Sub-Saharan Africa has only 10% of the world’s population but accounts for almost 70% of people living with HIV worldwide. Yet in most African countries efforts to respond to the HIV/AIDS crisis are still hampered by fear, denial and stigma.

Uganda has achieved greater openness about HIV than other African countries. Denial of the reality of HIV, which was widespread at the start of the epidemic, is now rare. HIV-related stigma, which helps to perpetuate secrecy and unsafe sexual behaviour, is also less common and still declining.

These achievements have contributed to a steady decline in HIV prevalence in Uganda since the early 1990s. The initial impetus for Uganda's national HIV and AIDS effort came from the highest level of political leadership, but it has been carried forward by a wide cross-section of civil society and government.

This book, and the accompanying video, describe how the Ugandan people, political leaders and government agencies have breached the wall of silence surrounding the HIV epidemic, reduced HIV-related stigma, and so made HIV/AIDS an ‘open secret’.
People facing up to HIV and AIDS in Uganda

by Noerine Kaleeba, Joyce Namulondo Kadowe, Daniel Kalinaki and Glen Williams
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In the last two decades of the twentieth century, the HIV epidemic has swept through sub-Saharan Africa with increasingly destructive force. According to the World Health Organization and UNAIDS, the epidemic has so far claimed the lives of over 14 million men, women and children in Africa south of the Sahara.\(^1\)

Worldwide, about 53 million people have contracted HIV, and 18.8 million have died of AIDS since the epidemic began in the late 1970s. Although HIV is a global phenomenon, sub-Saharan Africa is bearing the main brunt of the epidemic. With only 10% of the world’s population, sub-Saharan Africa accounts for 71% of the 34.3 million men, women and children estimated to be living with HIV at the start of the twenty-first century. In the most severely affected African countries, up to 25% of the adult population are infected with HIV.\(^2\)

Most people infected with HIV in Africa are parents with young children. As a result, Africa has experienced a catastrophic increase in the numbers of children living in AIDS-affected households or struggling to survive after the death of one or both parents. By the end of 1999, according to WHO and UNAIDS, the number of children worldwide orphaned by AIDS had reached 13.2 million, of whom 92% were in sub-Saharan Africa. The burden of caring for these orphans often falls upon the shoulders of aged grandparents, at a time when their own health, strength and economic wellbeing are starting to decline.

Hard-won gains in life expectancy and child survival are being wiped out in many countries. In Southern Africa, life expectancy at birth, which rose from 44 in the early 1950s to 59 in the early 1990s, is expected to drop back to 45 between 2005

Ugandan orphans with grandmother: the HIV epidemic has caused a dramatic increase in the number of children in sub-Saharan Africa who have lost one or both parents.
Once described as “the pearl of Africa”, Uganda is a land of plateaux and hills, marshes and lakes, between the two arms of the Great Rift Valley in East Africa. Between 1890 and 1962 Uganda was part of British East Africa. The name ‘Uganda’ was derived from the kingdom of Buganda, which occupies most of the central part of the country.

After independence from Britain in 1962 Uganda prospered briefly, then entered two decades of political upheaval, state-sponsored terror, economic decline and civil war. The National Resistance Movement (NRM) led by the current President of Uganda, Yoweri Kaguta Museveni, came to power on 26 January 1986, after a five year-long civil war. The NRM government has largely restored security, re-established the rule of law, promoted freedom of expression, revived the economy, and enabled widespread democratic participation in community and national affairs.

During the 1990s Uganda’s economy grew at around 7% per annum. Yet Uganda remains one of the world’s poorest countries. It is ranked number 158 out of 174 countries on UNDP’s Human Development Index, and GDP per capita is estimated at US$330. 44% of the population is estimated to be living on less than US$1 per day, and only half the population has access to safe drinking water. Total per capita health expenditure is US $9.70, of which $4 comes from government and donor spending and the balance from families.

Uganda has a population of about 21 million, 86% of whom live in rural areas and are dependent on agriculture for their livelihoods. Coffee is the country’s main cash crop and accounts for up to two-thirds of income from exports. The main food crops are green bananas (matooke), maize, cassava, sweet potatoes, millet, sorghum, groundnuts and beans. The lakes, especially Lake Victoria, are an important source of fish, some of which is exported. Cattle herding is the main economic activity for many communities in the Northeast and also in the Southwest of the country.

The people of Uganda are divided into four main linguistic categories: the Bantu, the Luo, the Nilo-Hamites and the Sudanic, each of which consists of several smaller ethnic and linguistic groups. Religion is an important factor in community life and national affairs. According to official statistics, about two thirds of the population are Christians, divided into approximately equal numbers of Protestants and Catholics; about 16% are Muslims, and the remainder are animists.
and 2010. In East and Southern Africa, child mortality rates are expected to double or even treble by the year 2005.6

In most countries throughout the world the momentum of the HIV epidemic continues unabated. In 1999 an estimated 5.4 million people worldwide were newly infected with HIV, and a record 2.8 million people died of AIDS. In sub-Saharan Africa the number of people newly infected with HIV in 1999 was 4 million, most of whom are expected to die of AIDS within the next ten years.7

Yet in most African countries – and in many other parts of the world – the HIV epidemic has been surrounded by a wall of silence for the past two decades. Behind this wall of silence, the reality of AIDS has been concealed and denied. For too many political leaders and government officials, development planners and policy makers, teachers and educators, religious and community leaders, employers, members of the armed forces, local communities and families, AIDS has been a shameful secret, a disease “that dare not speak its name”.

Uganda: from denial to openness
AIDS was first observed in Uganda in the early 1980s. As in other countries throughout the world, many people in Uganda responded by denying the reality of AIDS, and by stigmatising those believed to have the disease. By 1993 an estimated 1.5 million Ugandans – about 15% of the adult population – were living with HIV; more than in any other country in the world. Yet the denial and stigma which had characterised the start of the epidemic in Uganda were beginning to wane. Official and public attitudes were marked by a growing degree of openness about the reality of HIV, and increased acceptance of people living with HIV/AIDS.

In the mid-1990s, surveillance reports from the Ministry of Health indicated that HIV prevalence was beginning to decline in Kampala and some other urban areas. By the late 1990s there was firm evidence of significant changes in sexual behaviour, especially among young people, and further declines in HIV prevalence were reported from several different parts of the country. Researchers in Uganda believe that these declines in HIV prevalence are linked to changes in attitudes and sexual behaviour, which in turn are related to the openness that has characterised Uganda’s national response to the HIV epidemic.

This book documents how, in Uganda, openness about HIV has been translated into action at the level of the individual, the family, the community and the nation. It describes how dedicated individuals, political leaders, civil society organisations and government agencies have breached the wall of silence surrounding the HIV epidemic, reduced stigma against people with HIV, and so made the HIV epidemic an ‘open secret’.

Much still remains to be done in Uganda to cope with the impact of HIV and to curb its further spread. Indeed, in the late 1990s there were worrying signs that the national response to the HIV epidemic in Uganda was beginning to weaken. What Uganda has achieved so far, however, gives cause for hope to other African countries struggling to come to grips with the unprecedented challenges presented by the HIV epidemic.
Chapter 9
The strength of personal testimony: NACWOLA

The National Community of Women Living with HIV/AIDS in Uganda (NACWOLA), is the only national NGO run for and by HIV-positive women in Uganda. Its members provide one another with emotional support and practical assistance. Many NACWOLA members also feel it is their duty to speak publicly about living with HIV. It takes enormous courage to talk about one’s HIV-positive status at a church, a workplace or a community meeting. The most daunting challenge of all is breaking the news of one’s HIV-positive status to one’s own children. Through the Memory Project, however, NACWOLA is addressing even this most heart-rending of all problems.

Beatrice Were
Beatrice Were was widowed in 1990. A graduate in social work of Makerere University, she has two daughters, aged 8 and 12, to whom she has disclosed her HIV-positive status. As Coordinator of NACWOLA, she frequently speaks in public about the problems of women living with HIV, and encourages others to do so as well:

“We believe that people with HIV, and especially women, face special problems. But if we want to see less stigma, if we want people to accept us, if we want people to have correct information about how we got HIV, then we must help to change the social environment. We must come out and demystify the ignorance and fears in the community, by showing that AIDS really exists, and that the people who have AIDS, or HIV, are human beings who deserve understanding and support.

“We also believe that we are best placed to help stop the further spread of HIV, because we know how it feels. We demonstrate the impact of AIDS on an individual’s life. We know the pain, we know the suffering it causes to humanity better than someone who doesn’t have the virus. If we were silent, then people wouldn’t see the seriousness of HIV and AIDS. So we feel that, by coming out and talking, we help to sensitize people and create greater awareness in the community of the need for behaviour change. We can make behaviour change real. People can see that, if we talk about abstinence or condom use, we are actually practising these things, and they really are possible.

“We run workshops to train our members in public speaking. We start by brainstorming about what difficult issues might come up when we give a talk. Then we do role plays when we imagine somebody giving a testimony at a school, or at a press conference, and someone asks a particularly difficult question. People often say to us: ‘Oh, you’re still quite young, you look beautiful and strong. Do you still have sex?’ And if you say yes, then they’ll ask you angrily ‘Do you have sex with?’ They want to know who you might be putting at risk. They don’t see it as a shared responsibility between the person who is infected and the one who is not. Or they might ask whether we fear death, or whether our children know that we have HIV. So in the training sessions, someone can pretend to be a journalist who asks really intimidating questions. This is good training for our members, most of whom are not used to speaking in public.

“But we also train our members to speak about particular issues affecting women living with HIV. In the past we could just tell our personal stories and that used to work with most audiences. But that’s no longer the case. Now we have to move a step further, and get across specific messages to our audience. One big issue concerning women with HIV is our property rights – the inheritance issue. Most of our
members have lost their property, which their children should have inherited, to the unkind hands of their in-laws and other members of their extended families.

“Many people believe that, once we have lost our husbands to AIDS, we are going to die soon and don’t deserve property. Also, according to our culture, you belong to your husband’s family so you don’t have a right to decide on property anyway. So that’s an issue that we feel we need to sensitise the general public and our own members about: the law of inheritance, a widow’s right to property, and making a will.

“But however much we are trained in public speaking, we ourselves still need a lot of emotional support. People often think that, when they see us speaking in public, we must be very brave. But they don’t realise that we feel a lot of pain, real emotional pain, when we do that, because we are risking our families, our friends, and our jobs. When you speak in public about living with HIV, your life changes forever. People no longer see you for what you are. They stop referring to you as the person they knew before, and start referring to you as that woman with AIDS – sometimes it’s not very nice. So you need a lot of
emotional support, you need friends who appreciate you for what you really are.”

**Reducing fears:** “I think by going public, people living with HIV in Uganda have helped many others to overcome their fears and misconceptions about AIDS. Many people are so scared when they first test HIV-positive. But we show them that, with support and care, it’s possible to make a meaningful contribution to life even though you have HIV or AIDS. This is also helpful to other family members. We have contributed to reducing the fears and misconceptions, and enabling families and communities to cope with the problem of HIV in a more acceptable manner. In some countries people with HIV are really feared and people won’t come close to them, but in Uganda there is a level of acceptance in families and communities.

“One of the changes that AIDS has caused in Uganda is that men and women are beginning to talk about sensitive issues with each other. Not so long ago, a woman couldn’t discuss sex with her partner. If you tried to, he would regard you as a prostitute. A woman was expected to be humble and to wait for her husband to make advances to her. In African culture it was taboo for a woman to show her sexual desire, or to express her dissatisfaction with her partner. You could never complain. Even if your husband was having ‘away matches’ (extra-marital affairs), you couldn’t object, because he had power over you.

“Now you find that, through a lot of sensitisation – on the radio, for example – the old taboos about husbands and wives discussing sex are gradually being broken. Women are starting to discuss sex with their husbands, and persuading them to use condoms. Women even go to pharmacies and buy condoms to take home, something

Beatrice Were (left) explains a point to Uganda’s First Lady, Mrs Janet Museveni, at the official inauguration of NACWOLA’s Memory Project.
that was culturally unacceptable even a short time ago.”

**Children - the last to learn:** “But even those of us who speak in public about having HIV or AIDS find it difficult to discuss our own HIV-positive status with our children. The fact that, in Africa, we traditionally do not talk openly with our children about sensitive issues like sex and death makes this hard for us. Also, AIDS prevention messages aimed at the general public often portray people with HIV/AIDS as being promiscuous and immoral. This makes it even more difficult for us to disclose our HIV-positive status to our children, because they have been made to believe that AIDS affects only morally bad people.

“The children of parents living with HIV are often the last to be told that there is HIV in the family. They are left in the dark to guess, or to learn from rumours why their Mummy or Daddy is often sick, or behaving strangely. And when they lose their parents to AIDS, these children suffer even greater trauma and confusion. So we think that children have a right to know their parents’ HIV status before any outsider does. They should not be left in the dark to worry by themselves. They deserve the truth more than anyone else. We should let them cry on our shoulders and wipe away their tears while we still can.”

**Memory Project**

When Jacqueline returns home from the NACWOLA office, she often finds her 11 year-old daughter, Jacinta, curled up in a corner of the living room, poring over the pages of her Memory Book.

For the past 18 months now, Jacqueline has been painstakingly putting together a Memory Book for each of her three children. Each book is divided into 30 sections, starting with “Your birth” and “As a baby you...”, moving on to “The story of your family” and “Your interests”, and going right through to “My hopes for your future”. On each page, Jacqueline has carefully and lovingly written some text, often illustrated with colour photos taken

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**How to reveal your HIV-positive status to your children**

Parents who decide to disclose their HIV-positive status to their children need to do so in a way that is sensitive towards the child. NACWOLA has found it useful to bear in mind the following points:

- Be conscious about timing. For example, avoid times of stress such as examination periods.
- Choose a quiet, sheltered environment, where your child can show his or her emotions without being exposed to other people.
- Be understanding and patient. For example, if your child reacts by crying, do not try to reason with him or her, but simply provide a shoulder to cry on.
- If you cannot handle the situation on your own, ask a friend, family member or counsellor for support.
- Be available for some time after you disclose your HIV-positive status. For example, do not do so the day before going on a journey.
at different stages of Jacinta’s life. A family tree shows Jacinta’s relatives on both her mother’s and her father’s side of her family.

The book is part of NACWOLA’s Memory Project, which aims to help HIV-positive mothers prepare their children for a time when they will have to cope without parental guidance and support. Traditionally, Ugandan parents do not discuss sensitive issues such as illness, death and sex with their children. In the era of HIV/AIDS, however, traditional customs may no longer be appropriate. Unless children are prepared for the premature death of their parents, introduced to future carers, and provided with detailed information about themselves and their families, there is a high risk that their grief will be compounded by fear, panic and loss of identity.

Jacinta’s Memory Book contains a section entitled “People who are special to you”, in which her mother reminds her of people to whom she can turn for assistance in the future:

“As you grow up, you will face many temptations, especially as you are a girl. Your fellow girls will tell you how to live your life. The moment you believe them you will be in trouble. They'll say things like you've got to have sex, otherwise you become narrow, or rigid, or loveless, or no man will want a virgin. That's all idle talk. If you are in doubt, ask a doctor or a nurse. A man who wants you to prove your love to him by having sex with him is just passing the time. He will leave you anyway. I say these things through experience.

“And if you ever decide to get married, marry a man because of love, not for any other reason.

Excerpt from Jacinta Namwalira’s Memory Book.

Remember that love lasts but other motives wear off quickly. Also remember to introduce him to your family, whichever uncle you decide to go to. Don’t just run off with a man. You have a family, and if he really loves you he will be willing to meet your family. Just as I told you, remember that True love waits’.

“Lastly, remember this deadly disease AIDS. It has no cure, but if you follow what I have told you, you’ll be safe because I know you and your partner will go for testing before you marry. But if you block your ears, you will follow in my miserable footsteps. Your father died of AIDS and I will too some day, unless there is a miracle. Please be careful.”

- Mega Nekesa: she might look strict, but never hesitate to tell her any of your problems or difficult decisions. She is there just for you and always patient.

- Your uncle Peter Wafula is more than ready to help.

- Your father had some friends who remained faithful all these years, especially Ouma Oguttu, and Yoana Wafula and his wife, who is a doctor.
The Memory Book was first developed in London in 1992/93 by the children’s charity Barnado’s, with help from a group of parents from different parts of Africa and the UK. Despite their diverse cultural backgrounds, these parents found that they had much more in common than being HIV-positive. Because they were facing the likelihood of premature death, they all wanted to ensure that their children were informed about their own early lives, their family’s origins and who their relatives were. Above all, however, they wanted to express their own beliefs and values, and their aspirations for their children’s future lives.

NACWOLA decided to adopt the Memory Book in 1996, as a way of helping Ugandan parents living with HIV to move towards greater openness in their relationships with their children. With financial support from Save the Children, NACWOLA members are being trained to develop their own Memory Books, using guidelines and headings covering different aspects of their family history, way of life, culture and beliefs. The Memory Book package has been produced in Luganda, Kiswahili and Luo, as well as English. Uganda’s First Lady, Mrs Janet Museveni, visited the project in October 1999 to demonstrate her support for the initiative.

Jacqueline:
NACWOLA member
Jacqueline is a 34 year-old widow with three children: Jacinta (11), Kenneth (8) and Edwin (7). She works as a volunteer at NACWOLA’s head office in Kampala, and is also a volunteer counsellor in the HIV/AIDS clinic of a large Catholic hospital. - Harriet Erumbi and Peter Wafula will help you to trace any of the above people for you.”
She and her husband were both diagnosed HIV-positive in early 1992:

“... My husband had been losing a lot of weight, and he also lost his job because of being off sick so often. I suggested we should take an HIV test but he refused. Then he got a fever which never left him. He was tested for malaria but that was negative. He still refused to have an HIV test but I had one anyway, and it was positive.

“I’m not the hiding type, so I came home and told him that as I was positive he must be too. Then he went for a test and it was positive. We told all our relatives on both sides of the family. We thought it better to tell them sooner rather than later. They were quite supportive. They encouraged us by saying we could still live a long time. Medicine could be discovered to treat AIDS. At that time there weren’t many Ugandans who had come out about being HIV-positive, and they had all died. My brother had already died.

“After a month, I was surprised to find myself still alive, and even more surprised after a year. My husband died a few months after testing HIV-positive. Eight years later and I’m still here, and it’s because of positive living. I now know that the virus weakens your system, so I strengthen my system through good food, especially lots of green vegetables.

“I didn’t tell my children that I have HIV until 1997, when NACWOLA started the Memory Project. I introduced the subject by asking whether they knew anything about ‘Slim’. Kenneth said that you can tell that someone has it because they scratch themselves a lot. Jacinta said you get it from a blood transfusion or from sleeping with someone. Edwin just kept quiet.

“Being trained for the Memory Project was important. We learned about listening to our children and observing their body language. We realised that we usually expect them just to listen to us, but we should listen to them too. And also that we should be honest with them, because they can exaggerate small problems into major ones. We also learned a lot about opening up to our children on really sensitive issues like HIV. It’s better that they learn from their parents than from other people, like their neighbours, if their parents have HIV.

“My children look through the Memory Book on their own, or with me. They like the happy pages best, and they want to add their own photos to it. They keep taking photos out of the family album to put into it. I don’t talk much about AIDS with my children, but I remember how last December, when I was very ill and thought I might die, Jacinta was asking her uncles where she and her brothers would live if I died. Would they have to go to school in a village? But her uncles said no, they would go to live with them in Kampala and so they could continue going to school here. So the children were very reassured to know that.

“Being open about having HIV means I have nothing to hide so I don’t have to live under a burden of secrecy. Once you accept that you have the virus, you gain inner strength. You realise that it doesn’t stop you from doing anything you want, except of course having babies. It’s better to get your diagnosis early rather than late. Once you know your status you stop feeling anxious and worried. You can enjoy laughter. You feel freer.

“I haven’t told my neighbours that I have HIV. I moved here after my husband died. But they must know I have HIV because they know I go to NACWOLA every day. We get on well with one another.

“My relatives sometimes ask me for advice about AIDS. There’s a niece who had a persistent cough. When she came to me I suggested she should go for an HIV test, which she did, and she was positive. My brothers-in-law still visit me and I have a good relationship with them. My first boy, Kenneth, stays with one of them. None of my husband’s brothers wanted to inherit
me after he died. They are all educated people and they know my HIV-positive status, and they understand the implications.

“But my husband’s relatives in his village are not so educated. After my husband’s funeral all his relatives gathered around a fire at night and they told me that I had to choose one man as my husband. I told them that I’m HIV-positive so I couldn’t marry one of them and have children, but they didn’t believe me. They thought that if one of them didn’t inherit me, my husband’s ghost would come and haunt them afterwards for not keeping the tradition. There was a lot of shouting and I told them that if a ghost did come and haunt them they should send it to me! But they were still not satisfied.

“‘There have been other men wanting to marry me since my husband died. I’ve found that they don’t believe me if I say I’m HIV-positive, so I just make some other excuse for not accepting them. I would think seriously about marrying again if I met the right man. My children are so young and it would be good for them to have a man in the home.’

Rebecca: NACWOLA member

Rebecca and her eight year-old son live with her parents in a low-income neighbourhood of Kampala, where she runs a small hair-dressing salon. Widowed in 1993 at the age of only 18, Rebecca wanted to remarry and have more children. She decided, however, to go first to the AIDS...
Information Centre to be counselled and tested for HIV. Her worst fears were confirmed: she was HIV-positive.

She decided to postpone indefinitely the idea of remarrying, because of the high risk of passing HIV on to her child. But she faced another dilemma: whether to conceal her HIV-positive status, or to disclose it to others – and if so, to whom? In the meantime she had joined the local branch of NACWOLA, where she discussed the pros and cons of disclosure with other HIV-positive women. She also joined the NACWOLA drama group, which was performing songs and plays about HIV/AIDS at public meetings.

Rebecca made her first public declaration of her HIV-positive status in 1995, in a church in a suburb of Kampala:

“I told the people that, although I am young, I have the HIV virus. People responded in various ways. Some cried, others just stared back at me. Many were sympathetic. But nobody said anything bad or negative to me.”

As Rebecca became more and more involved in testifying in public about her HIV-status, she realised that she would have to tell the members of her family:

“I decided I would have to tell my mother. It was hard, but I had to tell her, in case she heard from other people first. When I told her she was upset, but she tried to comfort me. She said that many other families were affected by the same disease, so I shouldn’t worry about it.

“The news got out to other people in the neighbourhood, and they also responded in a positive way. In fact more people started coming to my hair salon because they wanted to support me financially.”

Rebecca’s mother-in-law is also very supportive, for example, by making sure she receives a share of the income received from renting out the house which she and her husband owned. Her father-in-law, however, is neither sympathetic nor helpful towards her.

Still only 24 and attractive in appearance, Rebecca has a hard time fending off the young men who come courting her:

“I turn down their offers and tell them that I am HIV-positive. By being open about my HIV status, and by abstaining from sex, I try not to infect others. But I also advise others to use condoms, and partners to be faithful.”

Losing her husband to AIDS has also meant that Rebecca has acquired new skills, responsibilities and decision-making power:

“As a woman, if my husband were alive, he would do most of the planning and decision-making in the family. But as there is no man, I make all the important decisions.”

She has informed her son about her HIV-positive status:

“My son knows that I am HIV-positive but he never talks about HIV or AIDS. He is a quiet boy and his feelings are not easy to analyse.”

**Apofta Naikoba: Nurse and NACWOLA member**

Working as a nurse and an HIV/AIDS counsellor at Iganga District Hospital, Apofia is thoroughly familiar with the symptoms of AIDS. When her own husband died in December 1993, after many months of ill health, her grief was compounded by anxiety about the probable cause of his death:

“The neighbours were whispering that he had died of AIDS. In fact I suspected that he had secretly taken an HIV test, and that he was positive. But we had never talked about it. Finally I decided that I had to be tested for HIV. I was counselled by a colleague and in December 1994 I took the test, which turned out positive.

“First I told the hospital administration, who are my employers, about my HIV-positive status. They responded with a lot of understanding. I was put on light duties. For example, I don’t do night shifts, and I don’t do work that would bring me into contact with a lot of blood. I’m in charge
of the family planning unit, and I am also an IDAAC volunteer (see Chapter 6).

“Then I told my sister, but it took some time to tell other people. Then in July 1997 I attended a leadership training course run by NACWOLA in Kampala, where we went through many activities involving positive living. Some of my colleagues were open about their HIV-positive status. They were nice looking, they were comfortable about being open. So I thought ‘Why not me? After all, I’m a medical personnel. Why don’t I also come out and do that thing?’

“When I came back to Iganga I met with my fellow counsellors in the hospital, and asked them if I could testify to my fellow clients. They said yes, so on the next IDAAC clinic day I picked up courage and stood in front of the clients – there must have been over 50 – and I said ‘My friends, look, I am just like you. I am positive’. They were very touched to learn that I was one of them.

“I also told my mother, and my three oldest children. The first-born is 26 – she’s a teacher – and the next two are boys aged 20 and 18 years old. My daughter had seen how her father died so she wasn’t taken unawares. Also, some of the neighbours had said harsh things about AIDS to the children when their father died. During the last school holidays I also told my 12 year-old daughter about my HIV status, because I didn’t want her to hear about it first from someone else. At first she was worried that people would mistreat me if I talked openly about being HIV-positive, but I reassured her that this wouldn’t happen. I haven’t told the two youngest children yet – one is 10 and the other six years old – but I plan to talk with them about it when they are 12.

“I have no regrets at all about going open about having HIV. When you are open,
the stigma that was there before somehow disappears and you no longer feel that you are living in a cocoon. You feel comfortable, because nobody can talk about you behind your back any more about you having AIDS. You’ve already been open about it, so there’s nothing for them to spread rumours about. You just accept that that’s how the world is, and you cope with the situation.

“Being open about having HIV also helps to stop people talking about you being bewitched. When I die, I want my relatives and my children to know what I have died of, and not to think that someone else has bewitched me. Being open also helps you to control your own sexual behaviour. When men come and try to start a love affair with me, I just say ‘My friend, I am HIV-positive, and if I want to live longer I have to avoid playing sex’. So I have been abstaining ever since my husband died in 1993. The men always say that I am telling them lies to put them off, but I know my status and I know what I have to do to live longer.

“I am so busy that I don’t have time for another relationship, or even for a hobby. I have my job as a nurse in the District Hospital. I’m the Information Officer on the Village Council. I am a Vice Chairperson of NACWOLA at national level, and coordinator of four Districts including Iganga. We often put on drama performances or do personal testimonies on occasions like World AIDS Day, Independence Day, Nurses Day, and also at churches on Sundays. As an IDAAC volunteer, I sometimes do home-visiting of clients. So when I get back home at night I’m very tired. Maybe you could say my hobby is Bible reading. I pray twice a day and whenever I have time I do read the Bible.

“The Ugandan Government has helped people with HIV a lot by giving job security, and by not having pre-employment testing, at least in public service jobs. This has enabled more people to be open about their HIV-positive status. If you’re open about having HIV, you can also get proper treatment for your opportunistic infections, because the doctor will understand your condition. But if you stay isolated in your cocoon, the doctor won’t be able to prescribe the most appropriate drugs for you, as a person living with HIV or AIDS.

“People have to realise that having HIV or AIDS is not a disgrace. It’s a disease like other diseases. If you come out and declare that you are positive, the stigma will automatically go away and you will fit into the community more freely.”
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