fees and feed her family. Jabu and her husband know their HIV status.



Left: Jabu in her garden. She shares some of her vegetables with those in need

Alex is determined to educate others

SIERRA LEONE - Forty-five-year-old Saah Alex Joe lives with his wife and five children in Dormah Town, Gbenseh Chiefdom, Kono district, Eastern Sierra Leone.

Alex worked as an artist at a Printing Press in the same district. He was responsible for designing textbooks and exercise books at the printing press but lost his job the day his employer discovered that he was HIV positive.

Although Alex's situation became very unfriendly after his family and other people discovered his status, this did not hold him back. It was, however, a difficult process.

The journey led him to become an ambassador for HIV and AIDS since 2005. He has been actively involved in educating people in his community. Since 2006, World Vision Sierra Leone has been inviting Alex to assist in facilitating various HIV and AIDS workshops.

"It is my joy to see stigma and discrimination being reduced within the community. The rate of discrimination now is minimal. People feel free to talk and live with people living with HIV. There is now full awareness and consciousness of the virus. People are now going willingly to the hospital to get tested," Alex says.

Alex's source of income now is a small plot of land at the back of his house. He grows rice, potatoes, cassava and bananas. He sells some of the harvest and shares with other people living with HIV who have formed themselves into groups. But it has taken him time to get to where he is now.

"In 2003, I was experiencing frequent illnesses. Twice every month, I would be admitted at the Government Hospital for some sort of illness, allergy or severe pain. No one knew the cause of my frequent illness. Doctors could not come up with a diagnosis. In June 2004, I became paralyzed," he says.

"I was again admitted at the Koidu Government Hospital for over a month."

While admitted at the hospital, one of the doctors said to me one day, "This time, we are going to do a thorough medical check-up on you. You will be required to do a series of tests so that we will be able to identify the real cause of your frequent illness."

Several tests were carried out on Alex, including HIV.



Alex and his two brothers working on his farm

"I was given different medications after the tests and when the doctors noticed I was responding to treatment, I was discharged," Alex says.

Alex was requested to stay at home for two weeks before resuming work so that he could recover properly.

"As I sat one evening outside my house," Alex explains, "I saw one of the doctors who was treating me at the hospital walking towards my house."

He spent time with Alex and then went on to reveal that his HIV test came back positive.

"Soon after, I ran down the road, went into a bar, bought six bottles of beer, a packet of cigarettes and consumed them all in no time. I had never drank alcohol or smoked before in my life," Alex says.

"The doctor was a man of courage and determination," he says.

"He never stopped visiting me, though I tried avoiding him. He would encourage me to go to the hospital and start taking anti-retroviral drugs. When he noticed I was adamant, he brought the medicines home and convinced me to start taking them."

"There is no need to take these medicines. I will die soon, in one or two

weeks time,” Alex had told the doctor.

The doctor helped Alex to understand that being positive does not mean death.

“After much persuasion from the doctor,” Alex says, “I started taking the anti-retroviral drugs. After two months of taking the drugs each day, I realised that I was still alive and I can still live and contribute meaningfully to society.”

Meanwhile, Hawa, Alex’s wife, a small scale trader was in neighbouring Guinea when the doctor visited Alex and told him about his HIV status.

Says Alex: “When my wife, Hawa, returned, she noticed I was taking drugs daily. She asked me why and I told her I was in pain so the doctor prescribed them for me. I didn’t know how to tell her I was HIV positive.

“I worried that she might also be infected. I thought also of our five children. Will all of them be infected? I did not know how I contracted the virus. There used to be a lack of awareness on my part on how HIV spreads. For instance, I used to share one blade with two or three people for shaving.

“One day as we lay in bed, I collected enough courage to tell Hawa that I was HIV positive. She shouted and threw my hands off.”

The next day, Hawa packed her belongings and left home to stay with her mother.

After a series of counseling, Hawa and the five children were tested for HIV and all except the two-year-old daughter tested positive. Everyone in the family is now on anti-retroviral drugs.

Meanwhile, Alex continued working in the printing press for another year between 2004 and 2005.

“My employer got to know that I was HIV positive and he was furious,” Alex explains.

“One day, I was binding some souvenirs and an iron pricked my finger and blood started flowing.

“My supervisor saw the blood. He shouted, ‘You have spoilt my machine with your blood’. Then he quickly drew the machine from my hands and told me to go home. ‘I will send for you later when I need you,’ he said.

“It is now three years and he has never sent for me to work with him again nor has he given me any terminal benefits,” Alex sighs.

Alex has been attending a series of workshops where he discovered that people have different views about people living with HIV - some accept them just like anyone else while others have negative feelings towards them.

“This reminds me of my former employer and my former landlord, who demanded the keys to his house when he found out about my HIV status. He told me that I was no longer strong enough to work and so would not be able to pay bills for the house,” says Alex.

“I decided to be an advocate,” he says, “to speak for the voiceless, to help minimize stigma and discrimination of people living with HIV and AIDS. I thought: Why should HIV be treated differently from cancer, for example?

“My dream is to continue educating the public about HIV and AIDS, not only in Kono district but throughout the country. I believe with support from different people, the National AIDS Secretariat (NAS) and other organizations, stigma on HIV and AIDS will be wiped out of Sierra Leone.

“I pray God will touch the hearts of certain authorities to know that people living with HIV and AIDS need love, care and protection. They need proper food in order for the anti-retroviral drugs to work properly.”

**“I realised that I...
can still live and
contribute
meaningfully
to society”**



Alex and his wife display oranges from their farm

Patty calls on people to break silence

SOUTH AFRICA - "Don't let today's disappointments shatter your dreams for tomorrow."

That is Patty Thomas' motto since she discovered that she is HIV positive.

Stigma and discrimination are the main issues that she tackles as she talks to people about HIV.

"My call is strongly for breaking the silence and stigma. I hope to open the door for those in the closet," she says.

Patty has been speaking out about her status for 13 years as a way of dealing with her situation and moving forward with her life.

"Before I started sharing about my situation, I felt like everyone could look at me and see my status. It was self – destructive, it was like a death sentence," describes Patty.

"I ...work towards helping each woman to get her place back in society"

Currently she is working for a mothers programme promoting Prevention of Mother to Child Transmission (PMTCT) in the Western Cape in South Africa.

"I walk the path with those mothers for nine months and work towards helping each woman to get her place back in society, to educate and empower them, giving them the emotional support they need. The best reward for me is to see how these mothers grow from strength to strength and have taken ownership of their own lives," she said.

Patty has a daughter, Yadah, who supports her mother all the way and describes her as "my role model". She also has a younger son, Baruch.

Patty is married and she owes her ability to cope with her situation to God and her very supportive husband who is HIV negative.

There was a time when she got very sick and thought she was dying. "My CD4 count was very low and I was very sick. One day I was



Patty with her children Yadah and Baruch Brooks

talking at a workshop and a doctor who heard my story suggested I go on anti retroviral treatment. In 2004 after preliminary tests I went on treatment," she says.

Since then she has been living a very healthy life.

Her main message to people she comes across and interacts with is that "we are all loved, wanted, accepted and we all have our mountains to climb, some just seem higher than others".

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