

## Chapter 8

### Religious leaders: open to God

Religion is inextricably woven into every aspect of life in Uganda. For most Ugandans, religious beliefs play a major role in their sense of personal identity, their thought patterns, their moral judgements and their perceptions of disease.

Religious leaders in Uganda are highly respected. Through the spoken, broadcast and printed word, through religious symbols, ceremonies and traditions, and often as providers of health care and advice, they are in a unique position of influence and authority. Religious leaders can therefore play a pivotal role in determining how individuals, families and whole communities respond to the unique challenges posed by the HIV epidemic.

Catholic, Protestant and Muslim hospitals and health centres have played a leading role in providing medical care,

counselling and social support to people with HIV/AIDS in Uganda. However, many religious leaders have also added to the misery of people living with HIV by condemning them as 'wrong-doers' or 'sinners', thus contributing to the stigma to which they were already subjected from other sections of society.

Yet facing up to the reality of HIV is not simply a matter of condemning sin, but of being open and honest to oneself, to one's community and to God. Many religious leaders in Uganda now realise that stigmatising people with HIV is not only unjust but counter-productive. Moreover, growing numbers of priests, ministers, imams and other religious leaders are taking a more open, non-judgemental approach to HIV prevention, including the use of condoms. This is



**The Rev. Gideon Byamugisha (centre), who publicly declared his HIV-positive status in 1995, has received the support of his church in living with HIV.**

helping to create greater mutual understanding and trust between religious leaders and people living with HIV/AIDS.

### Rev. Gideon Byamugisha

The Reverend Gideon Byamugisha was ordained a priest in the Church of Uganda in 1992. Three years later he became the first practising priest in Africa to declare publicly that he was living with HIV. He is Director of the HIV Prevention and AIDS Care Project in the Diocese of Namirembe, Kampala. He also works as an AIDS educator and campaigner on behalf of people living with HIV, both within Uganda and internationally.

“My wife died after only a short illness in 1991. We had been preparing to go abroad for further studies – she for a Bachelor degree, me for my Masters. After her death I decided to stay in Uganda with our daughter, who was only a baby at the time. So I stayed here, asking God so many questions. About a month after my wife’s death something happened. My wife’s elder sister came to see me, and gave me some information which had a profound effect on my life. She told me that she had arranged for my wife’s blood to be tested for HIV, and the result was positive. I felt devastated – we both did. We wept and held each other, and prayed to God for strength.

“I then went and was tested for HIV, and the result was positive. I felt that the future had just collapsed in my face. I told my sister-in-law and the principal of the training college where I was teaching at the time. Next I told my brother, and then my close friends. They gave me a lot of support, but they were not sure it was time for me to go public. However, I did tell the people I was going to be training for HIV/AIDS work in the Church.

“For four full years I stayed without a woman. But that couldn’t last indefinitely. I would go to a workshop, and people would ask where I came from and if I had a family, and I would have to say that unfortunately my wife had passed away.

So at the end of the workshop young ladies would come to talk with me and ask why I was not married. Believe me, when you are living alone, you lack a companion, you are feeling depressed, and a girl comes and shows sympathy with you, it’s difficult to say for sure that you’re always going to be able to resist temptation.

“So in 1995 I made a decision to re-marry. My second wife was only 21 at the time, and she had recently lost her husband. Before getting married we talked a lot about whether she should be tested for HIV. She decided to have the test, and it was positive. We also discussed having children. In Africa everyone, especially women, wants to have children. I wanted to marry someone whose husband had died, and who wasn’t yet thinking about having children of her own. My wife and I agreed to use safer sexual methods, but of course we could not tell our relatives that we weren’t planning to have children. We just said we were postponing.

“We have always used condoms in our marriage. I even buy condoms in the shops. Sometimes people who see me say ‘Hey, here’s a reverend buying condoms!’ But I just say ‘Don’t get excited. I’m a person living with HIV. I’m married, and that’s why I need to buy condoms.’ Sometimes we don’t feel like putting them on, but we encourage each other to keep using them. You see, lawful sex and safe sex are not the same thing. But we believe our sexual acts should be not only lawful but safe.

“Being open about HIV can be contagious. Sometimes I appear in the newspapers or on television, and people at my wife’s workplace say ‘Hey, your husband is in the news again’. They expect her to react, but she just says ‘I know. When they were interviewing him I was there. We do these things together.’ And my wife can use that situation as a good starting point for a discussion about AIDS.”

Coping with stigma: “But it isn’t always easy to be open. I remember how I

once received a letter from my daughter, who was at boarding school. She was only eight at the time. Some other children had been taunting her, saying ‘Your father has AIDS’ and so on. So I drove to the school and I sat down with her and we talked about it. I said ‘This is a problem, but how sure are you that the fathers of these children don’t have AIDS? So next time they say your Dad has AIDS, you just ask them ‘Are you sure your Dad is safe?’ So she did that, and it worked. Since that time, she says, everybody is minding their own business.

“Stigma towards people with HIV is still a problem in Uganda, but it exists on two

levels. There is stigma that we imagine people feel towards us, but in reality might not exist. And there is real stigma, which means that people harass you because you are open about your HIV-positive status. I honestly haven’t experienced much of the second kind of stigma.

“Of course people still say hurtful things, like ‘Oh, you are a priest with AIDS, and you are still preaching? Why are you still wearing church robes and conducting Holy Communion?’ Or they ask ‘Reverend, you have said that you are HIV-positive, but have you repented?’ Once I went to Rwanda, where I was not allowed

## HIV/AIDS work in Namirembe Diocese

In Namirembe Diocese\*, Kampala, the Church of Uganda runs an integrated health programme consisting of the following components:

- **Reproductive health**
- **Hygiene and sanitation**
- **Nutrition and immunisation**
- **HIV prevention and AIDS care.**

The programme is based on local church structures and works through a series of clubs in four different age groups:

- **Sunday schools and primary schools**, using a Child-to-Child approach
- **Young people**, using a Youth-to-Youth approach
- **A post-test club**, consisting of people – mostly aged in their 20s and 30s – who have been tested for HIV, some of whom have tested positive and others negative
- **Parents**, through a positive parenting programme, which helps spouses improve their relationship skills with each other, and also to develop better communication with their children.

All the groups carry out prevention work as well as care and support activities. The post-test club, for example, presents HIV prevention messages through music and drama, and also visits people who are chronically ill with HIV/AIDS to provide emotional, spiritual and practical support.

In September 1999, Namirembe Diocese started a series of fortnightly prayer services for volunteers, supporters, service providers and other staff involved in HIV/AIDS and reproductive health programmes. These are held in St Paul’s Cathedral, and are addressed by prominent Church leaders and representatives of the Government of Uganda and international agencies.

\* In Kampala the Church of Uganda is divided administratively into two dioceses – Namirembe and Kampala.

to address a Christian rally because of my HIV-positive status. In many people's minds, HIV/AIDS still seems to be associated with sin. But recently I went to Rwanda again and this time, thank God, they had changed their mind and they allowed me to minister to the people about living with HIV as a Christian.

"Some people come up to me and ask me why I don't pray to God for miracle healing. I always reply that as far as I'm concerned, just being alive is a miracle. When you study the Bible, you find situations where difficult situations were turned into opportunities. Paul, for example, never waited for God to release him from prison so he could preach the Gospel. He used the circumstances he was in to spread the Word of God."

On being open: "I believe that being open about HIV can be a very positive thing for everyone. If you're not open, first of all you are afraid of going for an HIV test, even though you might have good reason to suspect that you are infected. And if you have the test and it is positive, you might not tell anyone, so you miss getting the support and the services that could help you live longer. Many people are still doing that, unfortunately.

"Take the example of a husband who tests positive but doesn't tell his wife and family. The wife realises there is a change – he seems depressed, irritable, or he is absent-minded or daydreaming. The children also notice that their Dad is behaving strangely, and they are confused. The man needs emotional support from his family but they can't offer it because they don't know what his problem is. So he is torturing his family and also himself.

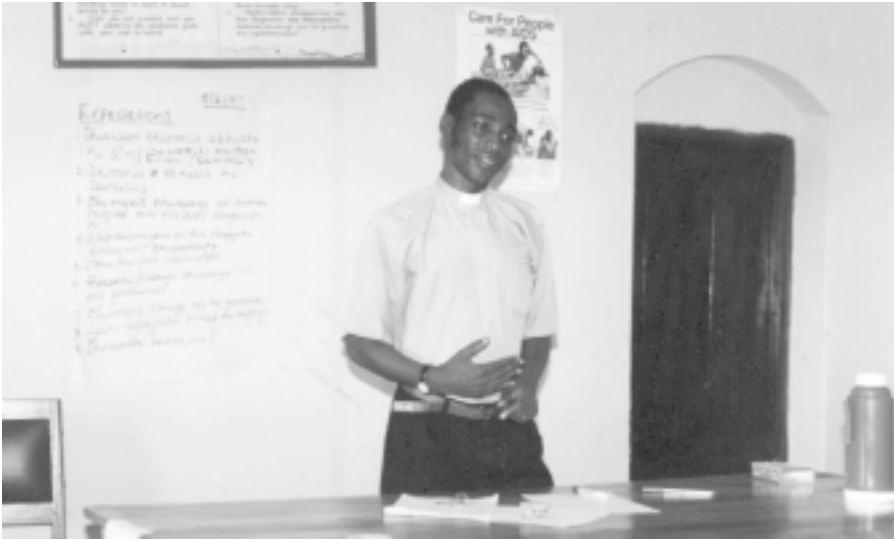
"Then there is transmission of the virus. If you aren't open about being infected with HIV, you risk passing it on to other people. If you are HIV-positive and you fail to tell your wife, maybe that night you have sex and infect her. Or if your partner dies and you remarry without telling your new

partner that you are positive, you are likely to infect that person and kill him or her.

"So many people accept that AIDS is 'out there', but they don't go beyond that and do anything about changing their own behaviour. You see, to be really open about AIDS, you have to acknowledge that it could affect you personally, that you could be at risk, and many people still find that very difficult. I have seen this in the youth. A young man could have some reason to believe that he is infected with HIV, but instead of being tested he says 'I'm already dead' and carries on with his risky behaviour. I also see it with older men. When I speak to a Fathers' Union group I ask them if they've ever tested for HIV and they say 'Ah no, we fear that!' I ask if they are using condoms and they say 'No, they can fall off so easily'. So then I ask them 'If you're not being tested, you're not using condoms, and you are still having sexual relations, how are you helping to defeat AIDS in Uganda?'

"To be open about AIDS is not just a matter of saying 'Yes, I know AIDS exists'. You also have to act upon that knowledge, as an individual and as a member of your community. I've learned that people, in their heart of hearts, know that openness is one of the keys to defeating AIDS, and they appreciate those who come out and admit that they have HIV. But people also know that those who are not open are likely to be spreading the virus. So communities sometimes stigmatise and harass people who they believe are not being open about their HIV status. They don't say 'Write it on your back', but just share it with a few people in your community, those who really matter to you.

"There must be other priests in Uganda who are HIV-positive, but they have not yet come out in public, and very few have talked with me in private. They must be lonely, suffering quietly, lacking counselling and treatment. If more of us did come out in public about our HIV status, it would have a greater impact. We



**The Rev. Gideon Byamugisha: trying to bring together religious leaders and people living with HIV/AIDS.**

would be better able to influence official policies and public attitudes towards becoming more caring and supportive.

“My own experience of coming out openly has mostly been very positive. When I joined Namirembe Diocese I told my Bishop, the Rt. Rev. Samuel Ssekakade, about my HIV status. He and his wife were incredibly supportive and understanding, and even offered us the use of the house where we now live. He said ‘Gideon, don’t worry. I’m going to pray for you. And you have a special mission here.’ So I left my teaching job at the theological college and came to Namirembe Diocese to strengthen the AIDS programme here. All the support, the care and the acceptance that Pamela and I have received here from the bishop, his wife, the clergy and the Christians of this diocese has helped us to live positively and to dedicate our lives to the fight against HIV.”

A national alliance: “One of the things we are trying to do is to promote

interaction and openness between religious persons and institutions on the one hand, and people living with HIV on the other. The one big hurdle we have to overcome is the negative attitudes of each group towards the other. People with HIV say that religious leaders are not being supportive, that they label them as sinners and fornicators who are responsible for other people’s suffering. Religious leaders, on the other hand, often say that people with HIV or AIDS are not being cooperative, that they are immoral and they go around spreading the disease.

“We are trying to bring these two groups together, so they can open themselves up to each other, find out where the negative perceptions are coming from and why, and see if they can do something about it. Once each group understands the fears, the concerns and the dilemmas of the other, they can start to build a good working relationship. We organised the first dialogue of this kind in July this year, and to everyone’s surprise, the participants

asked for more such workshops. We are now setting up a national alliance to promote cooperation between religious organisations involved in HIV/AIDS work, other AIDS care organisations, and people living with HIV/AIDS in Uganda.

“One of the big issues we want to explore further is that of care for people with HIV/AIDS. Care is often portrayed simply as a burden on communities. Even some religious leaders, and some health professionals too, have said that care for people with HIV/AIDS is a waste of resources because these people are going to die anyway. But we strongly believe that care is a very important component of prevention. When people show that they appreciate you, that they trust you and they value your contribution to society, you also feel a responsibility to protect others from HIV infection.

“Better care, treatment and support will encourage more people to come for HIV counselling and testing, and if they are HIV-positive, to be open about their status. As things now stand, many people with HIV feel that the disadvantages of being tested and going public outweigh the advantages. They risk facing stigma and rejection, but with no tangible benefits. If there were some clear benefit, like access to better medical treatment, many more people with HIV would be willing to come out.”

Beyond the individual: “In Uganda we have had some successes in controlling HIV infection, especially in urban areas, but we still face tremendous challenges. I think openness is still lacking – on the individual level, the family level, the community level, and also at national level. If you look at our AIDS programmes, you will see that they target the individual: ‘Be faithful, abstain from sex, and so on’. We assume that the individual has the power and the resources needed to do whatever we are telling him or her to do. But that, to me, is a very defective approach. Because my behaviour as an individual

depends very much on the interactions between me and my environment.

“Here in Uganda – perhaps in Africa in general – society says that we won’t recognise you as a man until you are married and have had children. But AIDS educators tell us that the best way to avoid AIDS is to abstain from sex, which means you can’t get married, or if you have sex to use condoms, which means you can’t have children. Or look at the issue of HIV testing. An individual can say ‘Let me go and test’, but where can he be tested? It might involve a whole day’s travel, and another day to get the result, and of course the cost of the test and the travel.

“So when we are designing programmes, we need to target not just the individual but also the wider community. We need to create a social and economic environment where safer sexual behaviour is accepted as part of the new ethical demands for the AIDS era, and where the individual, the community and the government all play their parts. This will require greater mutual respect among religious leaders, community leaders and politicians – everyone in a position of power.

“It will also require a greater willingness on the part of everyone to listen to others. Many people are so convinced that they are right on issues like sexual behaviour that they are unwilling to re-examine their views, even in the light of the new situation created by HIV/AIDS. For example, here in Uganda 60% of all HIV infections occur among the youth, but there are very few fora where young people can give adults their views on why this is the case.

“But there are some hopeful signs of change. We see some very influential religious leaders who are willing to re-examine some of their positions. Many religious leaders are beginning to recognise, for example, that not all sex within marriage is safe sex. That has helped to create a new theology which says that, although condoms must never replace morality, in the present AIDS situation

morality demands that we don't disregard condoms. And I know some bishops who are now saying 'Yes, I think condoms within the marriage context could be accepted'.

"Similarly, many religious leaders have come to accept that 'unlawful' sex – that is, sex outside marriage – is not necessarily unsafe sex. They insist on the Christian virtues of abstinence before marriage and faithfulness within marriage. But they also teach that if one does not abide by these Christian ideals, one is still under an obligation to protect one's partners from HIV infection. There is a growing feeling among religious leaders that even in a sinful relationship, condom use can help to prevent the even greater evil of HIV transmission leading to the premature deaths of parents, many of whom leave behind orphans who have to struggle for survival without parental guidance and support.

"Another area which religious leaders are thinking about is the theology of AIDS as a punishment from God. Many new

positions are being explored to create a new thinking about AIDS as a disease like any other, like malaria or TB, affecting human-kind. So I am happy that many people are not just defending their positions, but are also finding creative ways of responding to the new situation brought about by AIDS."

### Sheik Yazid

Sheik Yazid Uthman Ngobi is a 30 year-old imam living in the town of Iganga, where he is attached to the Masjid Makkah mosque. He also teaches Islamic studies in two local schools. In 1997 he attended an AIDS seminar organised by the Islamic Medical Association of Uganda (see box opposite) for Muslim leaders in Iganga District:

"We learned about what to tell people so they can protect their lives. We talked about abstinence, condom use, zero grazing (staying with one sexual partner), or paddock grazing for those Muslims with



**Sheik Yazid (left) encourages people to talk more openly about HIV and AIDS.**

## AIDS education through Imams

The Islamic Medical Association of Uganda (IMAU) has taken the lead in educating Muslim religious leaders about HIV/AIDS, and in mobilising their support in response to the HIV epidemic.

Between 1992 and 1997, IMAU implemented the 'Family AIDS Education and Prevention through Imams' (FAEPTI) project, which covered 11 of Uganda's 45 Districts. In each District, five-day training workshops were organised for imams, their assistants, and volunteers known as Family AIDS Workers. Imams from 850 mosques in the 11 Districts participated in the workshops, and 6,800 community volunteers (half of whom were women) were trained.

Workshop participants studied topics such as basic facts about HIV/AIDS, STDs, behaviour change, safer sex, and principles of communication and counselling. In the first year, after objections from Islamic leaders, the topic of condoms was omitted from the workshop curriculum. After further dialogue, the Islamic leaders agreed that education about the responsible

use of condoms, within Islamic teachings, was acceptable, and the topic of condoms was re-instated.

A follow-up survey found that there were significant increases in knowledge about HIV/AIDS in the project areas. Community members in the project areas also reported fewer sexual partners and increased condom use.

In the national capital, Kampala, IMAU took a different approach. Here, the project trained not only religious leaders from local mosques, but also members of Christian churches and of local government Councils. The project also developed an AIDS education programme for youth at Muslim schools. The Madrasa AIDS Education and Prevention Project started in 1995 with 350 schools in the Districts of Mpigi and Kamuli.

These three programmes were funded by USAID, UNDP and UNICEF. In 1998 they were featured in a case study booklet entitled *AIDS education through Imams: a spiritually motivated effort in Uganda*, published by UNAIDS in its Best Practice Collection.

more than one wife, and treating STDs early so as to reduce the chances of getting AIDS.

"AIDS has become a big problem here. For a while it was just a rumour that we heard from areas like Masaka and Rakai. But after 1990 people around here started dying and we realised that the disease had reached us. At first people were ignorant about the disease. They would avoid AIDS patients because they were afraid of getting infected just by touching them. And people who thought they couldn't get infected used to laugh at those with AIDS. Some people were saying this new disease was a

form of witchcraft. Patients were scared and avoided appearing in public, where people would gossip about them.

"Things have changed since then because people have learned that anyone can be infected. They now look after AIDS patients until they die. But people with AIDS don't usually talk in public about having it.

"AIDS has brought death in many families, and has resulted in there being many orphans. I know many orphans and I feel very sad because they are deprived of the love and care of their parents. AIDS has really affected me as a person, because

many of my brothers, and my friends and relatives are dead or are dying from this disease. As an imam, I am emotionally affected when I see anyone with HIV. The Koran prohibits promiscuity, but it also commands us to look after the sick, and that includes people with AIDS.

"I preach to my flock about the AIDS problem, and advise them against promiscuity. Some Muslims don't support the use of condoms, but as for me, I preach to the people that if they cannot abstain from having sex they should use condoms to protect themselves from AIDS.

Sheik Yazid says that his preaching is starting to bear fruit:

"Many of the young men were sexually active and many had more than one sexual partner. Now, some of them are abstaining while others are settling down to one sexual partner. A good number have also started using condoms, which they get from the District Hospital in Iganga and from the shops."

The young women are also changing:

"The girls here used to be very loose and have sexual relations with several men, especially the trailer drivers, who have money, but after I started preaching many have now realised the dangers of this and have stopped."

Sheik Yazid's preaching has also had an impact on marriages: "I used to wed couples who were very young. You could find a bride of 15, 16 years getting married, moreover with the consent of her parents. The parents and the girls themselves have now realised that these young girls are very vulnerable and often suffer so these days many of the people I wed are older; most of the girls are above 18 and recently I even wed a girl of 26."

"We have also changed the way we carry out circumcision. In the past about ten boys would be circumcised with the same razor blade, but now we do it in a clinic using a different razor for each one.

"Some people still don't like to talk about AIDS, and try to keep it secret. But others are starting to talk about it openly, especially in their own homes. There was a woman here who left her husband for another man but later she came back to him. But she suspected that she had got AIDS while she was away, so she and her husband agreed not to sleep together. She just stays with him and looks after their children. People are also talking more in public about the need to change their behaviour and to use condoms to be safe from AIDS. In the past people didn't do that.

"Some people are also going for the HIV test to know their status before they go for marriage. At the mosque here, I only wed those who can bring some proof that they have tested for HIV. If they can't prove that they've been tested, I don't wed them. But if they are both positive and know it, or if only one of them is positive, I first preach to them about AIDS and condoms. Then if they feel they still want to go on with it, I wed them.

"Many people come to me, seeking help with their problems. I welcome them, talk with them and comfort them. Some people ask me for money to buy drugs, but I don't have any money to give them. For treatment or testing I advise them to go to the AIDS clinic at the hospital.

"As for me, I'm still not married because I am searching for a partner to whom I can trust my own life. But I will only get married after going for an HIV test with my partner."