



Positive Voices

Religious leaders living with or personally affected by HIV and AIDS

Edited by Gideon Byamugisha and Glen Williams



The **CALLED TO CARE** toolkit consists of practical, action-oriented booklets and mini-manuals on issues related to HIV/AIDS, designed for use by church leaders, especially in sub-Saharan Africa. The purpose of the materials is to enable pastors, priests, religious sisters and brothers, lay church leaders and their congregations and communities to:



- ❑ Reflect on and understand the spiritual, theological, ethical, health, social and practical implications of the HIV epidemic and the Christian call to respond with compassion.
- ❑ Overcome the stigma, silence, discrimination, denial, fear and inertia that inhibit church and community action to address HIV/AIDS-related issues more effectively.
- ❑ Guide their congregations and communities through a process of learning and change, leading to practical, church-based actions to help individuals, families and communities reduce the spread of HIV and mitigate the impact of the HIV epidemic.

CALLED TO CARE is an initiative of the Strategies for Hope Trust, which produces books and videos that promote effective, community-based strategies of HIV/AIDS care, support and prevention in the developing world, especially in sub-Saharan Africa.

CALLED TO CARE is implemented through a process of international, ecumenical cooperation involving churches, other faith-based organisations, international church bodies, publishers, distributors and other partners.

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Canon Gideon Byamugisha
Chairperson, ANERELA+

Glen Williams
Series Editor, Strategies for Hope

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANERELA+	African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
ARV	Antiretroviral
HIV	Human Immunodeficiency Virus
ICASA	International Conference on AIDS and STIs in Africa
KENERELA+	Kenyan Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
PHA	Person Living with HIV/AIDS
UNERELA	Uganda Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
VCT	Voluntary Counselling and Testing

Preface

About the CALLED TO CARE toolkit

Amidst all the pain and suffering caused by HIV and AIDS, many people find it difficult to discern the face of a loving God. Yet there is a strong Christian tradition that we come truly to know God, not through intellectual effort, but by showing love towards others.

The First Letter of John says: 'Dear friends, let us love one another because love comes from God. Whoever loves is a child of God and knows God.' (1 John 4:7) John's letter continues: 'If someone says he loves God but hates his brother, he is a liar. For he cannot love God, whom he has not seen, if he does not love his brother, whom he has seen. The command that Christ has given us is this: whoever loves God must love his brother also.' (1 John 4:20-21)

Putting this principle into practice, however, is not necessarily simple or easy. On the contrary, it can be extremely difficult to show love towards people whose beliefs, values, behaviour and living standards are markedly different from our own. Yet these differences do not make them any less part of the human family, created in the image of God. And if we do dare to take the risk of showing our love to others, our own knowledge of God's love grows.

Jesus said: 'Love your neighbour as yourself.' In many countries throughout the world, churches and individual Christians are responding to Christ's call by undertaking activities to address the massive challenges of HIV and AIDS within their communities. In sub-Saharan Africa, churches have often been in the forefront of efforts to mitigate the impact of HIV and AIDS. They are demonstrating, in many practical ways, that they feel 'called to care' for those who are infected or affected by the HIV epidemic. They have, for example, pioneered ways of

making basic health care available to people living with HIV, and of providing children orphaned by AIDS with education, social support and health care.

Churches have generally been much less effective, however, in addressing problems such as HIV prevention and HIV-related stigma, shame, discrimination, and cultural and gender issues associated with high-risk sexual behaviour. Denial of the reality of HIV and AIDS within church communities is also widespread. Moreover, although sex is the main means of HIV transmission in most countries, it is rarely discussed in church circles in an open, non-judgemental way.

Yet is this particularly surprising? Most of us find it difficult to talk about issues related to sex, gender and death. While our fears and inhibitions prevent us from addressing - or even mentioning - these sensitive topics, our societies are burdened by problems that have their roots in matters related to sexual health and gender imbalances: sexually transmitted infections, unwanted pregnancies, infertility, domestic violence, sexual abuse and HIV/AIDS. We urgently need to 'break the silence', not only about HIV/AIDS, but also about sex, sexual behaviour, and the unequal relationships between men and women. This applies especially to churches and other faith communities, which often - albeit unintentionally - reinforce HIV/AIDS-related stigma, denial and discrimination.

In fact, churches - especially in sub-Saharan Africa - have enormous potential for empowering individuals and communities with the knowledge, attitudes, skills and strategies they need to deal with issues related to sex, gender and HIV/AIDS. Their institutional infrastructure - extending from the village up to national level - is more extensive than



that of any government department. They have buildings where people can meet; administrative and technical staff; and contacts with community and political leaders, government officials, business people, NGOs and other faith groups. They have their own publications, as well as radio and television programmes. They operate hospitals, clinics, schools and other training and educational institutions which provide information and services to many millions of people. They have pastors, priests, religious sisters and brothers and other leaders trained to provide pastoral care, social support and information to families and communities.

Churches also have long-standing rituals - for example, for birth, marriage, death and sickness - which can provide entry points for new knowledge and skills. Their members are organised into networks of clubs, associations and movements - with their own structures, rules and regulations, office-bearers and activities - for particular sections of the population: children, youth, students, women and men. Moreover, all these social and material assets are already in place, and they are sustainable in the long term. As a whole, churches therefore constitute a huge - but greatly under-utilised - resource for community-based responses to the challenges of the HIV epidemic.

In recent years, growing numbers of church leaders have become aware of the need for a much more concerted effort to address the issues raised by the HIV epidemic in a broader, more comprehensive and open manner. In order to support this effort, the Strategies for Hope Trust is developing the *Called to Care* toolkit. This will consist of a set of practical, action-oriented booklets and mini-manuals on issues related to HIV/AIDS for church leaders (both ordained clergy and lay people), especially in sub-Saharan Africa. The *Called to Care* materials will be designed to enable pastors, priests, religious sisters

and brothers, lay church leaders, and their congregations and communities to:

- ❑ Reflect on and understand the spiritual, theological, ethical, health, social and practical implications of the HIV epidemic and the Christian call to respond with compassion.
- ❑ Overcome the stigma, silence, discrimination, denial, fear and inertia that inhibit church and community action to address HIV/AIDS-related issues more effectively.
- ❑ Guide their congregations and communities through a process of learning and change, leading to practical, church-based actions to help individuals, families and communities reduce the spread of HIV and mitigate the impact of the HIV epidemic.

The contents of the *Called to Care* toolkit will be 10 print materials of various shapes and sizes, for use with church groups and communities at different levels of awareness and experience in relation to the HIV epidemic.

The *Called to Care* project is being implemented through a process of international, ecumenical collaboration between churches, other faith-based organisations, international church organisations and networks, publishers, distributors and other partners. We invite you to participate in *Called to Care*, not only by using the contents of the toolkit in your congregation or community, but also by writing to us about your experiences, which we would be pleased to post on the Strategies for Hope website: www.stratshope.org.

Yours in faith and solidarity,

Glen Williams
Series Editor
Strategies for Hope Trust



About ANERELA+

The African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (ANERELA+) is a continental network of African religious leaders from different faith backgrounds. ANERELA+ was launched officially in October 2003 in Kampala, Uganda, during the 11th International Conference of the Global Network of People Living with HIV/AIDS. The members of ANERELA+ are

committed to working on an interfaith basis. ANERELA+'s participation in this publication – which features testimonies by 12 Christians and two Muslims – in no way changes that focus. Rather, it reflects the fact that a large part of ANERELA+'s current constituency is Christian. As such, most of the stories told here will be of particular relevance to churches, but they can be adapted for use in other faith contexts.

About World Vision International's HIV/AIDS HOPE Initiative

The Hope Initiative is World Vision's response to the global HIV/AIDS epidemic. Launched in 2001, the Hope Initiative aims to reduce the global impact of HIV/AIDS through a three-track approach of prevention, care and advocacy. The Hope Initiative recognises faith-based organisations as major partners in addressing all aspects of the HIV/AIDS epidemic. A key strategy of the Hope Initiative is therefore the establishment of effective

partnerships with churches and other faith-based organisations. Religious leaders living with or personally affected by HIV and AIDS have the potential to play an important leadership role in the responses of their faith communities to the HIV/AIDS epidemic. Recognising this potential, the Hope Initiative is pleased to be a partner of ANERELA+ and of the Strategies for Hope Trust in this important publication.



Foreword

by the Reverend Canon Gideon Byamugisha

Millions of people throughout the world continue to become infected with HIV and to die of AIDS. Some regions of the world are much more affected than others. Sub-Saharan Africa still accounts for the great majority of new HIV infections, AIDS deaths and children orphaned by AIDS. However, new infections continue to multiply in Asia and Eastern Europe, while Latin America and the Caribbean are not spared either.

The good news is that rapidly rising numbers of new HIV infections and AIDS deaths are not inevitable. On the contrary, new HIV infections can be prevented and HIV/AIDS can be managed, so people living with the virus can not only live longer but can also enjoy a high quality of life. This is entirely possible, providing we can defeat the stigma, shame, denial and discrimination which still prevent meaningful, effective action against the HIV/AIDS epidemic.

At the moment, however, the impact of HIV is greatly exacerbated by the stigma, shame, denial and discrimination with which it is associated, and which heighten individual and collective vulnerability and worsen the impact of HIV infection. Fear of being identified as HIV-positive prevents people from even being tested for HIV, let alone disclosing their sero-status if they test positive. It impedes efforts to break the HIV transmission chain, and discourages people from seeking and utilising all available services for HIV/AIDS prevention, treatment, care and support.

In addition, the emotional pain of individuals, families, communities and nations who are living with HIV is heightened and exacerbated by the fear - and the reality - of rejection, blame, shame, incapacitation and death due to HIV/AIDS. This leads to individual and collective denial of the epidemic, and to inappropriate or inadequate policies, programmes and actions aimed at HIV/AIDS prevention, care, treatment and support at all levels. Ultimately, stigma, shame and blame reduce the life chances of individuals, families, communities, nations and continents through prejudicial attitudes, inaccurate moral judgements and discriminatory policies.

But when members of faith communities see their leaders talking about their own HIV-positive status, it will liberate them. Those living with HIV will cease to feel stigmatised themselves, and the wall of silence within our societies will quickly be breached. Overcoming stigma is just the first phase of a much larger programme - unleashing the full potential of churches and other faith communities in Africa to combat AIDS head-on.

Every story in this booklet vividly depicts the courage, hope and confidence needed to successfully address and defeat both 'self-stigma' and 'societal stigma'. Some of these stories will make you want to weep. Others will make you angry. Some may make you shake your head in disbelief. If these stories help to break the silence surrounding HIV and AIDS in your place of worship, residence, work or education; if they help you to talk, openly and honestly about the myths and misconceptions that still prevent your congregation, community or nation from appropriate and effective action; if they can help you to discuss more and to do better as a group, a congregation or a community; then the efforts of these people, who found the courage to speak out, will not have been in vain.

The Reverend Canon Gideon Byamugisha
Kampala, Uganda



Introduction

This section presents the following information:

WHAT this booklet is about.

WHO this booklet is for.

WHY this booklet was written.

HOW this booklet can be used.

WHAT?

This booklet brings together the experiences of 14 African religious leaders – 12 Christians and two Muslims – who are either living with HIV or are personally affected by HIV and AIDS. They include ordained religious leaders and lay people who have a leading role in their faith community. All attended an international Skills Building Conference for Religious Leaders Living with or Personally Affected by HIV and AIDS, held in Mukono, Uganda, in November 2004.¹ This was an interfaith meeting, organised by ANERELA+ and World Vision International.

Eleven of the people who tell us their stories in this booklet are themselves HIV-positive. The other three have been tested and found to be HIV-negative, but their lives have been profoundly affected by caring for a close relative, friend or colleague who has died of AIDS-related illnesses. In these stories, they describe how HIV has profoundly affected their lives, but also how their religious faith has enabled them to face up to the daunting challenges which the HIV epidemic has brought into their lives. Most of these challenges have their roots in the stigma, denial, discrimination and misinformation about HIV and AIDS which exist within faith communities themselves.

WHO?

This booklet was written primarily for a wide range of church leaders, including priests and pastors; religious sisters and brothers; lay church leaders; staff and students of Bible schools, theological colleges and other church training institutions; staff of church hospitals and health centres; leaders of church-based women's movements, men's fellowships and youth groups; faith-based NGOs; and national, regional, and international church organisations and networks.

It can also be adapted for use by other faith communities, and by non-religious organisations such as Anti-AIDS clubs in schools, colleges and universities; teacher training colleges; as well as NGOs and community groups involved in HIV/AIDS care, support, advocacy and prevention activities.

The booklet is designed so that it can be used without the facilitator having to undergo any special training.

Although all the religious leaders who tell their stories in this booklet are African, their experiences have a relevance which transcends geographical boundaries.

WHY?

This booklet has three main purposes:

First, to enable church groups and communities to discuss HIV and AIDS, health, sexual behaviour, and issues related to religion and culture more freely and openly than is usually the case.

Second, to demonstrate that being HIV-positive is not a cause for shame, despair, fatalism or discrimination.

¹ The Post-Bangkok Conference of Religious Leaders Living with or Personally Affected by HIV and AIDS, held in Mukono Uganda, on 1-7 November 2004, was organised by ANERELA+ and World Vision International. For a report on the conference, please contact ANERELA+, 25 St Ermins Street, Hurst Hill, Johannesburg, South Africa 2092.



Third, to help reduce HIV-related stigma within faith communities by demonstrating that religious leaders too contract HIV, but that they can also live positively and openly with the virus, serving God even more meaningfully and effectively than before.

HOW?

The contents of this booklet are a rich source of inspirational experiences which individual readers can use for personal information, or to refer to in presentations, articles, sermons, interviews or workshops.

However, we also suggest that the booklet can be used by groups of 10-20 people in the following way:

1. Organisation: Each session should last for 60-90 minutes, and should be led by one facilitator.

2. Preparation: The facilitator should select a story for discussion. If possible, photocopy the story, so that each person in the group has a copy.

3. Opening: Start the session with a prayer, asking for God's guidance during our discussions, and the grace to respect different opinions and points of view.

4. Terminology: Using a flipchart, board or large cards, display the following words:

- ♦ Stigma
- ♦ Shame
- ♦ Denial
- ♦ Discrimination
- ♦ Inaction
- ♦ Misaction.

Ask the group to say what they understand by each of these terms in relation to HIV/AIDS, and write these explanations down where everyone can see them, e.g. on a flipchart, board or large cards. Check whether these interpretations match the definitions suggest-

ed in the Appendix of this booklet. Ask what words are used to refer to these terms in the local language or languages, and write these words down where everyone can see them.

5. The story: Hand out photocopies of the story to the participants. Ask three or four people to read out the story aloud. If the participants do not have photocopies of the story, allow them to make notes while it is being read out. Pause to explain anything which might be unclear.

6. Scriptural reflection: Read the passage from the Bible (or the Qur'an) listed at the end of the testimony. What does this passage teach us about the issues raised in the testimony?

7. Discussion: Ask the group the following questions, and write the responses on a flipchart or board:

(a) What does this story reveal about stigma, shame, denial, discrimination, inaction and misaction in relation to HIV/AIDS?

(b) What pains, fears, struggles and anxieties are revealed in the story?

(c) What else strikes you as important about the story?

(d) How could your group or congregation take action on some of the issues raised by the story?

8. Conclusion: Summarise the responses to questions 7 (a) - (d), above, and ask who in the group would like either to:

- become involved in whatever activity was agreed upon after discussing question 7 (d), or
- meet again to discuss another story in the booklet. In the next session, briefly review Step 4 (Terminology) before starting.

9. Final prayer: Finish the session with a prayer of thanks for God's guidance.



Story 1:

Ayano Chule

The Reverend Ayano Chule, from Ethiopia, was trained as a Lutheran pastor and ordained by the Anglican Church in Nigeria. He is currently living in Abuja, Nigeria, where he works as the Regional Coordinator for ANERELA+ in West Africa.

“ I was born in the town of Konso, in southern Ethiopia. I went to school in Addis Ababa, and I was then trained as an electrician. I worked in that trade for several years, until I met a bishop of the Lutheran Church of Christ in Nigeria, who invited me to his country for training in theology. So between 1994-98 I studied for my degree in theology in Nigeria.

In 1998 I married a Nigerian woman and we went to Ethiopia, where I taught at Konso Bible School until December 2000, when my wife gave birth to a boy. At the age of 6 months he had boils that never went away. The doctor referred me to the book *Where There is no Doctor*, where I learned that persistent boils can be a sign of HIV infection. My son was tested for HIV and found to be positive. I was also tested and found to be HIV-positive, but I didn't tell my wife. I suggested we should go back to Nigeria, which we did in 2001, and I got a job in the Anglican Diocese of Jos. I was studying for my Masters in Biblical studies while also teaching theology there.

My wife got sick in October 2002. She was tested for HIV and found to be HIV-positive. Her health deteriorated rapidly and she was hospitalised. I encouraged her to believe that dying was nothing to be afraid of. It just

meant going to be with Christ. I remember the moment when she died, waving goodbye to me, because she was too weak to speak. Before she died she said she had never known anyone who cared for her like I did.

After my wife died my son needed hospital treatment too, but he died on 26 September 2004. I ran up medical bills for my wife's treatment and my son's as well. By the grace of God and with the love and support of the Anglican Diocese of Jos and other friends in Nigeria, those bills have all been paid.

Before my son died, I was invited to meet Canon Gideon Byamugisha at a conference for pastors in Jos. The organisers invited me because they knew my HIV-positive status. I challenged the members of the audience to say how many were HIV-positive, but none had even been tested for HIV so they didn't know. Afterwards, I learned that 25 pastors were tested for HIV. After the conference Gideon visited my home and invited me to Uganda, where I spent six months with different organisations involved in HIV and AIDS work, gaining skills and experience for my present work with ANERELA+ in West Africa.

If religious leaders are able to translate the problem of HIV into ways of serving people



and pleasing God, that will be true worship for every religion, because all religions encourage compassion for other human beings. We must transform HIV into an opportunity for productive ideas and the overcoming of ignorance. But first we must admit our ignorance and create room for caring, loving and supporting people living with HIV.

I have learned that HIV has given me a better opportunity to serve God. Theology, which is my field of study and interest, is about how to deal with what is happening on earth in relation to God. The earth doesn't exist on its own, but has an owner, God. The earth has different religious groups, all owing their existence to God. Human life is the greatest asset which God has.

The theological significance of HIV is not that it's a sign of rejection by God. Nor is it simply an evil to be dreaded, or a curse to be avoided. God provides a solution for every human problem. It's up to us, as religious leaders, to identify God's solution to HIV. If we don't, it's our own fault. We should be able to translate HIV into a better way of achieving God's purpose for human society.

This implies that, for God, there is nothing surprising about HIV. We theologians must transform it into things like compassion, non-discrimination and non-judgementalism in order to alleviate our sufferings. God is there to help us - God helps his subjects - but most Christian theologians don't yet think of HIV in terms of serving human beings in a better way."



Biblical reflection: 'The love of Christ'

Who, then, can separate us from the love of Christ? Can trouble do it, or hardship or persecution or hunger or poverty or danger or death? As the scripture says, 'For your sake we are in danger of death at all times; we are treated like sheep that are going to be slaughtered.' No, in all these things we have complete victory through him who loved us! For I am certain that nothing can separate us from his love: neither death nor life, neither angels nor other heavenly rulers or powers, neither the present nor the future, neither the world above nor the world below - there is nothing in all creation that will ever be able to separate us from the love of God which is ours through Christ Jesus our Lord. (Romans 8:35-39)



Story 2:

Elsa Ayugi Ouko

Elsa Ayugi Ouko is Executive Director of the Kenyan Network of Positive Teachers, and Secretary of the Mothers' Union in the Anglican Church of Kitale, Kenya.



I have been a widow for nine years. When my husband died I tested HIV-positive. First I told my children - not only about my own HIV-positive status, but also that my husband had died of HIV. My nine year-old son accepted it best. In fact he had already guessed that both his parents had HIV.

I also told my relatives but they wouldn't accept it, so I decided to go public, starting with the church. I told my pastor that I wanted to announce my HIV-positive status to the congregation, but he asked me not to. I kept quiet for a while, but it was very hard. I like sharing my experiences, and if I can't I get disturbed. Finally, I decided I had to speak up. So after a service one Sunday, when people were invited to introduce themselves or to say where they had been visiting, I stood up and told the congregation about my HIV-positive status. I just said: 'I would like to use this chance to tell you that I am HIV-positive.' Afterwards my pastor took me aside and I told him I had to tell the truth in order to live a positive life. I wanted to live. I wanted to educate my children. And the only way I could do that was to go public about my HIV-positive status.

The changes in my church since I went public have been tremendous. More HIV-positive people have gone public, and the church has an HIV Desk. I talk about HIV whenever I give sermons. In 1999, Handicap International helped us a lot by sponsoring a group of three HIV-positive women and men to travel to different churches and give testimonies. My church has also sponsored me to attend international conferences, like ICASA² in Nairobi in 2003, and they also support me in the group TIPHA (The Involvement of People Living with HIV/AIDS).

I am now a grandmother and all my children have left home, but they are proud of me. One daughter, whose husband is a doctor in the hospital at Nandi Hills, invited me to give a talk about living positively with HIV to the hospital staff. Another daughter invited me to speak at her secondary school.

But I still want my church to be more involved in the fight against AIDS, so that PHAs can be fully accepted by their church leaders and congregations. This will help PHAs to keep living. Without such changes, stigma and discrimination in the church against PHAs makes

² International Conference on AIDS and STIs in Africa.



most of us die of stress and depression. But if people are open it reduces the spread of HIV within the congregation. Like me, for example - no men approach me because they know my HIV-positive status.

I have never felt tempted to go with a man just to satisfy my sexual needs, because I don't feel such needs. When a loved one dies, you feel stressed and depressed, so you

don't feel like sex and it's easy to abstain. Also, I wanted to preserve my Christian values and the good name of our family. But you can't keep it up indefinitely. Now that I'm living on my own in a big house, I feel the need for companionship, which is a problem for me. Men of my age or older prefer to marry young women, not someone like me, in her late 40s. I want to talk with my pastor about this problem."



Biblical reflection: 'Believers doing things together'

Many miracles and wonders were being done through the apostles, and everyone was filled with awe. All the believers continued together in close fellowship and shared their belongings with one another. They would sell their property and possessions, and distribute the money among all, according to what each one needed. Day after day they met as a group in the Temple, and they had their meals together in their homes, eating with glad and humble hearts, praising God, and enjoying the good of all the people. And every day the Lord added to their group those who were being saved. (Acts 2:43-47)