HIV AIDS
Treatment Literacy Guide
for
Church Leaders

Church Leaders Bridging the Gap
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**WHAT A CHURCH LEADER NEEDS TO KNOW TO SUPPORT ANTIRETROVIRAL TREATMENT**

**What is known about HIV and AIDS and its terrain (knowledge)**
- Causes and prevention
- Treatment
- Care and support
- Responses to stigma and discrimination, etc.

_Everything to the glory of God_

**HIV and AIDS reality**
- Deaths
- Suffering
- Orphans
- Loss of dignity and hope
- Spiritual breakdown

_My people perish for lack of knowledge_

**Bridging the gap – Action by church leaders**
- Promote and uphold the basic rights of people living with HIV
- Advocate for comprehensive antiretroviral treatment and HIV care
- Counselling and spiritual support
- Awareness of social, theological and technical issues of HIV and AIDS
- Fight stigmatisation and discrimination in all areas
- Participate in antiretroviral treatment advocacy programmes
- Involve people living with HIV in programmes
- Networking
- Provide care and support
- Create opportunities for public interaction between church leaders and people living with HIV
- Encourage people to know their HIV status
- Support antiretroviral treatment literacy in the community
- Care for children and orphans

_I was hungry and you gave me food_

**Desired situation**
- Hope and protection of human dignity
- Church as the centre of love
- Drugs and treatment available for all
- Justice shown to the vulnerable and marginalised

_Imago dei – made in the image of God_
_(Church upholding human dignity)_

_YET_
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AACC</td>
<td>All Africa Conference of Churches</td>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ANC</td>
<td>Anti Natal Care</td>
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<td>ARV</td>
<td>Antiretroviral</td>
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<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>FBO</td>
<td>Faith Based Organisation</td>
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<td>GF</td>
<td>Global Fund</td>
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<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<td>IEC</td>
<td>Information Education and Communication</td>
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<tr>
<td>MTCT</td>
<td>Mother to Child Transmission</td>
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<td>OIs</td>
<td>Opportunistic Infections</td>
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<td>PEP</td>
<td>Post Exposure Prophylaxis</td>
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<td>PEPFAR</td>
<td>President’s Emergency Fund for AIDS Relief</td>
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<tr>
<td>PLHIV</td>
<td>People Living with HIV</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission of HIV</td>
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<td>STI</td>
<td>Sexual Transmitted Infections</td>
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<td>TL</td>
<td>Treatment Literacy</td>
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<tr>
<td>UN</td>
<td>United Nations</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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<td>WCC</td>
<td>World Council of Churches</td>
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<td>WHA</td>
<td>World Health Assembly</td>
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<td>WHO</td>
<td>World Health Organization</td>
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The Ecumenical Pharmaceutical Network (EPN), a former programme of the World Council of Churches (WCC) with membership in over 30 countries, is an independent, non-profit Christian organisation that works to support churches and church health systems provide and promote just and compassionate quality pharmaceutical services. In its HIV and AIDS programme, EPN seeks to maximise the strength inherent in churches and church-related health services to address HIV and AIDS treatment issues.

Through context-sensitive activities, which are informed by research, EPN conducts antiretroviral treatment literacy workshops specifically for church leaders. The workshops empower these strategically placed opinion leaders of society to assist those in need to access HIV treatment, care, and support. The treatment literacy work is undertaken with the conviction that the Church and its institutions can become centres of support for people living with HIV.
This guide was developed and tested through a series of workshops and meetings. EPN is grateful to all those who played different roles in ensuring that the guide is what we envisioned it to be. It is not possible to mention all who read and gave constructive comments on the different drafts of the guide but we sincerely thank you all.

The publication also includes information from various sources, including organisations, institutions, books, reports, presentations and speeches made by different people. We are grateful to all the contributors whose work is quoted in this guide. We would particularly like to acknowledge the work of Treatment Action Campaign (TAC) whose excellent materials and publications, especially on the diseases and the treatment issues, were very helpful.

Nonetheless a selected group deserves a mention for their special contribution:

Dr. Eva M. A Ombaka former coordinator of EPN (1992 - 2008) who spearheaded the process of developing this guide.

The technical working group which included Dr. Peter Okaalet, Rev. Simon Mureithi, Fr. Jonathan Kathenge, Dr. Stephen Watiti, Mr. Ephraim Kimotho, Ms. Jacinta Maingi and Mr. Jonathan Mwiindi, who gave critical input and invested valuable time and energy to review the various drafts.

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Last, but not least, to our partners in Germany, The Netherlands and Canada for financial support to EPN work in HIV and AIDS over the years. EPN reiterates its commitment to the prudent use of the resources entrusted to it by partners and supporters.

Finally, we are grateful to the almighty God for providing us with life, time and resources to write and compile this guide.

May God bless you all.
Sub-Saharan Africa has at least two thirds of the global population of adults and over 90% of the children living with HIV. In some countries in Africa, as many as one in every ten people is living with HIV. HIV is also the number one cause of mortality in Africa.

HIV impacts not just the individuals affected but also households, entire communities and countries at large. We are now witnessing many homes headed by children who need care themselves. We are recalling grandparents from retirement to give care to those affected and infected. Moreover women, who are often the backbone of families in Africa, are disproportionately affected by HIV due to, among others factors, gender inequalities and sexual violence.

Our Lord and Saviour Jesus Christ came that we all may have life and have it abundantly (John 10:10). It is therefore only logical that the ministers of the church take up the challenges that HIV presents to our generation by emulating Jesus Christ through the practice of true inclusive ministry: preaching the gospel and healing the sick.

While new infections appear to be on the decline there is no room for complacency. Church leaders are essential to changing attitudes, behaviour and practices that promote the negative trends of HIV and AIDS in Africa. Church leaders are opinion leaders in the majority of Christian communities. People are receptive to their leadership and this provides the opportunity for pastors and ministers to influence perceptions and encourage people to get tested and therefore have the possibility to access treatment. Still it must be noted that partnerships with other players as well as unity of purpose among church leadership is crucial if universal access to prevention, care and treatment is to be achieved. This guide seeks to provide church leaders with a tool to help them understand treatment issues, as well as their role in caring for those who are sick.

The focus of this guide is treatment literacy - i.e. providing knowledge and information to help the church leaders better understand HIV and AIDS treatment. HIV and AIDS treatment became widely available earlier in this decade largely due to global initiatives such as PEPFAR and the Global Fund. However, in many countries, there is still a huge disparity between the people who need to be treated and those actually on treatment. Although the resources available globally are insufficient to address all aspects of the pandemic fully, many do not seek or access treatment because of lack of information, fear, and lack of awareness about their status. Church leaders are strategically placed to reach out to people from all walks of life and help communities overcome silence, denial and fear. Indeed church leaders have a responsibility for the well being of their communities.
They can place themselves at the centre of the fight and they can provide the leadership that makes a difference in promoting health and saving lives. In spite of lapses in the past, the church can still be the place where believers feel comfortable to talk about their HIV status in the confidence that they will receive the support that they deserve.

One of the challenges that churches have to face as they address HIV and AIDS treatment is faith healing. The guide provides some insight into this matter. Nonetheless, theologians and the church leadership would do well to speak out boldly providing clear direction not just to congregations but also to fellow clergy so that the church can have a Christ-centred approach to faith healing that benefits all people.

The universal access campaign is aimed at providing universal access to treatment by 2010. However, without community mobilization, this goal will remain as elusive as some of other global targets have been in the past. In order to access treatment they must first know their status and in order for them to feel free to seek for testing, stigma and discrimination must be reduced and eventually eradicated!

Church leaders are key to making this happen. They can do so by becoming key players in influencing policy, as well as becoming more active as frontline advocates for affordable, available, safe and effective antiretroviral drugs - including those for children. What a great day it will be when we all- including church leaders - play our respective roles towards universal access to prevention, treatment and care and support!

Archbishop Desmond Tutu
Cape Town
31 July 2009
THE ORIGINS OF THIS GUIDE

At last, there is good news! Antiretroviral drugs (ARVs), a treatment for HIV, now means that HIV is no longer a death sentence. This means a change in thinking – HIV and AIDS issues and facts have changed, so we all need to retrain and rethink what we are doing in our churches.

Antiretroviral treatment still presents challenges to the Church. This guide focuses specifically on ARVs because they are a more recent development, and less has been written about them than other issues, such as understanding HIV and AIDS, and fighting stigma in churches. Of course, all these subjects overlap and where they do, this guide addresses the issues.

The World Health Organization and UNAIDS are leading the efforts for universal access to ARVs. Their goal is that eventually everyone in the world who needs ARVs will have access to them. Currently, however, access to antiretroviral treatment is lowest in Africa, where the prevalence of HIV is highest. It is also estimated that church health services provide at least 40% of health services in Africa.

A three-country study by EPN carried out between 2004 and 2005 in Burkina Faso, Kenya, and Rwanda found a widespread need for church leaders to increase their understanding of antiretroviral treatment and their role towards the fight against HIV. This guide has been developed to respond to this need.

The study showed that the commendable efforts of donors to increase physical access to ARVs and to focus on medicines and distribution had led to a focus on treatment literacy only for those receiving ARVs. This created a knowledge gap - those who are not currently receiving ARVs can also benefit from treatment literacy, to encourage people to come forward for HIV tests, to support treatment adherence and to practice safer sex.

The hospital focus for training and dissemination means that messages reminding people not to share or sell ARVs, to practice safe sex among others, are not reaching people in the wider community. There are a large number of treatment literacy programmes for patients, but very little for wider communities. People living with HIV are an important factor in the possible responses to this gap, as are churches.

In both churches and church health services, the issues surrounding ARVs require the rethinking of ‘old’ approaches, as well as the introduction of new ones. Despite many years of efforts to address HIV and AIDS stigma in churches, there remain significant problems in this area. Whether it is the casting out of leaders who are HIV-positive, or the linking of HIV to immoral behaviour on the part of the infected person, there are still very few churches in which stigma does not exist in some form, which reduces the positive impact of ARVs.
If church leaders can become advocates for ARVs and lead their communities to this lifesaving treatment, then they can also be part of important public health activities.

As with any disease, the gathering of people to worship and hear from church leaders offers an opportunity that has the power to transform the health of congregations. For this to happen, church leaders need to be reached by health messages, they need to feel confident in delivering those messages themselves, and they need to be clear about the role of the church in the mission to heal, as laid out in the Bible.

While church health service hospitals possibly fear the expense and the dependence of patients on regular supplies of ARVs, Africa (in particular) and its people cannot afford to have their churches or their church health services lag behind on treatment issues. Out-of-date information and poor leadership in this area is increasing the negative impact of HIV on families, communities, and nations, as well as on congregations and churches.

In response to this, EPN has developed activities designed to change this situation by increasing the capacity of church leaders and church health services to deal with antiretroviral treatment and related organisational management issues in target countries.
THE PURPOSE AND USE OF THIS GUIDE

The objective of this guide is to enhance church leaders’ abilities to ‘bridge the knowledge gap’ around antiretroviral treatment. The guide contains information sheets and activity exercises that church leaders can use to support their own knowledge and use in their daily work with their congregations and church groups, from bible study to youth groups. Through developing sermons, providing useful and accurate information and understanding what people are thinking, church leaders will be able to take effective action in assisting their congregations and communities to benefit from antiretroviral treatment.

Specifically, this guide is aimed at enabling church leaders:

• As individuals, to deal with difficult questions, situations and trauma that they and their congregations or communities face, including understanding ARVs, the dangers of the lack of adherence to antiretroviral treatment, and the ways to support people who are trying to build a positive life for themselves.

• To work with different groups in their congregations to show the relevance and importance of antiretroviral treatment from a Biblical perspective, and to enable them to know what to say and how to intervene, as well as to see and appreciate the power of God in performing miracles through man and science to deliver His people. As such, church leaders will become counsellors of faith, with the ability to link clinical counselling with pastoral counselling.

• Together as a church, to develop HIV and AIDS policy, become advocates of justice and support changes within the church health services, not least through stronger links between their churches and the church health services.

It is expected that, through using this guide, church leaders will be in a better position to take action and promote antiretroviral treatment awareness, drug availability, and adherence to treatment practices in their daily work. The guide aims to enhance individual church leaders’ abilities to learn for themselves and help their congregations learn about antiretroviral treatment.

For many centuries, the church has followed Jesus’ example of taking care of the sick and suffering as prophesied by Isaiah and practised by him in Galilee, according to the Holy Scriptures. It is under this premise that, as a church body, we have to continue taking care of the sick, irrespective of the illness and the circumstances around it. HIV and AIDS is just like any other illness. Jesus Christ, as an example to us, healed the sick. He did not judge or ask the reason behind the sickness but simply healed.

With this treatment literacy guide, EPN hopes to extend the reach of information on antiretroviral treatment for HIV to church leaders far and wide. By using and referring
to this guide, church leaders will be better informed on how to work with individual members of their congregations, support groups and their whole congregation, engage their churches and communities, and advocate for access to antiretroviral treatment.

The guide can be used as a reminder for a church leader and as a resource for activities. The information sheets focus on information about antiretroviral treatment and the role of the Church. The exercises support the development of knowledge, the understanding of what people are thinking, and the communication of correct information. The exercises can also be used as case studies and discussions to encourage the development of activities and approaches to the fulfilment of the role of the Church.

Everything has been written so that a church leader can use the information and exercises in an oral (spoken) approach. Throughout the guide, ideas are offered on ways to lead exercises, but church leaders themselves can choose when and how to make use of the tools.
WHY DO WE NEED TO KNOW ABOUT TREATMENT LITERACY?

Human Immunodeficiency Virus (HIV) is a retrovirus (a type of virus) that infects cells of the human immune system, destroying or impairing their function. In the early stages of infection, a person has no symptoms. However, as the infection progresses, the immune system gets weaker, and the person becomes more susceptible to opportunistic infections. This leads to advanced stage of HIV infection called Acquired Immunodeficiency Syndrome (AIDS).

HIV is transmitted through unprotected sexual relations (oral, anal or vaginal), transfusion of contaminated blood, sharing of contaminated syringe and needles, and between a mother and her infant during pregnancy, childbirth and breastfeeding. HIV cannot be transmitted through saliva, sweat, tears or urine. Transmitting the virus does not mean that the virus has left one person and moved to the other – both people are now infected.

Antiretroviral drugs (ARVs) are medications for the treatment of infection by retroviruses, primarily HIV. When someone is taking ARVs, they are said to be receiving antiretroviral treatment (ART). ARVs are not able to completely eliminate HIV from the body (even though they can reduce the symptoms to almost nothing), so it is necessary to stay on ART for life. Taking ARVs regularly (every day and at the right times) is called adhering to treatment, or treatment adherence (sticking to your treatment regimen).


There is overwhelming evidence that ARVs improve the quality of life of people living with HIV.

There is a role for church leaders to play in helping people access this life transforming treatment, particularly as there is widespread fear, misunderstanding, and stigma surrounding HIV and antiretroviral drugs (ARVs).

People who have access to ARVs need to be empowered and helped to share their experiences freely so that others may benefit and they need the stigma they face to be removed. Those who already take ARVs need support so that they can maintain their treatment regimen. Those who don’t need to take ARVs also need to understand them in order to support those that do need them.
1.1 This is an issue for each and every person in church

The HIV pandemic is not only a personal, family, and national tragedy, but also a faith concern. Church members, ministers, and leaders cannot afford to look the other way as did the Priest and the Levite on the Jericho Road. The Church has resources, capacity, and the moral authority to intervene. The ultimate test of the Church is the spiritual maturity of its people and its leadership. Nowhere is this maturity more tried than in the way the Church responds to the needs of suffering communities.

Many Churches have taken up the challenge of responding to the pandemic but now they need to respond to the issues surrounding access to antiretroviral treatment as this is the key to the long-term survival of people living with HIV. Equally important is knowledge and understanding about treatment and adherence to ARV regimens.

The challenge of antiretroviral treatment goes beyond the availability of ARVs and into people's daily behaviour. Where Churches and church leaders have found it easier to ignore HIV, they should take up the message of ARVs. Where Churches and church leaders have been trained to address the issues of HIV and AIDS, they should be retrained so that they can respond to the challenge of ARVs.

1.2 Involvement of church leaders in treatment of HIV and AIDS

In 2007, there was an average HIV prevalence of 5.0% in Sub-Saharan Africa, 0.3% in South and South-East Asia and 0.5% in Latin America. This means that there are a number of effects of HIV and AIDS on society and the Church. However, all of the problems below are reduced by the use of ARVs.

- HIV and AIDS has a devastating demographic impact. It has already killed over 20 million people worldwide. Between 1980 when the epidemic emerged and 2025, it is estimated that AIDS will have caused about 100 million deaths out of 500 million total deaths in Sub-Saharan Africa.

- The burden of HIV and AIDS on families and households is staggering. The long periods of illness, the loss of income and the cost of caring for family members impoverishes households. Adult deaths, especially of parents, often cause the break-up of households, with children being sent to live with relatives or even becoming homeless.

- HIV and AIDS seriously threatens the education of children. In households affected by HIV and AIDS, children are often taken out of school to help at home with care-giving or to earn an income. In addition, teachers are dying as a result of HIV. This erodes the quality of education.

- HIV and AIDS threatens the viability of health care systems.
• The loss of farm workers to HIV-related illnesses undermines food security. The 10 most severely affected African countries will lose between 10% and 26% of their agricultural labour force by 2020 due to AIDS.

• HIV and AIDS affects business enterprises. Sick workers are less productive, as are those workers who must care for ill family members. The costs of replacing experienced workers and paying health and death benefits is becoming a serious financial drain on businesses.

• HIV and AIDS weakens the economy and has begun to stall economic development. Where HIV prevalence is high, experienced workers are lost and funds for investment may be diverted to pay for health care and support of affected families. Lower investment in human capital in terms of health and education of the next generation will undermine prospects for development for many years to come.

Do church leaders want their people to have these burdens lifted from their shoulders? If yes, then the Church needs to play an active role in restoring hope and dignity to millions of people in the world through prevention, treatment, and care and support interventions.

The Church has been involved in HIV and AIDS interventions in a number of ways:

• Church-sponsored Voluntary Counselling and Testing (VCT) centres
• Church-based health services including the provision of ARVs
• Homes for HIV-positive children
• Ministries on prevention and awareness on HIV infection
• Pastoral care programmes for the infected and affected
• Material support: provision of clothing, food and shelter
• School assistance for orphaned children
• Income generation and vocational training
• Home-based care programmes, counselling, and psychological support
• Awareness campaigns

Though the Church has done a lot of work in the area of HIV and AIDS, it has done much less around treatment through ARVs. Now is the time to change this.

1.3 This is an opportunity to be a faithful witness

HIV and AIDS presents people of faith with the opportunity to be faithful witnesses to God’s love and healing grace, even in the face of suffering, death, and grief.
Following the example of Jesus, people of faith are called to eat with people living with HIV and to share their home with them (Matthew 25:6); to touch them and show them love and care (Matthew 8:2–4); and to heal people with HIV and AIDS (Luke 17:11–19).

A faithful, intimate presence in the lives of those with HIV and AIDS, witnessing to them of Jesus' healing touch, is one of the most important responsibilities of all people of faith. Jesus said, “The Truth shall set you free,” (John 8:32), yet too often, people deny the truth, or avoid learning about HIV and AIDS because of fear.

It is the responsibility of all people of faith to educate themselves so as to effectively educate others. Many people have fears about the risks of contracting HIV and AIDS. That fear can be overcome with facts on how HIV is transmitted, how it affects the body, and how it can be managed.

1.4 What is treatment literacy?

Treatment literacy means understanding the treatment that is required for HIV. This includes understanding what antiretroviral drugs are (as individuals and communities), what they do and how they must be taken. To achieve this, medical information about antiretroviral treatment is translated into simple language and terminology that is accessible and easy to understand. It is also important to address any myths or misconceptions that have built up around antiretroviral treatment and to give compassion.

Treatment literacy is not aimed at transforming church leaders into medical professionals. It is intended to enable them perform a number of tasks related to the support and care of people infected and affected by HIV and AIDS. This means:

• Providing accurate information about antiretroviral treatment, the challenges, and addressing myths and misconceptions around these issues;
• Encouraging people to know their HIV status early enough to get life-prolonging antiretroviral treatment;
• Explaining how to get access to antiretroviral treatment, offering support and ideas for adhering to treatment.

Treatment literacy for church leaders recognises that the responsibility of passing on correct information on antiretroviral treatment is the duty of us all, including the Church.

In Deuteronomy 29:29, the Bible says that secret things belong to God. Those things that are revealed are for us and our children. During the journey through the wilderness, the children of Israel were attacked and bitten by poisonous snakes. Many died. However, God told Moses to make a bronze snake, so that whoever looked at it was saved or healed.
EPN believes that, through medical science, God has revealed ways of addressing HIV and AIDS through drugs such as ARVs. We need to look at them in that light and use them to help alleviate the suffering of millions of people infected and affected by the HIV and AIDS pandemic worldwide.

### 1.5 Leading the discovery of good news

A church leader may be defined as any person with a regular role in the administration or implementation of church activities – from archbishops and bishops, to pastors or reverends, lay workers, as well as staff of faith-based organisations.

The Church, being close to its congregations, is strategically positioned to curb the spread of HIV. Supported by church-based health facilities, the Church provides real opportunities for intervention through love and actions and through this, its presence offers hope not only to people living with HIV but to entire communities. The Church is particularly well placed to act because:

- The Church establishes weekly contact with its congregation.
- People respect the Church and this provides it with a regular opportunity to influence behaviour change and give support and care;
- The Church possesses a network that is sustainable and has been in existence for centuries;
- The Church possesses the moral authority to speak about various issues that touch on lives in the community;
- Church leaders are opinion leaders in communities.

In view of these factors, antiretroviral treatment should be understood by church leaders within the following context:

- Antiretroviral treatment really works and gives hope to millions of people living with HIV and their families. It also restores their dignity and their health.
- In understanding ARVs and ART, church leaders can greatly help to increase treatment uptake and bring the benefits to society. Church leaders can help society to avoid misinformation on treatment when they themselves have the correct information.
- Church leaders can demystify treatment and demonstrate the advancement of science as God's work, i.e. God intervenes through people and scientific progress.
• Treatment is part of the continuum of care for people living with HIV. Church leaders are involved in various aspects of this care. Treatment literacy is part of this.

• ARVs require a lifelong commitment and church leaders’ involvement gives moral and material support that is necessary for adherence and for coping with any side-effects of the ARV drugs.

• In understanding treatment, church leaders act as intermediaries in interpreting wisdom for people.

• The spread of HIV infection is fuelled by lack of information and knowledge. Church leaders can be a key source of information and support the spread of knowledge that can reduce the impact of the HIV pandemic.

• Churches have human resources and infrastructure to support the response to HIV as well as people living with HIV.
Chapter 2

Antiretroviral Treatment

Antiretroviral drugs (ARVs) are medications for the treatment of infection by retroviruses, primarily HIV. When someone is taking ARVs, they are said to be on antiretroviral therapy (ART). ARVs are not able to completely eliminate HIV from the body (even though they can reduce the symptoms of AIDS to almost nothing), so it is necessary to stay on ART for life. Taking ARVs regularly (every day and at the right times) is called adhering to treatment or treatment adherence (sticking to your treatment regimen).

Viral load is a measure of how many copies of the HIV are in a person’s blood (the virus ‘replicates’ itself in order to infect other cells in the body). The higher the viral load, the more likely it is that a person’s immune system will begin to fail and they will suffer from advanced HIV infection or Acquired Immune Deficiency Syndrome (AIDS). A person who is taking ARVs may have a very low viral load (even an undetectable level), but the virus is still present in the cells and body fluids, and may even be trans in the blood to other people, so a person is still infectious and can still pass on the HIV.


2.1 Objectives and benefits of treatment

The primary goal of antiretroviral treatment of people infected with HIV is to keep the viral load at a low enough level so that the patient does not become sick. ARVs reduce the viral load to levels that cannot be detected by most available antibody tests. ARVs, together with other immune boosters such as good nutrition, vitamins, micro nutrients, and good hygiene, enable the body to mount its natural immune action for as long as possible.

There is no cure for HIV, even though ARVs can return a person to health and strength and prevent the symptoms of AIDS. People who start on ARVs, must take their daily dose for the rest of their life. If someone stops taking his/her ARVs, the viral load will increase and they will become sick. It is also possible that, if a person stops taking their ARVs, the HIV can change (mutate) and become resistant to the ARVs, so that if the person starts taking them again, the drugs will not work against the HIV. This is why someone on ART must not take a treatment holiday (one must not stop taking his/her ARVs, even for a day).

Many people who were so sick that they could not get out of bed have enjoyed productive lives after starting ART. However, people who start treatment late, when the immune system is too badly damaged, may not improve through ART. It is particularly important
that people know their status and are tested for their **CD4 count** to know how they are progressing. If someone does not know their status, then they can’t start taking ARVs in time for it to help them.

The CD4 count is a measure of the body’s immune system. The lower it is, the less ability the body has to fight off disease. It is recommended that if someone has a CD4 count of 350 or below they should start taking ARVs.

It is also recognised that, because of the difficulty in maintaining access to ARVs, e.g. being able to access or afford them and the need to take them every day, it may be necessary to delay starting ARVs for as long as possible – but not below a CD4 count of 200.

ART offers a number of benefits, such as:

- Providing a better quality of life for people living with HIV.
- Leading to a decrease in the number of orphans, since fewer parents will die;
- Giving health workers the motivation to serve, by helping them realise they can do more for people living with HIV;

**ART Really Works**

“I am Joseph and I am HIV-positive. I was already very sick when I went for a test. The health worker told me I had AIDS and she advised me on how I could regain my strength with antiretroviral therapy or ART. I found out that ART is not just about drugs. It’s about living positively with HIV and AIDS – by treating illnesses early, eating well and staying alive. And look at me now! I am just like I was before I got sick.”

*National Aids Control Council, Kenya, Poster. 2003*

### 2.2 Antiretroviral drugs

The drugs that act against HIV are called antiretroviral drugs (ARVs). ARVs must also be taken for life, as there is no cure for HIV. ARVs can have undesirable side-effects partly if they are not taken properly. Therefore, adherence and support for those on antiretroviral treatment (ART) is crucial.
There are three main groups of antiretroviral drugs currently in use and which may be used in combination, namely:

- Nucleoside reverse transcriptase inhibitors (NRTI or nukes).
- Non-nucleoside reverse transcriptase inhibitors (NNRTI or non-nukes).
- Protease inhibitors (PI).

There are two key issues in the use of ARVs: resistance and adherence.

**Resistance:** A drug is only useful for as long as the organism that is being targeted is sensitive to its action. When an organism that causes the disease loses sensitivity to a drug, the organism has become resistant to the drug.

There are a number of ways by which an organism can become resistant to a drug, but the most common is for the organism to change its form, or, in scientific terminology, to mutate. One of the characteristics of the HIV is that it replicates very quickly and mutates very easily. This makes it difficult to develop vaccines and the virus can become resistant to drugs very quickly.

One of the ways to delay the emergence of drug-resistant viruses is to use combinations of drugs in therapy. It is possible for an organism to become resistant to one drug at a time, but it would be difficult for it to become resistant to several drugs at the same time. This is the basis for combined drug therapy. In the case of HIV, at least three ARVs are used.

Resistance can also be triggered when a treatment regimen is not followed correctly and there are gaps in the treatment. This is why treatment holidays and poor adherence to treatment guidelines are so dangerous. If the particular form of HIV being treated becomes resistant to the first line of drugs (those most easily accessible at this time) then more expensive (and more difficult to access) ARVs, called second-line ARVs, will have to be used.

**Adherence:** Commitment to antiretroviral treatment protocols is very, very important. Even with three-drug combinations, the human immunodeficiency virus (HIV) can still develop resistance if it is given the slightest chance. But it is still possible that someone could miss some tablets, perhaps because of:

- The unpleasant side-effects of the drugs (see Table 2.1);
- The burden of taking drugs everyday. It may be overwhelming and depressing;
- Absence of other requirements, such as nutritious foods;
- A simple human weakness - forgetting.

To prevent treatment failure, it is important, therefore, that any person starting antiretroviral treatment is adequately counselled and provided with accurate information.
The availability of the ARVs and access to adequate food must be assured at all times. It is important to have a family and community support system that does not stigmatize or discriminate and it is important to have access to adequate health care facilities. With such a support system, people on treatment can remain productive members of the family, the Church, and the community.

### Table 2.1  Examples of side-effects caused by ARVs

<table>
<thead>
<tr>
<th>SIDE-EFFECT</th>
<th>PRESENTATION / COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis (inflammation of the liver)</td>
<td>Abdominal pain, rash, jaundice (yellow skin and eyes), nausea/vomiting</td>
</tr>
<tr>
<td>Pancreatitis (inflammation of the pancreas)</td>
<td>Abdominal pain that radiates to back, nausea</td>
</tr>
<tr>
<td>Rash</td>
<td>Can be severe, e.g. blister, skin loss, or minor, e.g. itching</td>
</tr>
<tr>
<td>Lactic acidosis (sensation of severe heartburn)</td>
<td>Fatigue, nausea, fever, abdominal pain, weight loss</td>
</tr>
<tr>
<td>Anaemia (low red blood cell count)</td>
<td>Fatigue, pale skin, fast beating of the heart</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Loose stools, mild abdominal pain</td>
</tr>
<tr>
<td>Nausea and abdominal pain</td>
<td>Many ARVs can cause mild nausea, vomiting and abdominal pain. Some may cause bloating and flatulence (gassiness). These symptoms pass with time.</td>
</tr>
<tr>
<td>Lipodystrophy</td>
<td>Transfer of fat to the abdomen and back of neck</td>
</tr>
<tr>
<td>Lipoatrophy</td>
<td>Loss of fat in the arms and legs</td>
</tr>
<tr>
<td>Peripheral neuropathy</td>
<td>Numbness, tingling, painful burning sensation in toes/fingers, symmetric (left and right)</td>
</tr>
<tr>
<td>Dizziness/sleepiness/bad dreams</td>
<td>Dizziness, nightmares, feeling sleepy. In severe cases symptoms of mental illness, hallucinations, depression, mania. Some may have suicidal tendencies. However, this is rare</td>
</tr>
<tr>
<td>Kidney problems</td>
<td>Usually no symptoms; maybe fatigue, tiredness</td>
</tr>
</tbody>
</table>
2.3 Antiretroviral treatment enrolment criteria
Not all people living with HIV will benefit immediately from ART. Eligibility for treatment is based on:

- The amount of HIV in the blood (viral load)
- The level of immune suppression (based on CD4 cell count)
- The presence of AIDS-defining illness (based on WHO HIV disease clinical staging criteria);
- Social factors such as availability of a support system
- The patient’s acceptance of their HIV status.

2.4 Key elements of HIV care and treatment
Antiretroviral treatment for HIV has the following crucial features:

- Antiretroviral treatment is a lifelong treatment and requires a continuous care approach.
- Adherence to antiretroviral treatment of 95% and above is necessary to prevent drug resistance and treatment failure.
- Availability of antiretroviral treatment may motivate people to use HIV counseling and testing services leading to accelerated HIV prevention activities.

Some people suffer from side-effects when taking ARVs. If a person has not started ARVs soon enough (if they wait until they are very sick), they may not survive. These two factors have contributed to the myth that ARVs can kill. Side-effects do include weight gain, which some people do not like. However, ARVs can bring the return of appetite for people who were becoming too thin. In places where there is insufficient food, this can be difficult. Other side-effects are reviewed below.

People who are taking ARVs sometimes stop if they begin to feel sick due to side-effects, rather than going to their doctor to find out what can be done (this should be encouraged). They may feel better for a few days without the ARVs, but the long-term consequences (such as drug resistance and a recurrence of AIDS) need to be avoided. The best advice is to seek medical help immediately. A number of the side-effects can be successfully treated.

It is important to remember that not everyone suffers from side-effects.

In order to optimise adherence to ART and to improve quality of life for people living with HIV, it is essential to develop an understanding of treatment.
2.5 Importance of nutrition in antiretroviral treatment

Good nutrition means getting enough macronutrients and micronutrients. Macronutrients contain calories (energy). They include proteins, carbohydrates, and fats. They help to maintain body weight. Micronutrients include vitamins and minerals. They keep the body cells in proper working condition, but will not prevent weight loss.

Good nutrition can be a challenge for many people with HIV. When the body fights any infection, it uses more energy - this requires more food intake. Yet, people generally eat less than normal when they are ill.

Some medications upset the stomach and some opportunistic infections can affect the mouth or throat, making it difficult to eat. Also, some medications and infections cause diarrhoea. In these conditions, the body gets less energy and goodness from the food that is eaten. When someone loses weight during illness, they might be losing fat or lean body weight like muscle. When this happens, the body chemistry changes, resulting in a condition called wasting syndrome (or cachexia). This can kill.

Good nutrition is therefore very important for people living with HIV. A person infected with HIV will need to increase the amount of food she/he eats in order to maintain his/her lean body weight. A balanced diet, including plenty of protein and whole grain foods, with some sugar and fat and a regular exercise programme, will help build and maintain muscle.

Figure 2.1 Nutrition and HIV

- Poor nutrition (weight loss, muscle wasting, weakness, micronutrient deficiency)
- Increased Nutritional needs due to absorption of food and in order to address infection and viral replication
- Weakened Immune system (poor ability to fight HIV and other infections)
- Increased vulnerability to infections (Enteric infections - flu, TB and faster progression to AIDS)
2.6 Antiretroviral drugs and children

Where antiretroviral drugs and good medical care for pregnant women are available, HIV infections in children can be reduced significantly. Most children are infected with HIV from their mothers during pregnancy at birth, or through their milk when breastfeeding, particularly in situations when the mother’s HIV status is unknown and precautions have not been taken. Other children may get a transfusion of infected blood or become infected through sexual abuse.

HIV in children needs special attention because:

- Children’s immune systems are still developing. They have a different response to HIV infection.
- Children also respond differently to ARVs.
- Children have a very high rate of metabolism. This gradually slows as they mature.
- The liver processes drugs and removes them from the body. It takes several years to mature. As it matures, drug levels in children can change a lot.
- Bones develop quickly during the early years of life.
- ARVs for babies and children are required in different dosages than for adults and they often have to be taken in a different form, e.g. mixed in a sweet liquid.

Children with HIV should be treated by a doctor who has experience with paediatric cases of HIV. The correct doses for children need to be administered. Children’s doses are sometimes based on their weight or body surface area, using a formula that considers both height and weight. Dosing needs to be adjusted several times as the child grows up.

HIV-related diseases show up much faster in untreated children than in adults. Children are treated according to WHO staging for children or CD4 count.

Sometimes mothers resist treatment or can’t afford to have their children tested for HIV and when they get ill, they share their own ARVs with them. This is highly dangerous and will not save the child, and can make the mother sick too.

Fear of HIV testing is usually due to the stigma surrounding HIV and AIDS.

2.7 Prevention of mother-to-child transmission

Prevention of mother-to-child transmission of HIV (PMTCT) refers to the use of ARVs to reduce the chances of a child contracting HIV from their mother during pregnancy, labour and delivery and breastfeeding. This can be achieved with universal access to ARVs and proper training of clinicians. The challenge is to assist expectant mothers to get HIV counselling and testing early in their pregnancy.

Most (around 9 in 10) of the children living with HIV acquired the virus through mother-to-child transmission (MTCT). In the absence of any intervention, the risk of mother-
to-child transmission of HIV is 15–30% (between 1 and 3 children in every 10 births) if the mother doesn’t breastfeed; if the mother breastfeeds her child, the risk of HIV transmission increases to 20–45% (up to nearly 1 in every 2 children born to mothers living with HIV).

This risk can be reduced to below 2% (less than 1 child in every 50 births) by interventions that include antiretroviral prophylaxis given to mothers during pregnancy and labour and to the infant in the first weeks of life, appropriate delivery practices, and completely avoiding breastfeeding ¹. Some women refuse to test for HIV when they are pregnant because, if the test is positive, they fear that they will be blamed for bringing HIV into the family. This means that they do not benefit from ARVs to prevent the transmission of HIV to their child and do not address breastfeeding issues.

If a woman is the first person to be tested positive for HIV, it does not mean that she is the one that brought it to the family. The most important issue is to ensure that the mother receives ARVs to prevent transmission of HIV to her child and that she (and any other members of her family) are tested and assessed for whether they need antiretroviral treatment themselves.

Many women do not see a doctor or attend health services when they are pregnant because it is too expensive. Every pregnant woman should attend an antenatal clinic to ensure that they are assessed for any risks to themselves or their child. They should be encouraged to deliver in hospital or under skilled health workers. It is always worthwhile, as the cost of a sick child can be much higher.

PMTCT programmes provide the following interventions:

- HIV counselling and testing during ANC, labour and delivery and postpartum
- Provision of antiretroviral (ARV) drugs to mother and infant
- Safer delivery practices
- Infant feeding information, counselling and support
- Referrals to comprehensive treatment, care and social support for mothers and families with HIV infection.

2.8 Post-exposure prophylaxis

Post-exposure prophylaxis (PEP) refers to the prescribing of ARVs for a limited period of time following accidental exposure to infective body fluids (blood, semen, vaginal fluids, breast milk) of someone whose HIV status is unknown or is positive. This procedure is effective for professionals, such as health workers who are exposed when carrying out procedures such as surgery, or for individuals, such as someone who is raped.

Different countries follow different guidelines for this protocol. Within the health sector, PEP should be provided as part of a comprehensive universal precautions package that reduces staff exposure to infectious hazards at work.

When there is a risk of HIV transmission, post-exposure prophylaxis should be initiated as soon as possible, within hours and no later than 72 hours following the potential exposure. Studies have shown that initiating PEP within 12, 24 or 36 hours of exposure is more effective than initiating it 48 or 72 hours following exposure. Such studies have also established that PEP is not effective when initiated later than 72 hours following exposure.²

(See “Supporting information A” for more information on the scientific basis of treatment)

CHAPTER 3

CHALLENGES OF ANTIRETROVIRAL TREATMENT

The challenges to successful antiretroviral treatment (ART) include overcoming stigma and discrimination, misinformation, lack of information, and insufficient resources to meet basic nutrition and health care needs. However, churches are in a position to overcome some of the challenges.

3.1 Knowing one’s status

To get antiretroviral treatment, a person must know his/her HIV status. Antiretroviral treatment can help more people, if more people know their HIV status. Stigma often discourages this and leads to late testing for HIV, which results in missed opportunities for reducing the spread of HIV infection and increasing treatment.

The only person who need not be tested is someone who has already been diagnosed HIV positive. Anyone else could have HIV from a variety of sources (and not just unsafe sex). Some of the real reasons why people hesitate to learn their HIV status are listed below:

- The stress of a positive test result.
- The issues that a positive result would raise among family members, friends, and sex partners.
- Stigma and discrimination that would come with a positive diagnosis.
- Fear of losing their jobs, insurance, housing, etc.
- Fear of how the Church would react to their positive status.

However, there are a many other reasons that are based on incorrect information.

- Fear of death (which comes from lack of knowledge that treatment offers an opportunity to live).
- Fear that the first person to be tested positive in the family is the person that brought HIV to the family (this is often not true).

Assumptions of safety or of ignorance such as:

- I believe in God.
- I am faithful to my partner.
- It’s too expensive.
- I am not ill, so why should I go for a test?
• I feel sick, but I am sure it is something else.
• I have been healed since my last test.
• I am too important and it would not look good to other people if I thought I might have HIV.

The Church can play a significant role in encouraging people to know their HIV status. Further, church leaders can prompt voluntary testing for HIV and behaviour change. The availability of treatment also encourages testing because it gives the assurance to people who test positive that they can still live a fulfilled life. Most of all, church leaders can provide accurate information that addresses myths and misconceptions. Leaders can also lead the way by publicly going for a test themselves and showing understanding and compassion for those who are already living with HIV.

3.2 Stigma and discrimination

“Silence kills, stigma kills. We should not want those living with HIV to be the modern equivalent of the biblical leper who had to carry a bell and a sign saying, ‘I am unclean’.”

Archbishop Desmond Tutu, July 2004

Stigma and discrimination undermine many HIV programmes and efforts to reduce the impact of the disease. Stigma and fear of discrimination discourage people from seeking testing and treatment of HIV, and therefore keeps them away from life-prolonging treatment.

HIV and AIDS attract stigma because of the association of the conditions with sex, death, and with behaviours that are considered to be immoral, forbidden, or taboo.

People living with HIV are often held responsible for their own infection. In a religious context, HIV is sometimes perceived as punishment for immoral behaviour. In addition, fear of infection and lack of knowledge about HIV increases stigma. Stigma can be divided into four, loosely defined groups, namely: physical, social, verbal and institutional stigma (see Figure 3.1).
Many religious leaders and churches have created the stigmatisation of people living with HIV by perceiving HIV infection as a punishment for immoral behaviour or a curse from God.

In November 2001, the World Council of Churches (WCC) convened a meeting of African church leaders in Nairobi to draw up an ecumenical plan of action for responding to the HIV epidemic. It was unanimously agreed that churches should prioritise the eradication of HIV and AIDS-related stigma. A resolution has since been regionally and internationally endorsed by individual Church denominations. The plan of action itself led to a range of international initiatives, including the Ecumenical HIV and AIDS Initiative in Africa (EHAIA).

“Our earlier approach in fighting AIDS was misplaced, since we likened it to a disease for sinners and a curse from God.” - Archbishop Benjamin Nzimbi. Anglican Church of Kenya, speaking to a group of HIV positive Christian and Muslim clergy.

Figure 3.1 Forms of stigma

Verbal stigma
- Gossip, taunting, scolding
- Labeling: in Africa: “moving skeleton”, “walking corpse” and “keys to the mortuary”
- In Viet Nam: “social evils” and “scum of society”

Social stigma
- Isolated from community
- Voyeurism: any interest may be morbid curiosity or mockery rather than genuine concern
- Loss of social role/identity: social “death”, loss of standing and respect

Institutionalized stigma
- Barred from jobs, scholarships, visas, etc.
- Denial of health services
- Denial of home care
- Police harassment (e.g. of sex workers, HIV-positive activists)

Physical stigma
- Isolated, shunned, abandoned
- Separate living space, eating utensils
- Violence

Churches and church leaders should play an active role in the ongoing fight against stigma and discrimination. By offering an open and welcoming approach, the Church provides a good example of how to work and live with people and groups infected and affected by HIV and AIDS. Table 3.1 lists possible actions that can be taken to decrease stigma.

**Table 3.1 Effective responses to stigma**

<table>
<thead>
<tr>
<th>INTERVENTION AREA</th>
<th>ACTIONS TO REDUCE STIGMA</th>
</tr>
</thead>
</table>
| Education and Information | • Educate the clergy and congregation on HIV prevention and treatment  
• Use public education opportunities to put a human face on HIV  
• Involve people living with HIV in public education  
• Show antiretroviral drugs as an opportunity for giving glory to God  
• Encourage families to get information about HIV and its treatment, and to visit people living with HIV  
• Understand that HIV is not sin nor a result of sin |
| Policy Development | • Involve the clergy and congregations in programme design, development, and evaluation  
• Demonstrate the church policy by involving people living with HIV in church activities (those who volunteer to do so)  
• Support and engage the Church in promoting confidentiality and non-discrimination  
• Promote community development and mobilisation |
| Statutory/regulatory environment | • Familiarise yourself with applicable laws and regulations of your country  
• Initiate or support actions to advance or strengthen protection of people living with HIV in your community |
| Church programmes and services | • Maintain a proactive presence in the community  
• Involve and support families and communities (infected and affected)  
• Engage church leaders from the business as well as faith communities  
• Encourage testing and treatment knowledge in various church programmes & arms  
• Develop and implement training, policies, and procedures for all staff activities and programmes  
• Communicate that HIV-related discrimination is improper behaviour  
• Ensure access to confidential and anonymous HIV testing  
• Support church-based health facilities  
• Build capacity by networking with other agencies |
3.3 Poor access to antiretroviral drugs (ARVs)

Access to antiretroviral treatment has increased substantially in recent years. However, in low and middle income countries, only about 41% (about 3.9 million people) of an estimated 9.5 million in need of ARVs are receiving them. The global need is far from being met.

A lot of progress has been made with regard to reducing the cost of ARVs mainly due to competition from generic versions, simplification of regimens, scaling up of treatment through decentralisation and increased involvement of communities. However, there are still many challenges, including:

- People unable to reach health care facilities because of lack of money for transport or lack of time to complete the journey;
- Lack of community support;
- Lack of funding for health staff and affordable antiretroviral treatment;
- Limited availability and high prices of second-line ARVs, which patients will have to change to due to drug resistance;
- The financial burden associated with the required laboratory tests in some countries.

There are many ways the Church can help alleviate some of these problems, perhaps helping to arrange transport, income generation activities or childcare. Remember that access to food is also an important aspect of taking ARVs.

3.4 Lack of suitable drugs for children

While ARVs for adults are becoming more available, the situation is very different for treatment formulations that are appropriate for children. Paediatric formulations are quite expensive. Moreover, the limited number of paediatric formulations implies that there are less treatment options for HIV-positive children. More advocacy for ARVs for children is needed.

Antiretroviral treatment for children also suffers other limitations:

- There is limited knowledge about treating children with HIV.
- Adherence in children is a unique challenge, not only because of social situations, but also because many of the drugs are in formulations that are not easy to administer to children (e.g. there is inadequate supply of syrup formulations).
- There are children who do not have social support, and may have no one

to give them medication while at school or when their parents are not at home.

- Elderly caregivers may not be in a position to understand the treatment regimens and the instructions. Children under their care may not get the correct regimen of ARVs.

The Church could provide support to children in need and raise awareness among caregivers, teachers, and the community.

### 3.5 Treatment adherence

Adherence to antiretroviral treatment means that a patient is taking the prescribed drugs according to a treatment plan. This implies taking the correct dosage, at the right time, and following instructions with regard to food intake.

*Figure 3.2  Take medicines as instructed by the doctor

Adherence to treatment is a major challenge for people living with HIV because the treatment has to be taken for life. The number of tablets to be taken is often high (described as a pill-burden), food restrictions need to be followed, and the medication often has side-effects.

It has been shown that about 95% adherence is needed to achieve good treatment results. Treatment failure rates (when the ARVs don’t work) increase sharply as adherence decreases.\(^5\)


HIV & AIDS Treatment Literacy Guide for Church Leaders
Adhering to the prescribed medication keeps the viral load at very low levels (the HIV cannot be completely eliminated from the body) and increases the count of CD4 cells, which strengthens the immune system and prevents opportunistic infections. The patient can live a healthy and productive life again.

Lack of adherence allows the viral load to increase, leading to opportunistic infections. It also raises the risk of the virus mutating and rendering itself resistant to one or more of the ARVs being taken. Patients with resistant HIV strains may have to switch to second line treatment, which is expensive and often not available.

Failure to adhere to antiretroviral treatment includes:

- Missing doses of drugs occasionally;
- Taking only part of the prescribed drugs;
- Not observing the time intervals between drugs;
- Not following dietary instructions;
- Stopping the medication for a period of time, or completely.

Through offering messages of adherence to the community, the Church can play a crucial role in supporting and encouraging people living with HIV to adhere to treatment. The Church can also encourage the formation of support groups where people living with HIV share their issues and get support from each other.

Table 3.2 discusses in more detail some of the factors that interfere with adherence to antiretroviral treatment.

### Table 3.2   Factors affecting adherence to HIV Treatment

<table>
<thead>
<tr>
<th>FACTORS</th>
<th>REASONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factors related to people living with HIV</td>
<td>• Stigma and discrimination</td>
</tr>
<tr>
<td></td>
<td>• Psychological reasons</td>
</tr>
<tr>
<td></td>
<td>• Stress</td>
</tr>
<tr>
<td></td>
<td>• Depression – giving up hope</td>
</tr>
<tr>
<td></td>
<td>• Discouragement</td>
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<tr>
<td></td>
<td>• Lack of knowledge/misinformation</td>
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<tr>
<td></td>
<td>• Low literacy</td>
</tr>
<tr>
<td></td>
<td>• Lack of adequate drugs supply</td>
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<tr>
<td></td>
<td>• Poverty: Lack of finance/transport</td>
</tr>
<tr>
<td></td>
<td>• Lack of social support</td>
</tr>
<tr>
<td></td>
<td>• Drug and alcohol abuse</td>
</tr>
<tr>
<td></td>
<td>• Dietary problems: Have not eaten</td>
</tr>
<tr>
<td>FACTORS</td>
<td>REASONS</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Personal discipline</td>
<td>• Competing priorities: work, child etc</td>
</tr>
<tr>
<td></td>
<td>• Sharing drugs with others</td>
</tr>
<tr>
<td></td>
<td>• Lack of faith</td>
</tr>
<tr>
<td></td>
<td>• Non-disclosure</td>
</tr>
<tr>
<td>Provider-based factors</td>
<td>• Poor communication</td>
</tr>
<tr>
<td></td>
<td>• Shortage of drugs supply</td>
</tr>
<tr>
<td></td>
<td>• Lack of counselling skills</td>
</tr>
<tr>
<td></td>
<td>• Lack of adequate personnel</td>
</tr>
<tr>
<td></td>
<td>• Overwhelmed by the number of patients (High workload)</td>
</tr>
<tr>
<td>Society-based reasons</td>
<td>• Stigma</td>
</tr>
<tr>
<td></td>
<td>• Cultural and societal norms</td>
</tr>
<tr>
<td></td>
<td>• Lack of knowledge/misinformation</td>
</tr>
<tr>
<td></td>
<td>• Displacement in emergency situations</td>
</tr>
<tr>
<td></td>
<td>• Rigid or changing work schedules, such as hourly workers</td>
</tr>
<tr>
<td></td>
<td>• Being Homeless</td>
</tr>
<tr>
<td></td>
<td>• Poverty</td>
</tr>
<tr>
<td>Treatment-related factors</td>
<td>• Characteristics of the medical regimen: The longer the regimen the poorer the adherence. More complex regimens for instance high number of tablets (pill burden) have been similarly associated with poor adherence.</td>
</tr>
<tr>
<td></td>
<td>• Side-effects: ARVs can have some side-effects that patients find difficult to cope with. When this happens, some people living with HIV may discontinue the medication.</td>
</tr>
<tr>
<td></td>
<td>• Long-term treatment: ARVs are a lifetime commitment and one cannot discontinue. Some patients get discouraged of taking drugs for life. They may wrongfully choose to discontinue just for a change. This is dangerous, as it makes the viral load in the body to go up.</td>
</tr>
</tbody>
</table>

### 3.6 Food and nutrition

People living with HIV have specific nutritional requirements, irrespective of whether they are on treatment or not. It is crucial that they take good amounts of food (the need for energy is higher for HIV infected people) and that they also eat a balanced diet of green vegetables, proteins, starches, fruit, and some fat. Proper nutrition strengthens
the immune system, which helps to fight opportunistic infections, increases the body’s ability to tolerate medication, and helps to slow down the progression of HIV infection to AIDS.

**Figure 3.3 The role of nutrition in the immune system**

Nutrition influences the efficacy of ARVs and the ability of the patient to adhere to treatment. Some ARVs require fat in order to be absorbed in the body; others are absorbed more easily when the stomach is empty. Some drugs might cause irritation of the stomach and should therefore be taken after meals. However, nutrition remains a challenge for people living with HIV, mainly due to:

- Lack of quality food in adequate quantities mainly due to poverty;
- Inability of the patient to eat and digest food properly because of poor appetite, diarrhoea, nausea, mouth sores, opportunistic infections and treatment side-effects;
- High food safety needs: people living with HIV need to be especially careful about germs because their weakened immune systems may not cope as effectively as healthy immune systems to keep away opportunistic infections.

Nutritional interventions are necessary to support people living with HIV and to ensure the success of antiretroviral therapy. Through providing information that supports nutrition interventions, the Church can offer much needed support to people living with HIV.

HIV and AIDS also affect the nutritional wellbeing of those who depend on people living
with HIV. When people living with HIV are bedridden and are unable to work, their dependants may also not be in a position to obtain food. This may lead to illnesses and exposure to high-risk behaviour. By supporting communities to provide for those infected or affected by HIV, church leaders can assist in giving hope, saving lives, and maintaining human dignity.

3.7 Importance of care and support from family and community

Care and support from the family and the community is important for people living with HIV. Health care systems in many low and middle-income countries are overwhelmed by the need to provide treatment, care and support for people living with HIV. They have to rely on ‘informal’ caregivers such as parents, siblings, children, relatives and friends for care and support.

People living with HIV who receive care and support from their families and communities are in a better position to overcome challenges, as opposed to those who have no such support. Furthermore, a welcoming and caring community helps to fight stigma and discrimination, encourages people to get tested and if test is positive, to seek treatment in order to live a wholesome life despite their HIV status.

Churches don’t necessarily have the resources to make food available for free, but through bulk buying they can reduce prices for those with HIV, or subsidise transport to cheaper shops or start income generating activities.

3.8 Lack of care for caregivers

While it is widely acknowledged that support and care is required for people living with HIV, support systems are also needed for those who care for them. Health workers in hospitals and health centres are in need of psychological and emotional support. They have been trained to care for and heal people and are now often caring for dying patients as drugs are not readily available, especially in rural areas in some countries. They are often overworked because the numbers of patients have increased. Furthermore, they could be affected themselves, either through a family member who is sick at home and needs their care, or a colleague who is not well, leading to an increased workload. They could also be HIV positive.

The ‘informal’ caregivers also need a support system which should include:

- Basic training on how to care for their HIV positive family members and friends
- Financial support
• Psychosocial and emotional support
• Spiritual support

Churches are in a position to provide support and care, and could offer a supportive environment for people living with HIV as well as for their caregivers.

3.9 Faith healing and antiretroviral drugs

In August 2008, the Botswana government was left with no alternative but to deport a Zimbabwean pastor for providing false information regarding antiretroviral treatment. Preaching false information is not a new phenomenon and is actually very common among those who don’t understand antiretroviral treatment.

Healing through medicine is not contrary to healing through faith. If my Pastor or Priest lays hands upon me, it does not mean I should stop taking my ARVs, diabetes or high blood pressure medicine. ARVs are God’s miracle as well. The earth and everything in it belongs to the Lord.

Jesus Christ was not averse to using medical resources. He once mixed water with mud and healed a blind man; he urged those who were ill to seek the services of a physician. The healing power of Jesus Christ cannot be denied. However, claims of miraculous healings that are not properly documented exist. Those who pray for healing should not ask their client to stop taking ARVs. Devious preachers are taking advantage of the situation to proclaim healing, usually for their own benefit. This brings shame to the gospel of Christ.

Church leaders could learn from the story of the thankful leper (Luke 17: 12–15). As Jesus was going into a village, ten men who had leprosy met him. They stood at a distance and called out in a loud voice, “Jesus, master, have pity on us!” When he saw them, he said, “Go, and show yourselves to the priests.” And as they went, they were cleansed.

One of them, when he saw he was healed, came back, praising God in a loud voice.

If HIV was to be equated to leprosy in the times of Jesus, then it would be important to ensure that those who are healed show themselves to the priests. They need to go to a reputable testing facility to verify their HIV status. If the healing is confirmed, then glory needs to be given to God.

The whole healing ministry of Jesus underscores that it is a God-given right that people should be well; with access to resources that make them well - be it faith resources or medical resources. It is God’s will for all of us to be healed.
If ARVs make people much better to the extent that they can resume their normal lives, we should praise God that such a resource has been found from God’s earth and abundance.

3.10 Culture

On the basis of the Mexico Declaration of 1982, culture is broadly understood within UNESCO to include “Ways of life, traditions and beliefs, values, representations of health and disease, perceptions of life and death, sexual norms and practices, power and gender relations, family structures, languages and means of communication, as well as arts and creativity”.

From this definition, it is clear that culture influences attitudes and behaviours. In relation to the HIV and AIDS epidemic, culture can manifest itself in gender relations and roles that put women and men at risk of infection. These relations and roles can also prevent them from accessing treatment and care, and could also result in being supportive towards or discriminating against PLHIV and their families.

The difficulty in establishing effective HIV and AIDS programmes stems from a lack of openness regarding sexuality, male-female relationships, illness and death, and taboo subjects deeply rooted in cultures. Cultural practices such as wife inheritance among some communities can lead to infection with HIV and re-infections of PLHIV.

Culture can influence VCT visits as well as disclosure and openness of the society, thereby re-enforcing the terrain in which HIV thrives and making treatment difficult.

3.11 Poverty, inequality and HIV

The HIV pandemic has not spared any part of the world. It is present in rich and poor countries. However, the poorer countries are more affected. The highest prevalence rates and the highest numbers of new infections and deaths related to HIV occur in Sub-Saharan Africa.6

Poverty worsens the impact of an HIV infection and makes people more vulnerable to HIV:

• It is often linked with a lack of education, which makes people more vulnerable to HIV because they don’t know how to prevent it.
• It forces women and young girls into prostitution and sugar daddy situations, further exposing them to HIV.
• Poverty forces men to migrate to larger cities in search of work, often leaving their partners behind. This results in multiple sex partners, which heightens the risk of HIV infection.

• Makes it difficult for infected people to obtain enough food to eat a balanced diet that is necessary to strengthen their immune systems and recover their strength with ARVs.

• Poverty can prevent infected people from accessing health care services.

In addition, HIV infection can lead to poverty or increase it, especially where access to treatment is still an issue. This is because:

• People living with HIV may not be able to go to work and therefore will lose their income.

• Partners of people living with HIV may drop out of work in order to care for their sick partners.

• People often spend a large amount of money on treatment and funeral costs, which leaves the family impoverished.

Furthermore, inequalities render certain groups more vulnerable to HIV than others. Women and girls, for example, are more vulnerable to HIV because of certain inequalities. For instance being denied proper education subsequent lack of economic independence hinders them in most cases, from taking charge of their own lives sometimes. They are unable to access proper health care, and often have no power to refuse sexual relationships, especially in exchange for certain favours, such as basic foods or accommodation. In addition, certain cultural traditions and practices, such as the inheritance of widows, lead to an increased risk of acquiring HIV. In many situations, women often have fewer legal rights than men. Church leaders need to advocate for the rights of the poor and the marginalised in society. Programmes to alleviate the impact of poverty and to support poor and marginalised groups should be on the Churches’ agenda.

3.12 Challenges of antiretroviral treatment in emergency situations

Emergencies such as famine, war, floods, and other humanitarian crises that cause the displacement of large numbers of people undoubtedly affect antiretroviral treatment. Emergencies pose challenges to treatment adherence and might increase the spread of HIV because:

• People cannot carry their ARVs with them.

• The drug supply chain is broken.

• People end up living with different people who may stigmatise them if they find out.

• Home-based care is disrupted.

• Food and nutritional support is interrupted.
• In case of floods, the absence of clean water and basic hygiene exposes people living with HIV to infection.
• People develop new coping behaviours that expose them to HIV and other secondary infections that may not respond to first line ARVs.
• Hospitals and testing facilities are disrupted.
• Stress levels are increased within the community, leading to unsafe behaviour like casual unprotected sex.
• Women and young girls are more at risk of rape and HIV infection.

Church leaders can speak on behalf of those affected by an emergency; they can visit the decision makers and inform those who can bring ARVs about what is needed.

3.13 Lack of Church policy on HIV and AIDS response

“The Lord answered me and said, ‘write the vision, make it plain upon tables, that he may run that readeth it. For the vision is yet for an appointed time...’” – Habakkuk 2:2-3 KJV

A number of churches, such as the Catholic Church, Evangelical Lutheran Church of Tanzania, Kenya Evangelical Lutheran Church, and a few others, have operational HIV and AIDS prevention and treatment policy guidelines. However, many churches in Africa are yet to formulate HIV and AIDS policies.

This general lack of policy guidelines often leaves the clergy and other church programme leaders without a clear picture of the position of their churches on HIV and AIDS prevention and treatment. Church leaders are therefore not able to effectively bring correct HIV and AIDS messages into their day-to-day work. (See exercise 13 on how to formulate a policy)

3.13.1 What is an HIV and AIDS policy?

A policy on HIV and AIDS is a clearly stated opinion and advance decisions made by the concerned institution. It is a statement of commitment by the institution to respond to HIV and AIDS in a particular way.

3.13.2 Why should the Church have an HIV and AIDS policy?

A church HIV and AIDS policy defines the church’s position and practices in relation to HIV and AIDS prevention, treatment and its related impact. It prepares the particular church to deal with issues and challenges related to HIV and AIDS in the community. A church with an HIV and AIDS policy demonstrates that it is committed to taking active
steps to manage the HIV and AIDS pandemic. However, such commitment must be taken further into concrete action in the form of an HIV and AIDS programme.

A church HIV and AIDS policy is therefore central to the development and implementation of an effective HIV and AIDS strategic plan and response programme. It provides the framework for action, ensures consistency and lays down the standards of behaviour for all church workers and the congregation, whether infected or not. It pre-empts inaction and difficult decisions on HIV and AIDS response. The Church should not view the formulation of a policy on HIV and AIDS as an option, but as a responsibility to the people and a calling from God.

A Church policy on HIV and AIDS is intended to answer the following questions:

- Where does the Church stand regarding HIV and AIDS?
- What is the Church committed to doing from now on?
- What does the Church do, how does it do it, and in what regions?
- What is the responsibility of the organs of the Church in responding to HIV and AIDS?
- Who does the Church work with and what will be the role of the Church in the partnership?
- How does the Church respond to emerging challenges of HIV and AIDS and its related impacts?

Depending on the situation, a Church policy on HIV and AIDS may either be in the form of a detailed document, or a simple statement by the Church leadership. Care must be taken to ensure that the policy is not developed to support or justify any current Church programmes. Rather, it must provide guidelines for quality work in the present and in the future.
Chapter 4

The Role of Church Leaders in Antiretroviral Treatment

Given the opportunity, people who are taking antiretroviral drugs (ARVs) can lead a fulfilling life. They can work and contribute to their family and their society, take their children to school and see them grow. However, there remains a wide gap between what we know needs to be done today and what is actually happening in our societies.

Churches and church leaders should be encouraged to include antiretroviral treatment literacy in theological training. There is a need to undertake practical measures, such as promoting HIV prevention, encouraging early HIV testing and fighting social and economic injustices in the Church and in communities. Most importantly, church leaders need to take an active leadership role in advocating for access to antiretroviral treatment for people living with HIV. They should also consider developing strategies to:

- Promote and uphold the basic rights of people living with HIV
- Advocate for comprehensive care, which includes increased access to antiretroviral drugs
- Provide spiritual support for various groups and individuals
- Create awareness on social and theological issues about HIV and AIDS, that contribute to stigmatisation and discrimination through discussions, sermons, workshops, Sunday schools, and fellowship meetings
- Participate in advocacy programmes
- Involve people living with HIV in programme planning, implementation, and management for HIV and AIDS interventions
- Promote exchange visits aimed at information sharing locally, nationally and internationally
- Provide care and support to mothers, orphans, and children living with HIV
- Create opportunities for public interaction between church leaders and people living with HIV
- Support networking and collaboration among churches.
- Encourage formation of support groups
In 2008, an estimated 22.4 million adults and children in Sub-Saharan Africa were living with HIV. How can the Church play a role in ensuring that those among the 22.4 million who need treatment can access it?

A lot has been said about HIV prevention. Many people have been equipped with skills on home-based care. Various cadres of HIV counsellors have also been trained. However, less time has been spent examining the role that the Church could play in antiretroviral treatment.

In responses towards antiretroviral treatment, words mean a lot. Some words may have negative connotations and could reverse efforts to encourage acceptance of antiretroviral treatment. Language can be a potent tool for stigmatisation and exclusion. Leaders should watch their language when talking or writing about HIV and AIDS.

HIV positive pastors and others have the potential to be the most powerful resource people in combating stigma and discrimination, to the glory of our God.

When the Anglican priest, Gideon Byamugisha, risked scandal and discrimination by coming out and living openly with HIV, the Church in Uganda made him a Canon. He says: “We have to deal with our own denial before taking on stigma. Only then can we deal with stigma and discrimination on the outside.”

Table 4.1 suggests words and expressions that should or should not be used in HIV and AIDS interventions and when communicating with people living with HIV.

<table>
<thead>
<tr>
<th>DON’T USE THIS</th>
<th>USE THIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV / AIDS</td>
<td>Use HIV unless specifically referring to AIDS. Examples include people living with HIV, the HIV epidemic, HIV prevalence, HIV prevention, HIV testing, HIV-related disease; AIDS diagnosis, children made vulnerable by AIDS, children orphaned by AIDS, the AIDS response. Both HIV epidemic and AIDS pandemic are acceptable.</td>
</tr>
<tr>
<td>AIDS virus</td>
<td>There is no “AIDS virus”. The virus associated with AIDS is called the human immunodeficiency virus, or HIV. Please note: the phrase HIV virus is redundant. Use HIV.</td>
</tr>
</tbody>
</table>

Innocent victims

Use children with HIV or HIV positive people. The term “victim” is usually used to describe HIV positive children or people with medically acquired HIV infection (through blood transfusions, etc). It wrongly implies that people infected in other ways are guilty of some wrongdoing and somehow deserving of punishment. This feeds discrimination and should be avoided.

AIDS-infected

Avoid the term infected. Use person living with HIV or HIV-positive person. No one can be infected with AIDS, because it is not an infectious agent. AIDS is a surveillance definition meaning a syndrome of opportunistic infections and diseases that can develop as immunosuppression deepens along the continuum of HIV infection from primary infection to death.

AIDS test

There is no test for AIDS. Use HIV or HIV antibody test.

AIDS patient

Use the term patient only when referring to a clinical setting. Preferred: patient with HIV-related illness.

AIDS sufferer or victim

The word ‘victim’ is disempowering. Use person living with HIV. Use the term AIDS only when referring to a person with a clinical AIDS diagnosis.

Risk of AIDS

Use risk of HIV infection; risk of exposure to HIV.

Fight against AIDS

Response to AIDS


4.1 The Church has many roles

The theme of love is constant and consistent in the Bible. The Church needs to be the pivotal point of showing the love of Christ, particularly in these times of HIV. Church leaders need to be giving correct and appropriate information as regards antiretroviral treatment. The Church needs to be at the centre of mobilising the community, not only towards antiretroviral treatment, but also towards other associated projects within the community.

In Luke 5:17–21, the Bible offers a story of four people who had a very sick friend. They knew where to find healing, and they proceeded to take their friend there. They carried him in a rug, irrespective of obstacles, ensured he reached the point of healing, which was Christ.

There is great need for church leaders to maintain this role when it comes to antiretroviral
treatment. When the Church takes on this role, then an opportunity is created not only for treatment but also for healing.

The Church has a lot of resources. The unfortunate thing is the fact that, in many communities, resources are associated with finances. The portion of scripture in (Colossians 2:1-3 KJV) “For I want you to know what a great conflict I have for you and those in Laodicea, and for as many as have not seen my face in the flesh, that their hearts may be encouraged, being knit together in love, and attaining to all riches of the full assurance of understanding, to the knowledge of the mystery of God, both of the Father and of Christ, in whom are hidden all the treasures of wisdom and knowledge.” encourages us to not only have the resources, but also the wisdom on how to maximise them. This wisdom is found in Christ. For this to occur, church leaders need to lay down their doctrinal differences for the sake of the people God has called them to serve.

Matthew 5:13 puts it quite clearly to us that we are the salt of the earth. However when salt looses its saltiness, it becomes useless and should be discarded. As seen above, the Church has a critical role to play in treatment and should do so now. Otherwise, we stand the risk of allowing other voices and parties to be the salt in an issue where the Church should be providing leadership.

4.2 Supporting ART in times of emergencies

Church responses to HIV and AIDS in humanitarian crises need to encompass antiretroviral treatment. This should be considered as an integral part of humanitarian relief, considering also that HIV and AIDS are contributory factors to poverty in the long run.

Therefore:

- The Church and other humanitarian agencies need to mainstream the consideration of antiretroviral treatment issues, both internally in
organisational policies and externally throughout the programme cycle and across the different ministerial sectors of response.

- Churches and church leaders should endeavour to link humanitarian aid programming, where possible, to the development of local capacity for long-term antiretroviral treatment and care provision.

When responding to humanitarian crises, the Church should take into account that some of the affected people are in need of ARVs. This will enable the Church to respond more appropriately to the needs of the people.

### 4.3 Antiretroviral treatment advocacy

Advocacy for antiretroviral treatment represents the strategies devised, actions taken and solutions proposed to influence decision-making at the local, state or corporate levels to create positive change in the availability of and access to antiretroviral treatment, care and support.

It involves influencing people with power to correct an unfair or harmful situation. It is also the effort to change public perceptions and affect policy decisions and funding priorities.

Advocacy educates about an issue and suggests a specific solution. It involves making a case in favour of a particular issue, using skilful persuasion and strategic action.

Simply put, advocacy means actively supporting a cause and trying to get others to support it.

To be properly engaged in advocacy, one has to understand what he/she is advocating for. For church leaders, it is very important to ensure that they have all the correct information on the issues around antiretroviral treatment. The biggest issues that the Church needs to address are stigma and discrimination, when, stigma is addressed, the Church has to lobby for equitable resource distribution without discrimination. In addition, be in a position to understand antiretroviral treatment well enough to enable them demand high quality care for the people.
4.3.1 **Advocacy versus other change methods**

Advocacy is often confused with Information, Education and Communication (IEC) projects, community mobilisation and lobbying but there are differences, as explained below.

- **Advocacy** is used to bring about change in policies, programmes and/or positions through influencing specific people/groups/institutions.
- **Information, Education and Communication** is used to raise public awareness.
- **Community mobilisation** is used to mobilise community support/action.
- **Lobbying** involves activities aimed at influencing public officials, and especially members of a legislative body, to promote or secure the passage of particular legislation. In this context, it could be about passing laws seeking justice in the availability and access to ARVs for people living with HIV.

Advocacy is a problem-solving mechanism used to:

- Protect rights or change discriminatory or abusive behaviour to fair, equal, and humane actions towards people living with HIV;
- Improve services, gain eligibility for services, or change the amount or quality of treatment services to better meet the needs of people with HIV and the society;
- Remove barriers that prevent access to full participation of people with HIV in community life.

Advocacy work can include many different activities, such as lobbying, mobilisation, education, research, and networking. It can be undertaken single-handedly, by a group of people, or as part of a network. It can be spontaneous or carefully planned as a one-off intervention, or as an ongoing process.

Advocacy involves:

- Identifying something that needs to be changed
- Identifying how it should be changed
- Communicating to those who have control over the situation and convincing them that it should be changed.

Advocacy aims to change practices, policies, and laws in the following manner:

- Practices : How things are done in real life
• Policies: Formal or informal guidelines for how things are supposed to be done
• Laws: Legislation that provides legal guidelines regarding a certain issue or area.

4.3.2 Why Church leaders should advocate for treatment access

There is a great need for advocacy for access to antiretroviral treatment. Every year, millions of people in Sub-Saharan Africa die as a result of AIDS. Many of these deaths could be prevented if antiretroviral treatment was available to them.

No single person or organisation can address all the treatment needs of people with HIV. Church leaders must work with other partners and initiatives to improve the quality of the treatment that is provided, and to help reach more people.

Advocacy for access to treatment is required to:

• Increase public knowledge on available antiretroviral drugs that have been proven to be effective;
• Compel governments to guarantee the right to health for HIV-positive people;
• Lobby for increased access to life-long treatment;
• Ensure equitable access to treatment across regions, gender, and cultural and social groups;
• Lobby producers of HIV medicines and international lawmakers to keep prices at a minimum or for free.

Advocacy for access to treatment is necessary because:

• People have a right to health
• Antiretroviral treatment for HIV works and can save lives
• The number of people needing treatment is very high and increasing
• Access needs to be equitable
• The poor and marginalised, such as women and children, are usually left out
• Patent laws make it difficult to access cheaper medicines.

Being an advocate for a cause means many different things. It can be as simple as making sure your loved one is getting the best treatment and care possible, or challenging the government, community, doctors or pharmaceutical companies on treatment-related issues.
Advocacy is not confrontation. Developing an advocacy campaign requires clarity about the goals that the Church leaders may want to seek, available strategies and resources, and potential allies and opponents.

**Table 4.2  Summary of the role of church leaders in supporting antiretroviral treatment**

<table>
<thead>
<tr>
<th>ANTIRETROVIRAL TREATMENT CHALLENGE</th>
<th>WHAT CHURCH LEADERS CAN DO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of knowledge of one’s HIV status</td>
<td>Acquire knowledge and facts about antiretroviral treatment and share it with the congregations. Encouraging people to go for HIV testing</td>
</tr>
<tr>
<td>Stigma and discrimination</td>
<td>Break the silence: There is no doubt that silence around HIV and AIDS fuels stigma: Church leaders can help to break the silence by talking openly about sexuality</td>
</tr>
<tr>
<td></td>
<td>• Empowering church leaders and workers to talk about HIV developing their capacity in the language of compassion and support</td>
</tr>
<tr>
<td></td>
<td>• Avoid creating fear in people</td>
</tr>
<tr>
<td></td>
<td>• Partner with people living with HIV to deliver the message</td>
</tr>
<tr>
<td></td>
<td>• Use simple language to convey ideas on HIV and AIDS – “Invent new phrases because people are tired with the same old language of sin and death”</td>
</tr>
<tr>
<td>Availability of drugs</td>
<td>Provide drugs through church based health facilities</td>
</tr>
<tr>
<td></td>
<td>Lobby the government to make drugs available for all</td>
</tr>
<tr>
<td>Poor adherence</td>
<td>Educate the congregation on the need for testing, counselling and treatment adherence</td>
</tr>
<tr>
<td></td>
<td>Respond effectively to eradicate stigma in the church and in the community</td>
</tr>
<tr>
<td></td>
<td>Send the message of love and care</td>
</tr>
</tbody>
</table>
| Poor nutrition                      | • Provide food for those who need it most  
|                                   | • Challenge the church to support the sick  
|                                   | • Encourage the formation of support groups for HIV positive people in the church.  
|                                   | • Encourage Income Generating Activities (IGAs) e.g Kitchen garden, poultry etc  |
| Lack of access to health care     | • Take the medicine to the people  
|                                   | • Provide means for people to access the drugs  
|                                   | • Involve faith-based health facilities in HIV infection prevention and treatment activities/programmes.  |
| Poverty, injustices, governance, HIV and AIDS, and the Church | • Use the church as a platform for advocacy and as a voice for the poor to access treatment and care.  |
| Inadequate care and support       | • Challenge the congregations and families to support their sick and create a sustainable programme for reaching out to the sick.  |
| Lack of information and knowledge | • Keep the HIV and AIDS messages alive in the church and in the communities  
|                                   | • Keep the clergy and other church leaders informed about HIV infection and its challenges.  |
| Faith healing versus medical treatment | • Praise the treatment gift from God  
|                                   | • Inform about the role of HIV testing and faith healing  |
| Lack of adequate human resources  | • Create a system for provision of adequate health care personnel through both employment and volunteer programmes.  |
| Health infrastructure             | • Build new and strengthen the existing faith-based health facilities to deal with the HIV epidemic  
|                                   | • Challenge the government to improve the public health facilities.  |
| Church policy on treatment         | • Develop, communicate, and implement appropriate HIV and AIDS policies within the church, and set up a department and programmes that deal with HIV and AIDS.  |
| New developments in HIV and its treatment | • As new knowledge on the virus emerges, church leaders need to keep abreast with new developments and how they affect people. This will ensure that church programmes are relevant and responsive to the needs of the people.  |
| Accountability and management of drugs | The Church must remain accountable to the people and donor agencies if it has to access antiretroviral treatment. This may mean strengthening Church institutional and human resources capacity to access and be accountable for global HIV funds. |
KEY MESSAGES TO COMMUNICATE

- Everyone needs to know their HIV status so they can get help at the right time.
- Antiretroviral drugs (ARVs) are a treatment, not a cure.
- People who take ARVs must do so for the rest of their lives.
- ARVs should only be taken with a doctor’s recommendation.
- Sharing ARVs does not work and endangers lives.
- Even when someone is taking ARVs, they can still infect another person with HIV.
- Even when a person is taking ARVs, they can still be infected with a different type (or strain) of HIV.
- ARVs may not work if they are taken too late and the person is too sick.
- A person taking ARVs needs to adhere to their treatment instructions, taking them every day and on time. Other people can help them to remember this.
- Children need special types and amounts of ARVs.
- Someone taking ARVs will also need to eat the right types and amount of food.
- If a person taking ARVs has side-effects, they should go to the doctor immediately.
INTRODUCTION TO EXERCISES

SELF-TEACHING AND GROUP LEARNING AMONG CHURCH LEADERS AND CONGREGATIONAL GROUPS

Introduction

In churches and church health services (CHSs), the issues surrounding antiretroviral drugs (ARVs) require the rethinking of ‘old’ approaches, as well as the introduction of new ones. Despite many years of efforts to address HIV and AIDS stigma in churches, there remain large problems in this area. Whether it is the casting out of leaders who are HIV positive or the linking of HIV and AIDS to immoral behaviour on the part of the affected person, there are still very few churches in which stigma does not exist in some form.

A review of international responses from church-based organizations indicates that the following activities should be undertaken.

- New materials should be produced for church leaders that focus on ARVs and their impact on peoples’ lives and the work of churches.
- Re-training should be carried out for all church leaders in order to add ARV information to their knowledge base.
- Increased support for voluntary HIV testing, possibly with subsidised transport and through setting an example.
- Curricula in institutions that train church leaders should be updated to include antiretroviral drugs and treatment and key documentation should be made available in resource centres.
- New materials that focus on ARVs and systems-based requirements should be produced for senior church health service managers.
- Efforts should be made to contact the main local producers of HIV and AIDS church-related information in order to encourage them (through written and verbal briefings) to update any new or existing materials.

Whether you are teaching yourself through reading this document, or planning to run a workshop or group session, a number of exercises are described here that will help increase your own, or the group’s, treatment literacy.

Individuals will want to go through the exercises and follow the instructions for themselves. It is like playing checkers with yourself – you need to be disciplined and do the work if this part of the document is going to work for you. Reading the information sheets alone and not testing yourself with the exercises will mean that the information won’t be retained in your mind. One of the main ways that we all learn is through information being brought alive through using it.
If you are going to lead a group, use the exercise instructions to tell the group what you want them to do.

The information sheets are referred to throughout the exercises. When a person reads information, they may only remember as little as 20% of it. This is why we introduce exercises and other teaching tools, to help people remember up to 100% of the information.

In the following exercises, there are:

- Facts to find
- Opinions to discover
- Ideas to debate
- Challenging case studies, quotes and scenarios
- Opportunities for action.
EXERCISE 1

KNOWING THE FACTS

Ideas for using the facts

You might want to use these facts as a leaflet; on a notice board; to get people to learn them off by heart; make them into a song of praise; or use them to open meetings or workshops on the subject. Make them part of an advocacy campaign, particularly if ARVs are expensive or not easily available.

Whether you are teaching yourself through reading this document, or planning to run a workshop, you will need certain facts at your fingertips. These facts will not only help you to minister to those living with or affected by HIV, but also will encourage those around you who have compassion to give.

Information is the key to getting messages correct, so please take the time to fill in the information below. This will help you know the epidemic in your country and know where to send people locally for HIV testing or for ARVs.

If you have access to the internet, you may wish to look up the facts on HIV and AIDS for your country. These facts can help you make a big difference in many peoples lives.

HIV

1. What is the approximate number of people living with HIV in your country?

2. Some countries have areas with higher HIV prevalence (number of people living with HIV) than others; if there is a local figure for HIV prevalence, you should know this figure too.

3. Where should local people go to get tested for HIV?

4. How much does it cost to get tested locally for HIV?
ARVs

5. How many people are receiving ARVs in your country?

6. How many people are estimated to need ARVs in your country?

7. Where should people go to get ARVs?

8. How much do ARVs cost at this location and is there any assistance for people who cannot afford?

This information should enable you to help people gain access to ARVs. It is possible that more people need ARVs than there are ARVs available at the moment. But if a person has no knowledge of their HIV status and no contact with a hospital in order to be on a waiting list, then there is little chance that they will get them if they need them.

Protecting children

9. How many pregnant women are estimated to have HIV in your country?

10. What is the likelihood of HIV being transmitted to a child during birth?

11. What is the likelihood of HIV being transmitted to a child through breastfeeding?

12. Where can a pregnant woman go to be tested and receive ARVs for the prevention of mother-to-child transmission (ARVs for PMTCT) to protect their child?

This information should enable you to help parents protect their children and give those children an incredibly important birth present.
UNDERSTANDING PEOPLE’S OPINIONS

HIV and antiretroviral treatment with ARVs are not just scientific subjects; they are emotional ones. You and everyone around you will have varying ideas about these subjects. Sometimes people try to protect themselves through denial, by believing things are not true, when in fact, they are true. When people are given incorrect information, they can be genuinely confused. Before trying to change your own or other people’s ideas, it is important to know what you think, and what they think.

It is not possible to simply take new information and dump it on top of old information and hope that the old ideas will be forgotten. It is important to directly address the existing knowledge (right or wrong; up-to-date or out-of-date). So, the first step is to find out what you are really thinking and what they are really thinking.

No one is prepared to say what they think if someone else is going to laugh at them or make a show of correcting them, so this exercise is not a test of people’s knowledge. This is an exercise to find out what people think so that everyone can gain access to the right ideas and knowledge.

Fill in the answers to the questions below – there are no right or wrong answers, only truthful answers.

If you are teaching yourself, write down the answers and then look at the information sheets and see if you are right.

If you are working with a group, get each person in the group to fill in the answers to the questions. Explain that there will be no scoring and no individual results for the answers. Give them 30 minutes to finish, and then collect the answer papers. At the next break, go through the papers and pick out the main areas of concern. In the following session, draw attention to the relevant points in the information sheets while explaining any answers that were incorrect.

Don’t quote or identify individuals or say how many said this or that. This exercise is a good way to find out how much work is needed on treatment literacy. If everyone has been able to answer the first question correctly, then you can praise them and move on to the next question. If some people have got the answer wrong, then you should take time to explain to everyone what ARVs are, using the information sheets in this guide.
1. What are ARVs?

2. For how long does a person have to take them?

3. What are the main benefits of taking ARVs for a patient?

4. Who should be helped to take ARVs?

5. Is there any kind of person who should not get access to ARVs?

6. Please indicate what you think is the estimated number of people with HIV or AIDS in your country?

7. Currently how many people do you think are receiving ARVs in the country?

8. What information do you think people need about ARVs?

9. Are there any reasons why people might find ARVs difficult to take properly?

10. Have you heard any people saying things about ARVs which you don’t think are true?

11. If so what are they saying?

12. What do you think are the main obstacles against increasing the number of people who receive ARVs?

13. Do you have any questions about ARVs that you would like answered in the future?
EXERCISE 3

HOLDING A GROUP DISCUSSION ABOUT ARVs

If you are teaching yourself, you can’t hold a focus group on your own, but you can answer the questions below and think through the answers. For a group, the best size is from 3 people up to 15 people at the most. It is important to treat all ‘thoughts’ as valuable and to allow laughter and discussion. People need to feel free to talk and interested in what other people have to say, so avoid telling anyone that they are wrong or right, or correcting or praising particular ideas.

If you don’t want to hold a full focus group, simply chair a discussion group as a meeting of equals with the acceptance of different ideas.

Ideas for use

A focus group can be used as part of a discussion among church leaders, but it can also be held among congregations, with youth or women’s groups, etc. It’s a good way to start when finding out what people think, and people can learn from each other through being involved in a debate, rather than being lectured to in a school room environment, which often does not work so well.

This is a particularly good exercise if you can get groups of the same type of people together; young people rarely talk openly in front of their parents; women often don’t talk freely in front of men, etc. You need people to talk openly so that you can find out

Explain why the group has been called together, or introduce this as the next piece of group work. Explain that there are no right or wrong answers.

Open the discussion with question 1, and then move the group on to the other questions as they discuss each point.

1. Does anyone know what ARVs are?

If there are one or more answers, get the group to choose which one is more right or see if they agree on the answer given.

If they ask you, tell them very simply what ARVs are (referring to the information sheets in the guide).

(i) What are the good things about ARVs?

(ii) What are the bad things about ARVs?

2. Who would you ask about ARVs, if you had a question?

(i) Who is the best person to ask?
This may be different from the person that they would actually ask. Check who they would actually ask, and (if it is a different person) ask them why.

3. What do they think parents should know about ARVs?

4. What do you think young people should know about ARVs?

5. What do you think neighbours should know about ARVs?

6. If someone came to them and asked about ARVs, what questions would they dread being asked?

7. Have they ever been asked about ARVs and, if so, what were the questions. If no one has been asked – why do they think no one asks them?

8. Would you marry or advise marriage to someone on ARVs?

9. Do they have any questions about ARVs?

Perhaps other people in the group know the answer to their questions? If not, then the person leading the discussion has to answer (referring to the information sheets, if possible).
THINKING ABOUT WHAT WE WOULD SAY

It is sometimes easier to get a group of people to split into smaller groups and talk together, rather than have them work in one large group. This exercise should only be used after the group has become familiar with the basic facts about antiretroviral treatment.

Choose a number of quotes and give a copy of one quote to each group. Ask them to plan out a sermon or a speech using this quote and in the context of ARVs. Don’t forget to make sure that they have access to the information sheets in this guide and the facts list you have developed in Exercise 1.

Give them 30 - 60 minutes to decide on their answer, pick a speaker for their group, and prepare a 5-10 minute presentation. Call all the small groups back together again and then ask each group in turn to make their speech.

Listen carefully and make sure they get all their facts right.

You could choose to give all the groups the same quote and then see how many different interpretations are offered, or use a different quote for each group. Either way, after each speech, you can ask the rest of the group to comment on whether they agree or if there are any points missing.

This exercise allows the group members to voice their opinions without being judged and helps them bring out the messages and information they think people need to hear.

Ideas for use

Any of the quotes could be used for your own sermon, or in a bible study or special group meeting. They are inspirational and can draw out lots of good ideas for things that can be done. However, they do need quite a lot of thought, and if you use them in a sermon, you will need to include information from the facts list from Exercise 1 as well.

Quotations from the Bible

My people are destroyed for lack of knowledge (Hosea 4:6).

The Spirit of the Lord is on me because He has anointed me to preach good news to the poor. He has sent me to proclaim freedom for the prisoners and recovery of sight for the blind; to release the oppressed, and to proclaim the Year of the Lord’s Favour (Luke 4:8 - 9).
We shall remember, proclaim and act on the fact that the earth and everything in it belongs to the Lord and that He has given it over to all human beings for custodianship (Psalms 24:1 and Genesis 1:29).

The Church as a fountain of wisdom (Col 2:1-3).

The Church as a centre of love (Mark 12:31, John 15:12, Rom 12:9).

The Church as an embracing family (1 Timothy 5:8).

I was hungry and you gave me food. I was thirsty and you gave me something to drink. I was a stranger and you welcomed me. I was naked and you gave me clothing. I was sick and you took care of me. I was in prison and you visited me (Matthew 25:35-46).

We are all members of the body of Christ; if one member suffers, we all suffer together (Corinthians 2:26).

Quotes from other sources

We shall, therefore, openly and persistently undertake a prophetic and advocacy role for all the infected who are denied access to affordable HIV and AIDS drugs until anti-retrovirals are available to all who need them.

All Africa Conference of Churches (AACC), Covenant document on HIV and AIDS, Covenant 3: Treatment and HIV and AIDS drugs.

The Lord God is the creator of heaven and earth; the creator of all life forms in the earth community. He created all life and everything good. In this HIV and AIDS era, He sees the misery of His people, who are infected and affected by this disease. He has heard their cry on the account of this epidemic. He knows their sufferings and He has come down to deliver them from HIV and AIDS. So He calls to send us to the infected and affected, to bring his people, his creation, out of the HIV and AIDS epidemic.

All Africa Conference of Churches (AACC), Covenant document on HIV and AIDS, Preamble.

“Silence kills, stigma kills. We should not want those living with HIV to be the modern equivalent of the biblical leper who had to carry a bell and a sign saying, ‘I am unclean’”.

Archbishop Desmond Tutu, July 2004
“Our earlier approach in fighting AIDS was misplaced, since we likened it to a disease for sinners and a curse from God.” Archbishop Benjamin Nzimbi, Anglican Church of Kenya

“A study in Uganda by the Mildmay Centre found that limited knowledge and negative attitudes towards ARVs on the part of health workers and patients were the main limiting factors to ART uptake. Intervention to increase health workers knowledge and to use people already taking ARVs to educate others increased the uptake. Community education is also essential to ensure adherence, dispel unrealistic expectations and avoid increasing risk behaviour.”


“People are ready for the ARVs, but they will not take the medicine if they can’t find them and if they are not given the appropriate information on how to use them.” Person living with HIV, Zambia (International HIV and AIDS Alliance, 2002)
EXERCISE 5

ANSWERING QUESTIONS

The list of questions in this exercise could be used as a quiz game, asking the questions to teams or individuals and offering a small prize at the end. The aim is to make sure people can answer the questions easily and fluently, with the correct information.

Ideas for use

If you are inviting someone who is taking ARVs to talk to a congregation, you might want to ask them to make sure they tell the congregation the correct answers to these questions. Check with the speaker beforehand that they are comfortable with this idea – remember that not everyone who is taking ARVs knows all the answers.

Questions

1. I have got HIV - What have I got?

2. I have AIDS - Will I survive?

3. How is HIV transmitted?

4. What about marriage and children?

5. Is there a cure for HIV?

6. How do I get ARVs?

7. Why should I get tested for HIV?

8. I am frightened of knowing if I have HIV. What should I do?
9. Will the church reject me if I have HIV?

10. Are ARVs expensive?

11. If I am taking ARVs, can I still infect my wife?

12. Last week, I forgot to take my pills. What shall I do?

13. I am taking ARVs but I feel ill. What should I do?

14. I am frightened of telling my family that I am taking ARVs. What should I do?

15. I am having a baby but I am worried about HIV. What should I do?

16. If I get tested first, my family will blame me for bringing HIV to the family. What should I do?

17. Should I breastfeed if I have HIV?

18. My husband won’t go for an HIV test, but he is very ill. How can I get him to go?

19. I am not ill, so why should I be tested for HIV?

20. I was told that if I drank cow urine every morning for 40 days, God would heal me. Is this true?

21. I was told that if I slept with the animals for 40 days and 40 nights, I would be cured. Is this true?

22. My friend told me that if he had sex with a virgin, he would be cured. Is this true?
23. I know that you only get HIV through immoral sex. How else can you get HIV?

24. I don’t understand. I was faithful to my husband and yet I have HIV. What should I do?

25. I was born with HIV, but people think I have got it by sinning. What do I say to them?

26. Are ARVs the AIDS drugs that cure you?

27. There is no point in knowing your HIV status, as no one can help. Is this true?

28. My child is ill, so I am sharing my ARVs with her. Will this work?

29. I know ARVs can kill you. Shall I still take them?

30. Is it true that you can go for help too late?
LEARNING FROM THOSE WHO KNOW
In this exercise there are some quotes from people who know what living with HIV is really like and they have described how they feel about ARVs, and their experiences of their churches.

Give a quote to a small group or to individuals. Ask them to read it and identify what they have learnt from the story, and then to share the story and the lessons with the group.

Ideas for use

These stories could be written up on large sheets of paper and used in a display; if possible, include the experiences of people from the local community – everyone’s story is important. The exhibition could be called ‘experiences at home and abroad’. People may be shocked and even disturbed, but add an extra sheet of paper to ask people if they think this could happen in their village or church.

A youth group may be able to turn these stories into short plays that they could perform for other groups in the church or after services. Having young people act out these scenarios can really bring them to life and will certainly get people talking and learning about HIV and antiretroviral treatment.

They are all true stories.

True stories

Story 1
I found out that I had HIV in 1992 because the San Francisco clinic gave free VCT and promised to help people if they were positive. I did not tell anyone in the church or even my parents. I was strong and did not feel ill, but in my head there was a ‘critical madness’ versus ‘disappointment’ because all I could see was death. I am not afraid of the ARVs because I wanted them and there are no side-effects, but I hear a lot of people fearing them because of the side-effects. I was given the instructions ‘stop drinking and smoking’, ‘you can still pass it on’, ‘don’t overwork’, ‘be disciplined about taking the medicines’, and ‘eat properly’.

At the beginning, I didn’t tell anyone - I would have been left on an island if they had known. But now people are much freer to speak out. The government has pioneered
these changes but the church was sluggish. The church ignores the issue and looks away because it links the virus and sin. But how can you be more sinful than a sinner?

**Story 2**

The problem is in the hands of the top leaders of the church. There is a snake in the cooking pot – we must kill it, or we won’t eat, and we must not break the pot. The church knows the snake is in the room, but not where, nor how valuable the pot is.”

**Story 3**

I have had HIV since at least 1990 and I have been on ARVs for two months. I know that not all parish priests know about HIV properly, and certainly don’t know about ARVs. Most senior church leaders know, but they don’t speak in public. I am the leader of 11 HIV and AIDS support groups, and I am open about my status to those who are welcoming.

The problem is people only really go for VCT if they are going to get married or their partner or child has died. Most people don’t think about AIDS and get a test until it is very late, and they are already dying.

For those people on ARVs, the big problem is insufficient food. My church does give out food, but not enough and not linked to ARVs or HIV. I have a choir that sings in the streets to spread the message about VCT.

People do link AIDS to immorality, so most people don’t speak about it but when people are open about HIV, their burden is lifted. Each member of the group pays RFR 500 per month that goes to pay for members who are financially in trouble, for children’s school costs, or to repair their homes. This quickly adds up and it is important to be careful how the money is used.

I am most often asked how to get ARVs and whether they will kill people. People worry about this because some people come too late and die, even though they are on ARVs. I know that children can be treated, but I worry about children in foster families, as they are often used like slaves and often the family won’t spend any money or time on them.

Sometimes it seems that the church fears because it doesn’t want a sinner to stand among the sinless, but who is sinless? Initially the church wanted me to be quiet. It’s better now, but church leaders often go to sensitizing meetings but do nothing after. Pastors with HIV help people to understand that the snake is in the house, and if they are not careful, they will be eaten. But both the church and the government still have people who don’t want to admit that they have HIV.”

**Story 4**

“The main problem is that anything to do with money causes the church to shy away due to our limited resources.
There are no theological concerns about ARVs in my church, but perhaps more explaining needs to be done around ARVs. I don’t believe that my church is judgemental, but it does need more information. We are happy to pass on any experience or knowledge. There is work in the mothers’ union, sports outreach, priests, pastors, and support groups, but it is true that work varies between the pastors. I believe that the church needs money to bring everyone to sit together to learn about the issues, to produce materials, and to train trainers.”

**Story 5**

“I set out to develop a programme for nine areas. My first problem was stigma. Initially, HIV and AIDS was seen as proof and punishment of sin, but most churches have since changed their attitude but I am not sure what this means in terms of actions. They do some work to increase VCT, but at the moment do not do anything on ARVs.

The church is encouraging people to know more, to talk about their personal experiences, and address unanswered questions. We understand that personal stories help us to minister. We believe that every individual church should be doing something to help the affected and infected and to preserve the majority. Last year, November was HIV Month in terms of reflecting. We sent materials to every church and we asked for a feedback, but unfortunately we have not received any response.

My church supports an ecumenical group of religious leaders who are infected. In Rwanda, many pastors have no training on HIV and they are left to come to their own conclusions. None of our pastors have been trained on ARVs, but we are at the front of the fight against HIV. Now all churches want to be seen to have a programme, but this may not be real. Also, people are always going to ignore their bosses to some extent. In Butare, there is an ecumenical college but nothing is said on ARVs.

This church has three hospitals and three health centres but we have very little influence on what happens in them, which means that we can’t link our work together. All three hospitals do VCT and treat opportunistic infections, but there are no ARVs yet. We have tried to bring our doctors to the Catholic health centres and use the Catholic hospital as an example on nutrition and VCT, but it is very difficult to work with our hospitals.”

**Story 6**

“I know a little about HIV and ARVs but I am trying to start up an HIV and AIDS support group as I understand the need for positive living and support. I have not heard about the work of other pastors and I am very keen for them to come and tell me how to do it. I need to know how to get funds for the members and how to get people to be honest and involved. Our message has been that ARVs extend life, and we don’t say anything more. But now we think we want to say more about taking them for life, nutrition, and passing on HIV.”
**Story 7**

“I don’t agree with arguments about sin – we are not the ones to judge, the role of the church is to show mercy and care. Even if someone contracts HIV through sin, it is not the church’s job to cast them out. My Christian organisation teaches that we should love and comfort people with HIV and AIDS, and that AIDS is a disease like any other, that we should improve our nutrition by eating fruits and green vegetables, etc., and we should get medical help for opportunistic infections. But, friends tell me that the side-effects of ARVs are bad. I think we need more information.”
EXERCISE 7

GETTING PEOPLE TO KNOW THEIR STATUS

Idea for use

Get a youth group to make posters that would convince people to know their status if they were feeling in one of the ways listed below. Or use role play, where one person pretends to argue against going to get tested, and a church leader (or someone acting the role of church leader) has to convince them to go.

These can also be used as important sermon points, especially when linked to the idea that God walks beside us.

One of the best ways to show people the way is to get tested for HIV yourself. Get a group together and go together, share your worries, your fears, your results, your knowledge, and show your leadership on this difficult but important issue.

Ask members of the group to suggest reasons why people might not want to go for voluntary counselling and testing.

There are many reasons why people don’t want to know their HIV status. Some of the answers are likely to be in the list below.

1. Fear of the result.
2. Stigma, denial and fear of the community.
4. Fear of not being cared for.
5. Hopelessness and fear about the future.
6. Fear that ARVs are too expensive.
7. Fear that ARVs are not available.
8. It’s too far to go.
9. Fear of isolation
10. Fear of loss of employment if result is HIV Positive

When you have the reasons aim to take action to address the issues.
EXERCISE 8

THE STIGMA AND DENIAL CHALLENGE

Throughout the research work undertaken for this document, people in senior church positions indicated that stigmatization of people living with HIV was not a problem anymore. At the same time, discussions with people living with HIV and those closest to the issue indicated that social stigma (rather than institutional stigma) is still very strong, with the Church, in many cases, not handling stigma issues very well, for example, through a lack of confidentiality.

Tell the group that stigma is not always immediately obvious. Ask them to think about what they would say to the people quoted below. The quotes are real people speaking – do you hear similar things in your family, community, among friends, or in other groups? Ask people to add any examples they have heard.

Now ask the group (or each smaller group) to think about what they would say to people who said these things. They will need to have read the information sheets in this guide. You may also want to help them get the Christian message right.

Get each group to explain how they would respond. Remember, the people quoted may be right or some of them may be wrong.

Stigma quotes

“I have to hide my medicines. I can’t leave them at home. I can’t have too many as I keep them in my glasses case. The worst thing that can happen to me is for my medicines to be found or if it was discovered that I had HIV. Even if the medicines were free, I would still have to hide them. We are lucky – we are on a special scheme, but how would women normally find the 5,000 FCFA per month if their family cannot know?”

“When I first became sick, my brother told my father it was best to let me die. When I lost my husband, nobody would eat with me, and no one would touch me. They would not even lend me a pot for hot water when he died. Even with all the information, people don’t change – they are born this way. Despite that poster with the picture of the president and the lady on ARVs, they don’t believe. They think she is just doing it for the money. We live in fear. We are often discouraged by having to take these pills all our life and we often get depressed.”

“Every patient has a sense of abandonment as they come from a perverted life.”
“HIV and AIDS is linked to immorality and so are ARVs.”

“How shall we reduce the impact the church is having in increasing stigma?”

“Last year, we did 6,000 VCT tests. 300 were HIV-positive [about 5%] and probably 20 of them have now been cured through prayer, plants, and magic potions. I have seen many cures.”

“The problem is that people fear the stigma. If you have HIV there is no respect for you. We know it comes not only from sins but others don’t.”

“A woman died while taking ARVs. People ask why and worry about ARVs.”

“Shame is the real problem – government shame, people’s shame – it goes on.”

“I lost my job because I was HIV-positive. It is illegal to do that but I did not want to tell anyone else. Now the rest of my family knows except my father – he would be too angry.”

“Women are very much at the forefront of getting tested – partly because they are worried about their children – and when they know their husband’s status or he dies, they seek help.”

“After a man has gone for testing, he often hides the result or moves to somewhere else.”

“Many women only go for testing after their husband dies because there is much less stigma and they cannot be blamed for giving it to the husband. People think that the person who tests first brought it.”

“All religions have changed their view on HIV and AIDS from that of it being a curse to being like any other disease.”
“I don’t think anyone responds well to the fact that we are HIV positive. It’s very difficult to talk about. Every story you hear from us has stigma in it and we are the ones who don’t hide.”

“Now we understand a bit more about HIV and AIDS. We were kind but until recently were very afraid to touch people with HIV or AIDS. Stigmatization is disappearing fast – there is not much now.”

“Stigma is still strong because of the link to death.”

“We would like to do more income generation, but because people don’t understand HIV and AIDS, we can’t prepare food or be hairdressers. So it is difficult to find something to do. If we had some income then we could give something to the family and they might let us stay, but people would have to stop hating and being afraid of us.”

“People feel they would prefer to die than have people know.”

“People prefer not to know their status – the stigma is so bad. People only go when they are ill or they lose their partner. More women than men go because women are afraid for their children. We would never tell the pastor – even if he did not tell anyone our name, he would tell everyone that there was someone in the church with HIV, and that would embarrass us. The church is just not confidential. We all keep our status a secret, and the fact that we are on ARVs.”

“There is no stigmatization, but people on ARVs are short-tempered and they underestimate the amount of care that is given to them. They become demanding, depressed, aggressive and insulting. We are very generous people in an informal way. We help the handicapped, the very poor, hospitals, and prisons.”

“The stigma issue is a big problem, between couples and within the family, let alone in the community.”
Wouldn’t it be nice if we had no problems? One of the most difficult things that we face is admitting there is a problem. The list below is drawn up from problems identified in churches in Burkina Faso, Rwanda and Kenya. Distribute the list and ask each individual to tick the ‘yes’ or ‘no’ box, indicating whether they think their Church has a similar problem.

<table>
<thead>
<tr>
<th>DO WE HAVE ANY OF THESE PROBLEMS?</th>
<th>YES</th>
<th>NO</th>
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<tbody>
<tr>
<td>1. There is a general feeling that ARV issues are medical issues only and that, as such, they do not fall within the domain of the Church.</td>
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<td>2. It has been largely accepted that doctors inform patients on ARVs and that this is enough.</td>
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<td>3. Church leaders have not been trained to talk about ARVs.</td>
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<td>4. In general, churches do not focus on the development of support groups for people living with HIV, which can have a number of roles, including personal witness; income generation; advocacy for access to ARVs for members; community literacy; encouraging adherence; etc.</td>
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<tr>
<td>5. We don’t encourage associations of people living with HIV in our churches neither do we encourage them to work with our hospitals, even though they would be incredibly important to the work of understaffed and overwhelmed HIV and AIDS/ARV units in hospitals.</td>
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<td>6. Church leadership for HIV testing is lacking and we don’t understand how the availability of ARVs can encourage people to know their status.</td>
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<td>7. The link between ARVs and responsible behaviour is not understood so we don’t help people understand that even when someone is on ARVs they can still infect others.</td>
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<td>8. The materials we have to help us talk with our congregation are out of date and don’t include any messages on ARVs.</td>
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### DO WE HAVE ANY OF THESE PROBLEMS?

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<th>YES</th>
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<td>9.</td>
<td>The church schools are missing out on an enormous opportunity that young people represent in the fight against HIV and AIDS and support taking ARVs, and we don’t look at recreating invigorated church-based activities in these schools.</td>
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<td>10.</td>
<td>We don’t speak as one voice in advocating for change. National advocacy on the part of the combined church voice could have significant impact on the current situation. Whatever message the churches decide to advocate around (from the need for higher standards of testing, to access to free ARVs), with their strong media connections, congregations, and community work, can have a powerful and successful impact.</td>
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<tr>
<td>11.</td>
<td>We don’t talk to our congregation about PMTCT and the importance of this treatment for protecting babies.</td>
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<tr>
<td>12.</td>
<td>We never try to deal with the myths that people think are true about HIV and AIDS or ARVs.</td>
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<tr>
<td>13.</td>
<td>The church and church hospitals in this area do not work together.</td>
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<tr>
<td>14.</td>
<td>The churches don’t know where to get ARVs nor how people can get them and there is institutional resistance. These are medical issues and the church is not sure of its role</td>
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<tr>
<td>15.</td>
<td>The taking of ARVs is not well known. We are not confused, but we are silent.</td>
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CASE STUDY QUESTIONS
An examination of scenarios can bring the issues to life. By finding out about what other church leaders are doing, it is possible to encourage people to take action themselves, because they see that other churches in a similar situation have been able to make a real difference. Case studies are interesting, inspiring and informative.

Ideas for use
Case studies tell a story and ask questions. They are excellent for sermons and speeches.
Share the case studies here, either with the whole group or between smaller groups. Get each group to answer the questions in the case study, or ask them how they could achieve similar or better things in their own churches. With this second approach, the groups can start to develop plans for ways forward and a list of actions.

Real case studies

Case Study 1
Titi is a nurse at a clinic in Zambia and is active in her church. She finds out that Jane is HIV positive. Titi’s and Jane’s family are friends. She has known Jane since they were girls and she cannot believe that Jane has HIV. Titi is so surprised that she tells her mother about Jane.

Titi’s mother begins to snub Jane’s mother and makes disparaging remarks about how “filthy” Jane’s family is. Soon, the whole estate is talking about Jane and her family with disdain.

• How could this situation have been prevented?

Case study 2
Jona is 35 years old. He is married with five children aged between three and 13. He works at a local tea factory. Jona tested HIV positive three years ago. It has been a year since he started developing opportunistic infections. He visits the church clinic regularly. Jona is losing a lot of weight. His wife is HIV negative, although she knows that he is HIV positive.
The Church doctor has advised that Jona be started on ARVs without delay.

• What information does Jona need to make good decisions?
• What questions might Jona raise with the doctor?
• What questions should the doctor ask Jona?

Case study 3
Janet Zoa, 48, is a deaconess in her church. Previously on ARVs, she suddenly stopped visiting the church clinic for six months. One day, she showed up at the clinic and requested to be put back on ARVs. “I stopped taking my medicines, but don’t worry, I will never do that again. I will never go back to that woman. She lied to us, and my friends died,” she started.

Janet had met a nice couple in a support group for people living with HIV. They were all taking ARVs, but they had started getting tired of the daily medication. The fact that they were going to have to take the ARVs for the rest of their lives frustrated them. One day, Janet heard about a miracle healer who could offer special prayers to cure people of HIV. They went to see the healer, who asked them to stop taking the ARVs. They all agreed.

After the fourth month, Janet’s two friends got sick. They were hospitalised, and both died after two weeks. Janet was lucky. Her health had not deteriorated much. She was put back on ARVs, and her health improved. She went back to her social work of supporting other people living with HIV.

• What mistake did Janet make?
• Why might going back on ARVs not work?

Case Study 4
Jack Oduo, a 43 year-old man and a church worker, started taking ARVs five months ago. For the past three months, he has not been attending work regularly. Concerned, the church minister decided to pay his family a visit and found Jack outside his house, reading the Bible. Jack explained that he was fine, except that he had not been taking his ARVs. He said he did not know he had to take them for the rest of his life and anyhow, he is feeling much better now. He tells the priest that prayers are enough and that he would wait for a few more years before taking ARVs again.

• What would you advise him?
• What information should have been given to him before starting ARVs?
**Case study 5**

Dr. Smith runs the local church-owned hospital. He is currently in negotiation with the Clinton Foundation, in order to build an ARV clinic. While he is enthusiastic and caught up in this project, the issue of ARVs is seen as very specifically in the context of the hospital’s services. He is committed to treatment literacy for those receiving ARVs, but would need money to support this.

Literally next door, the pastor has much less information, but wants to start an HIV and AIDS support group.

- What would be a good way for them to work together?
- Why aren’t they working together?

**Case study 6**

Every year, St. Anna’s Church in Nairobi dedicates one week to discuss issues on health. Although HIV and AIDS is a declared national disaster in the country, the Health Week has addressed nearly all health issues except HIV and AIDS.

Today, the lay preacher is delivering a sermon on consciousness and clean hearts. She has two gourds. One is uniformly brown in colour and the other has many black spots. “When one has a clean heart, she or he is like this beautiful gourd which everyone likes,” she says, lifting the spotless gourd. “But when one has an unclean heart, she or he is like this spotted gourd, which no one likes. It looks like someone infected with AIDS,” she concludes, lifting the disfigured gourd.

- Why is the Health Week not addressing HIV and AIDS?
- What mistakes did the preacher make, and what are the possible effects?
- What could be done now?

**Case Study 7**

Violence erupted in Kenya following a disputed presidential election in December 2007. Action by Churches Together (ACT) International and a government crisis management committee estimated that over 255,000 people had been displaced from their homes, and were camping in churches and police stations.

Considering that most of the displaced persons had salvaged nothing from their homes, serious concerns had been raised that many people on ARVs would miss their doses if nothing was done to make the drugs available to them. Lack of adequate and clean water, sanitation, and shelter, could give rise to opportunistic infections amongst them. In addition, the local newspapers had reported several cases of sexual violence.
Churches and relief agencies appealed for donations in terms of food, clothes, shelter, water, and sanitation, to which people responded overwhelmingly. “We thank God our people are helping us, but I wish they could give us ARVs. I don’t know where to get more supplies...” One displaced person told the media.

- What action should the Church have taken?
- What other partner could the church collaborate with to provide ARVs?

**Case study 8**

“I am worried about adherence. Once people feel better, they forget, they might move away with a job, but most of all they try to hide the fact that they have HIV. There is some work on the radio about this, but it is not enough to deal with adherence. People in a support group have a closer relationship with each other and more information and are more likely to adhere. The income generation they do is not big enough to create food security but it is a start. We recognise the need for food as the biggest problem, but the donors don’t see this. We know that if you want ARVs to be most effective, there must be enough food.”

- What could the church do in this situation?

**Case study 9**

AIC Kijabe Hospital is a mission hospital 62km North-West of Nairobi, Kenya. The HIV programme in the hospital served over 2400 people living with HIV in 2007. The church has been a great source of help and encouragement for the programme at Kijabe. Four main themes stand out in the way the church has been involved in the HIV programme at Kijabe.

At the AIC Thigio Church, a community church 40km from Kijabe, Pastor Mahiga started the process of mobilising the community by way of bringing together orphaned children and those requiring nutritional assistance. By the time the Kijabe Hospital HIV team expanded its geographical boundaries to cover the Thigio Region, it found a well organised and mobilised community.

Psychosocial support, particularly for people receiving ART, is crucial. It is a key component in the healing process. At Kijabe Hospital in Kenya, for example, this is a key area of focus. At the inception of the psychosocial support groups, there was a huge need for venues in the communities. The Kijabe programme did not have enough resources to sustain the hiring of venues. However, within its catchment area, there were church leaders who were willing to open the doors of their churches for the support groups to meet.

One church that was at the forefront of this was the Deliverance Church located in a small town 15km from Kijabe. The Pastor at Deliverance Church Kimende, Rev Hiram,
was passionate about helping those on treatment, and understood the need for them to meet. He allowed the church hall to be used by this unique “fellowship” whenever they needed it. This action of love went a long way to make the people who were on HIV treatment in Kimende to feel warmly embraced.

The AIC Church in Limuru, 25kms from Kijabe, plays this key role with the pastor in charge by organising VCT services in the church hall after Sunday service. He usually and regularly invites Kijabe hospital to undertake these services. The pastor has also referred a lot of people living with HIV for treatment to the Kijabe Hospital AIDS Relief Programme.

In a very poor and remote area 40km from Kijabe, there is a Catholic dispensary that is run by the Sisters of Charity. The dispensary used to host a support group of over 80 people, though they did not have the expertise to deliver ART. On hearing this, the HIV programme at Kijabe (which lacked the resources to put up a clinic there) endeavoured to partner with the dispensary to assist the infected persons in that community by providing drugs. By 2007, over 300 people with HIV were receiving care from this clinic. This was made possible by wisdom from God and the willingness from both the Sisters of Charity and Kijabe Hospital to share the resources God had blessed them with.

So how could your church become:

- The Church as the centre of love?
- The Church as an embracing family?
- The Church as a bridge to care?
- The Church as a fountain of wisdom?
EXERCISE 11

PLANNING TO TEACH AND TELL

The EPN study showed that there are many myths and misconceptions around ARVs. Throughout the previous exercises, you will have come across some of these. In this exercise, the focus is taking on these problems and addressing them.

Misconceptions

To some extent, the place that a person first hears about ARVs sets the tone and correctness of knowledge. In the EPN study, people were asked where they first heard about HIV and AIDS. The list below shows their answers, with the most popular ones first.

- Media/TV
- Leaflets
- Father/mother
- School
- Friends
- NGOs.

It is significant that schools come so low on this list, and that churches do not even appear. Many schools are run by churches, many people attend church, and yet this important issue is not being communicated with the love and wisdom of the Church. Remember, there is no evidence that ARVs encourage immoral behaviour.

Discuss how you can make sure that people hear about ARVs through the Church, and how you can make sure that what they hear is accurate and useful.

Make a plan!
# EXERCISE 12

## FORMULATING CHURCH HIV AND AIDS POLICY

It is important for churches to have a HIV and AIDS policy. Below are the steps that you can follow when designing a HIV and AIDS policy for your church.

<table>
<thead>
<tr>
<th>STEP</th>
<th>ACTIVITY</th>
</tr>
</thead>
</table>
| Step 1 | Awareness/sensitisation and advocacy  
  • The policy will work well if its development is participatory and involves all the stakeholders in the church. The congregation should be informed that the church is coming up with an HIV and AIDS policy and be given an opportunity to comment. This will guarantee ownership and support in the implementation stage, as well as make it relevant to the local situation. |
| Step 2 | Formation of HIV and AIDS policy steering committee  
  • It is important to have representation of top church leadership. This gives the committee greater decision-making powers and demonstrates that church leaders are committed to the process. PLHIV should also be involved in the committee. |
| Step 3 | Situation analysis  
  • The church does not work in isolation. It must work with the government and other stakeholders (e.g. donors, other churches and faiths, hospitals, etc.). The team must look at both internal and external environmental factors that are likely to affect the working of its policy. The aim is to ensure that the policy complements other policies of like-minded actors. Of particular importance is that the committee looks at the church as an employer and therefore seek to comply with the International Labour Organization (ILO) guidelines. |
| Step 4 | First consensus meeting  
  • The steering committee calls for a consensus meeting to share, plan, and seek comments from stakeholders, with a view to understanding government policy / legal frameworks; church policy statements/guiding documents / declarations; and to identify problems, suggest solutions and build consensus around these. |
### Step 5: Production of a draft policy

Circulate the draft policy for discussion and comments, then revise.

**Sample content**

- Introduction
- Church vision statement
- Church mission statement
- The Church response to HIV and AIDS
- Situation analysis
- Objectives
- Policy statements
- Capacity building
- Partnerships and collaboration
- Mobilisation of resources
- Involvement of affected people
- Promotion of fair and respectful relationships, and advocacy
- Church resolution
- HIV and AIDS policy in the Church workplace

### Step 6: Second consensus building workshop and discussion of draft strategy

- Approval by the most appropriate level of the Church authority

### Step 7: Policy adaptation

### Step 8: Implementation

- Dissemination of the policy
- Formation of the organisational structures and training of key actors
- Demand that all actors within the Church follow the policy and include its implementation in the head office and congregational feedback reports / briefings
- Implementation must be clearly visible to the top church leadership, who should always demand results and accept no excuses.

### Step 9: Follow-up, evaluation, monitoring

This helps in making changes to the programme

- Share out the lessons learnt and the challenges encountered
- Review the policy regularly in light of new information about the epidemic and its treatment. Reviews could take place annually or at anytime as necessary
GLOSSARY OF HIV AND AIDS-RELATED TERMS AND ABBREVIATIONS

Antibody  A specific protein produced by the immune system in response to a specific foreign protein or particle called an antigen.

Antigen  Any substance that stimulates the body to produce antibodies

Autoimmunity  A condition in which the body’s immune system (the system that fights disease and infection) produces antibodies in response to its own tissues or blood components instead of foreign particles or micro-organisms.

AZT  Azidothymidine (also called zidovudine or ZDV; the Burroughs-Wellcome trade name is Retrovir). One of the first line drugs used to treat HIV infection. AZT is a nucleoside analog that suppresses replication of HIV. See also Nucleoside Analogue.

Caregiver  Any person who provides care for individuals with symptomatic HIV infection in the home or in a health facility.

CD4  A type of protein molecule in human blood that is present on the surface of 65 percent of immune cells. The HIV virus infects cells that have CD4 surface proteins, and as a result, depletes the number of T cells, B cells, natural killer cells, and monocytes in the blood. Most of the damage to an AIDS patient’s immune system is done by the virus’s destruction of CD4 lymphocytes.

CD4 count  A measure of the number of CD4 lymphocytes in the blood of HIV infected persons. This measurement is usually obtained to establish baseline information for a patient before initiating treatment with ART and thereafter monitoring the progression of infection.

Counselling  A confidential dialogue between a person and a care provider aimed at enabling the person to explore thoughts, feeling and behaviour, cope with stress and take personal decisions related to HIV and AIDS.
The counselling process involves the evaluation of personal risk of HIV transmission and facilitation of preventive behaviour.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Home-based care</td>
<td>The care of persons living with HIV infection and AIDS in their homes. This involves the provision of comprehensive care by community members, NGOs, Community Based Organisations (CBOs), health workers and family members. This type of care is complementary to the existing health care services.</td>
</tr>
<tr>
<td>HIV test</td>
<td>Refers HIV antibody tests. Laboratory tests are performed on a sample of a person's blood to detect the presence or absence of antibodies to HIV. The presence of antibodies in an adult indicates that the person has been infected with the virus. The most commonly used test is the Enzyme-linked immunosorbent assay (ELISA).</td>
</tr>
<tr>
<td>Lymphocyte</td>
<td>A type of white blood cell that is important in the formation of antibodies and that can be used to monitor the health of People living with HIV.</td>
</tr>
<tr>
<td>Immuno-deficient</td>
<td>A condition in which the body's immune response is damaged, weakened, or is not functioning properly.</td>
</tr>
<tr>
<td>Immune system</td>
<td>The body's defence mechanism against attack by bacteria, viruses, harmful food substances and some proteins.</td>
</tr>
<tr>
<td>Incubation period</td>
<td>The time between infection with a disease-causing organism and the development of the disease. When the immune system is depressed or destroyed, as in AIDS, opportunistic infections can take hold.</td>
</tr>
<tr>
<td>Opportunistic Infection</td>
<td>An infection by organisms taking advantage of lowered immunity, usually does not cause infection in people infection whose immune systems are working normally.</td>
</tr>
<tr>
<td>Macrophage</td>
<td>A large white blood cell, found primarily in the bloodstream and connective tissue, that helps the body fight off infections by ingesting the disease-causing organism. HIV can infect and kill macrophages.</td>
</tr>
<tr>
<td>Nucleoside Analogues</td>
<td>A medication that interferes when HIV tries to make copies of itself inside cells.</td>
</tr>
</tbody>
</table>
Protease Inhibitors | The second major category of drug used to treat an infection with HIV that works by suppressing the replication of the HIV.

PLHIV | Person Living with HIV. It recognises the fact that not everyone who has HIV virus has got AIDS.

PMTCT | Prevention of Mother to Child Transmission of HIV.

Retrovirus | Retrovirus is a class of viruses characterised by their ability to convert RNA to DNA during replication in the host cell (instead of the reverse as in most other viruses). To do this, an enzyme called reverse transcriptase is required. HIV belongs to this group of viruses.

Reverse Transcriptase | An enzyme that HIV uses to replicate itself. Much research is being devoted to finding a drug, which will inhibit this and thus prevent HIV replication.

RNA | An abbreviation for ribo-nucleic acid – the genetic material inside a cell that is used to make structural and functional components. HIV is an RNA virus.

T-Helper Cell | Also called T4 cells. These are one type of white blood cells or lymphocytes that helps in defending the body against disease by initiating antibody production. In people with AIDS, T-helper cells are so depleted that the immune system no longer fights off disease and opportunistic infections can occur.

T-Suppressor Cells | Also called T8 cells. These are another type of lymphocyte or white blood cells. They inhibit antibody production when the infection has been overcome.

T-Cell Ratio | The proportion of T-helper to T-suppressor cells. In a healthy person, this proportion is approximately 2:1. In a patient, with an HIV related illness it drops below 0.2:1 (i.e., it becomes inverted).

Transmission. | The spread of infectious agents from one person to another. The predominant mode of HIV transmission is through sexual intercourse.
REGIONAL EPIDEMIOLOGICAL DATA


Key Facts By Region

Global Overview

• An estimated 33 million people [30.3 – 36.1 million] were living with HIV in 2007. There were 2.7 million [2.2 – 3.2 million] new HIV infections and 2 million [1.8 – 2.3 million] AIDS-related deaths last year.

• The rate of new HIV infections has fallen in several countries, but globally these favourable trends are at least partially offset by increases in new infections in other countries.

• Sub-Saharan Africa has two thirds (67%) of all people living with HIV worldwide.

• Globally, women account for half of all HIV infections - this percentage has remained stable for the past several years.

• An estimated 370 000 [330 000 – 410 000] children (younger than 15) became infected with HIV in 2007. The total number of children living with HIV has increased from 1.6 million [1.4 – 2.1 million] in 2001 to 2 million [1.9 – 2.3 million] in 2007- almost 90% live with HIV in sub-Saharan Africa.

Sub-Saharan Africa

• Sub-Saharan Africa remains the region most heavily affected by HIV worldwide, accounting for two thirds (67%) of all people living with HIV and for three quarters (75%) of AIDS deaths in 2007.

• An estimated 1.9 million [1.6 -2.1 million] people were newly infected with HIV in Sub-Saharan Africa in 2007, bringing to 22 million [20.5-23.6 million] the number of people living with HIV. Sub-Saharan Africa’s epidemics vary significantly from country to country - with most appearing to have stabilized, although often at very high levels, particularly in Southern Africa.

• The nine countries in Southern Africa continue to bear a disproportionate share of the global AIDS burden – 35% of HIV infections and 38% of AIDS deaths in 2007 happened there.

Asia

• In Asia, an estimated 5 million [4.1- 6.2 million ] people were living with HIV in 2007.
The number of new infections and people who died from AIDS related illnesses were, comparatively speaking, in equal in 2007 - 380 000 [200 000 - 650 000 ]and 380 000 [270 000 - 490 000], respectively.

National HIV infection levels are highest in South East Asia. New HIV infections are increasing steadily , although at a much slower pace, in populous countries such as Bangladesh and China

Carribean

• In 2007, an estimated 230 000 [210 000 - 270 000] people were living with HIV, while an estimated 20 000 [16 000 - 25 000] were newly infected, and some 14 000 [11 000 – 16 000] died of AIDS related illnesses.

• Although surveillance systems are largely inadequate in several countries, available data indicate that most of the HIV Epidemics in the Caribbean appear to have stabilized, while a few have declined in urban areas – this is particularly evident in the Dominican Republic and Haiti. Both countries are home to the largest epidemics in the region.

• At the end of 2007, an estimated 30 000 people living with HIV were receiving Antiretroviral treatment in the region - a 50% increase since end 2006, when 20 000 people were on treatment. 8

Eastern Europe and Central Asia

• The estimated number of adults and children living with HIV in Eastern Europe and Central Asia

• Rose to 1.5 million [1.1 - 1.9 ] million in 2007 - almost 90% of those infected live in either the Russian Federation (69%) or Ukraine (29%). This figure has more than doubled since 2001, when some 650 000 [510 000- 1.1 million] were estimated to be living with HIV

• In 2007, around 110 000 [67 000 - 180 000] people became HIV positive while some 58 000[ 41 000 – 88 000] died of AIDS related illnesses.

• The largest HIV epidemic in region is in the Russian Federation - and it continues to expand, although at a slower pace than in Ukraine, where annual new HIV infections have more than doubled since 2001.

Latin America

• New HIV infections in 2007 totaled an estimated 140 000 [88 000 - 190 000] bringing to 1.7 million [ 1.5 - 2.1 million ] the number of people living with HIV in Latin America. An estimated 63 000 [ 49 000 – 98 000] peole died of AIDS related illnesses last year.

The regions biggest epidemics are in the countries with the largest populations, notably Brazil, which is home to more than 40% (730 000 [600 000 - 890 000]) of people living with the virus, followed by Mexico with 200 000 [150 000 -310 000] HIV positive people.

The HIV epidemics in Latin America remain largely stable, changing little in the past decade, but HIV transmission in the region is occurring mainly among men who have sex with men, sex workers, and (to a lesser extent) people who inject drugs.

**North America, Western and Central Europe**

- In 2007, the United States of America accounted for an estimated 1.2 million [690 000 - 1.9 million], or roughly 60%, of the 2 million [1.4 - 2.8 million] people living with HIV in North America and Western and Central Europe. Overall in these regions, 81 000 [30 000 - 170 000] people become newly infected with HIV and 31 000 [16 000 - 67 000] died of AIDS related illnesses.
- On both sides of the Atlantic, the estimated number of people living with HIV continues to increase because of wide access to Antiretroviral Treatment. However, the regions diverge in terms of new HIV infections - North America has remained relatively stable over recent years, whereas in Western Europe diagnoses are increasing.

**Middle East and North Africa**

- The limited information available for the Middle East and North Africa indicates that some 380 000 [280 000 - 510 000] people were living with HIV in 2007, including the estimated 40 000 [20 000 - 60 000] people living with HIV.
- Sudan represents the bulk of the region’s HIV epidemic, with an estimated 320 000 [220 000 - 440 000] people living with HIV.
- Although overall numbers of reported HIV cases in the region remain small, they have been increasing in several countries, partly due to expanded HIV testing efforts. One such example is Algeria, where the number of people living with HIV has doubled between 2001 and 2007.

**Oceania**

- An estimated 74 000 [66 000 - 93 000] people were living with HIV in Oceania in 2007, of which 13 000 [12 000 - 15 000] were new infections.
- The region’s epidemics are relatively small, except for Papua New Guinea, where the number of people living with HIV has increased from 10 000 [9 800 - 10 000] in 2001 to 54 000 [53 000 - 55 000] in 2007. In Australia, a total of 18 000 [11 000 - 36 000] people were living with HIV in the same year.
it is important to learn your HIV status to know if you are positive or negative. you should go for an HIV test, where you will also get counseling. if you are negative, stay that way with:

- prevention (safer sex /ABC)
- healthy living
- learn more about HIV and AIDS
- become a treatment buddy
- tell others about advantages of testing

if you are positive and don't need ARVs, you should take these steps:

- positive prevention
- healthy living
- positive living
- good nutrition
- treatment of OIs
- join support group
- disclosure

to prepare for ARV treatment, you need to take these steps:

- treatment is for life, so think about how you will continue to pay for pills
- disclosure (who will you tell?)
- who will support you?
- a treatment buddy
- treatment counseling
- adherence counseling
- treatment of OIs
- good nutrition
- positive living

Once you are on treatment, you must follow it for life. take the pills every day, the right times and the right way. continue positive living (good nutrition, treating OIs, preventing re-infection).

When you start treatment, you will find these benefits:

- you feel stronger and better
- your CD4 count goes up
- your viral load goes down
- prolonged life
- reduced stigma and discrimination

When starting treatment, you might experience side-effects, like nausea, vomiting. talk to your nurse or doctor.

do not stop taking the pills.

when you need ARVs, find a place and program that suits you. you must get proper medical supervision. get on a waiting list if necessary. start taking ARVs.

- good nutrition - healthy food and herbs/vitamins
- positive living - have hope and get support

If you are positive, then you need:

- CD4 count tests
- viral load tests
- other tests (like liver function and TB) to see if your body can take ARV treatment

FROM TESTING TO TREATMENT - THE ROADMAP

Back to regular illness. AIDS that can't be treated, and an early death
SAMPLE WORKPLACE HIV AND AIDS POLICY: WORLD COUNCIL OF CHURCHES

1. Preamble

Today, it is known that HIV infection is identifiable, preventable and manageable, and that with current medical know-how, there is no reason why anyone should be dying of AIDS related illnesses. The Christian community has done much across the globe to try and ease the pain and suffering of people caused by HIV and AIDS.

This workplace policy is in keeping with the on-going work of the WCC and with the statement adopted by the WCC Central Committee on the basis of the WCC Consultative Group on AIDS Study Process, September 1996, which outlined a series of actions which churches could undertake in responding to the HIV and AIDS pandemic in the “Conclusion: what the churches can do”. It is informed by the ILO and UNAIDS workplace policies.

2. Objectives

The World Council of Churches HIV and AIDS Workplace Policy is intended to:

- Minimise the possibility of HIV infection for all categories of employees and any of the aforementioned persons’ spouses and dependants
- Assure a supportive work environment for employees living with or affected by HIV or AIDS
- Assure that employees, their spouses and dependants have access to care, support and treatment, including antiretroviral therapy when necessary
- Manage and mitigate the impact of HIV and AIDS on the life and work of the Council
- Mitigate the impact of denial, stigma, and discrimination in the workplace, whether on the basis of real or perceived HIV status, or on vulnerability to HIV infection.

3. Responsibility for implementation

Responsibility for implementation of this workplace policy rests with the highest decision making authority of the Council and will be implemented by the Human Resources Office (HRO).
4. Confidentiality

4.1. The Council will encourage a supportive work environment in which employees can discuss HIV and AIDS openly, including their own experience in living with HIV and AIDS. Where employees disclose that they or their spouse and/or dependents are living with HIV and AIDS, the confidentiality will be respected. Disclosure under all circumstances will be treated as shared confidentiality between the parties, unless expressly stated to the contrary. If there is any doubt, the person living with HIV and AIDS should be consulted before further disclosure takes place.

4.2. HIV related information concerning prospective employees or current employees or any of the above mentioned people’s spouses and/or dependents will be kept strictly confidential.

4.3. Employees shall sign a confidentiality agreement (Annex 2), and shall be informed that the unauthorised disclosure of HIV related information is a disciplinary offence. It may also lead to legal proceedings against the person who disclosed the information.

5. Gender dimensions

5.1. Churches acknowledge that HIV and AIDS impacts on male and female employees differently in regard to physiological susceptibility to infection as well as reproductive health. It is also acknowledged that women normally undertake the major part of caring for those with AIDS-related illnesses, and that pregnant women with HIV have additional special needs.

5.2. Any assistance programmes will be designed to accommodate these differing impacts and as appropriate to redress gender inequalities, for example, by encouraging and supporting men as carers.

6. Safer practices (sexual or otherwise)

6.1. The HRO will provide employees with sensitive, accurate and up-to-date information to enable them to protect themselves from HIV and other sexually transmitted or blood borne infections as well as TB, Malaria and sleeping sickness.

6.2. Where staff travel to areas where the blood supply is deemed to be insecure, the HRO will provide information to employees as to where safe blood can be obtained or what action to take in case of illness.

6.3. Employees must wear helmets while travelling by motorcycle when on duty.
7. **Occupational or other exposure**

7.1. In the case of accidents involving the risk of exposure to human blood, universal precautions shall be used to ensure there is no risk of HIV transmission or other blood borne infections.

7.2. The HRO shall develop procedures for the immediate referral for counselling, assessment and medical treatment (with post-exposure prophylactics, where appropriate) of employees as well as their spouses and dependents exposed to the risk of HIV infection (e.g. through an accident or sexual assault), whether in the workplace or elsewhere.

7.3. Reasonable paid time off will be provided for counselling following occupational or other exposure.

8. **Voluntary counselling and testing**

8.1. Access to free, voluntary and confidential HIV testing and counselling (VCT) shall be made available to employees as well as to their spouses through the health insurance scheme, and/or where the service is not made available, information will be provided as to where the services are available.

8.2. The General Secretary will nominate a person, ordained or lay, from whom employees can seek confidential advice, counselling and referral on HIV or AIDS related matters.

9. **HIV screening and employment**

9.1. There is no obligation on prospective employees or current employees to inform the Council of their HIV status.

9.2. HIV status will in no way be taken into consideration for ordination, employment or placement within the Council.

9.3. HIV screening will not be required either as a condition of employment or for continuation of employment.

10. **Information and training**

10.1. The HRO will provide information and training on workplace issues raised by the HIV epidemic, on appropriate responses, and on the general needs of people living with HIV or AIDS and their careers.

10.2. Such information and training will be gender sensitive, as well as sensitive to race, disability, and human sexuality.
10.3. Information will include the availability of local support organisations for people living with HIV or AIDS, and other affected communities as well as people living with HIV or AIDS networks working in partnership with the Council.

10.4. Training for employees, if needed, on HIV and AIDS will take place during paid working hours and attendance by all employees will be considered as part of work obligations.

10.5. Such training will be open, where practicable, to the spouse and dependents of employees.

10.6. Relevant staff will be trained on the implementation of this policy.

11. **Reasonable accommodation**

11.1. Where appropriate, the Council will assure reasonable accommodation to match the special needs of employees living with, or directly affected by HIV or AIDS when and where practicable.

11.2. Reasonable accommodation may include flexible working hours and time off for counselling and medical appointments, extended sick leave, transfer to lighter duties, part-time work, and return-to-work arrangements.

12. **Stigma and discrimination**

12.1. The Council acknowledges that denial, stigma, and discrimination related to HIV and AIDS is a sin and against the will of God. As such, the Council will not discriminate on the basis of actual or perceived HIV status under any circumstances, including opportunities for placement and advancement.

12.2. Employees living with HIV or AIDS will be treated no less favourably than employees with other serious illnesses will.

12.3. The HRO will undertake activities to address HIV and AIDS related stigma in the Council, including through employee training and the promotion of an open, accepting, and supportive work environment for all who choose to disclose their HIV status.

12.4. Employees who discriminate against people living with HIV or AIDS will be subjected to disciplinary procedures in the event that counselling efforts fail.

13. **Advocacy for universal access**

The failure to deliver ARV therapy to the millions of people who need it is a global health
emergency. The Council will continue to be involved in advocacy work for access to treatments for all that need it.

14. **Travel, assignment and vaccination**

14.1. When arranging short-term travel to other countries for Council employees, the HRO will notify the individual of any legal restrictions on entry for people living with HIV. If an employee cannot undertake short-term travel for this reason or any other HIV health-related reason, reasonable accommodation will be made to identify other tasks.

14.2. When arranging long-term travel or reassignment for employees, the HRO will notify the employee of any legal requirements for HIV screening. When HIV screening is required, the HRO will ensure referral to pre and post-test counselling for the employee, and will reimburse the cost for such counselling if it is not otherwise available free of charge.

15. **Termination of employment**

15.1. HIV infection is not a cause for termination of employment.

15.2. Employees with an HIV related illness will continue in employment as long as they are medically fit for available, appropriate work.

15.3. In the case of termination of employment due to extended illness; employees with HIV or AIDS will be accorded the same benefits and conditions as apply to termination due to other serious illnesses.

16. **Grievance and disciplinary procedures**

16.1. The HRO will provide procedures that can be used by employees for work-related grievances, including failure to implement any aspect of this policy.

16.2. Disciplinary proceedings may be commenced against any employee who violates this policy.
CONFIDENTIALITY AGREEMENT (TO BE COMPLETED BY ALL EMPLOYEES)

1. I have read and understood this Workplace Policy.

2. I recognise that through association with the WCC, I may learn information of a highly personal and confidential nature.

3. I understand that such information may include information that someone:
   - May be living with HIV or AIDS
   - Has been asked to have an HIV test or been counselled about having an HIV test
   - Is receiving or has received treatment or counselling which suggests he or she may be living with or has HIV or AIDS
   - May have had experiences which put him or her at risk of contracting HIV; or
   - Has a close association or relationship with someone living with HIV or AIDS.

4. I will only disclose such information when authorised by the person in question.

5. I understand that breach of this agreement may result in disciplinary action, and possible legal proceedings against myself and/or my church.

............................................                                            ........................................
Signature             Date and Place
SUPPORTING INFORMATION A

UNDERSTANDING HIV AND AIDS

1. The cell

The body is made up of cells and the substances that cells make. The cell is the basic building unit of life. Some living things, for example bacteria, are made up of just one cell. Such organisms must do everything on their own within this one cell. Complex living organisms like plants and animals (including human beings) are composed of billions of cells. In such a system, the cells become specialised, each type performing a different function as they all contribute to the make up of one body.

Body cells can be likened to the bricks that build a house. When connected together, cells build up tissues, such as the muscle tissue, heart tissue, or brain tissue. Tissues then make organs such as the heart, the liver, the skin and so on. Different organs function together to form a system. Examples of systems include the digestive system, the skeletal system, the respiratory system, the reproductive system, the immune system, and others. We will later concentrate on the immune system.

The cells have a border around them. It is called the cell membrane. This membrane allows movement of substances such as nutrients, water, salts etc, in and out of the cell. These substances are needed to keep the cell alive. The cell membrane encloses the cytoplasm, which is a fluid containing the different organelles, the chemicals in the watery fluid, and the nucleus.

The cell must be able to allow passage of nutrients and to get rid of waste. It cannot do this if the membrane is totally solid. So the membrane is semi-permeable to allow entry and exit of substances. The cell must also have the ability to communicate with other cells. For this, it has receptors.

The body cell also needs energy. It gets this from the foods we eat or from our body reserves (such as fat), or even from broken-down cells.

The cell needs instructions on how to grow, change, function, etc. It does this through a set of chemical instructions from the genetic material called deoxyribonucleic acid (DNA), which is contained in the nucleus of each cell. The DNA is double-stranded and is the genetic code. We could call this the “programme” of the cell. The DNA is made up of a set of four chemicals called nucleosides, which form the code for all the information for the cell. It is like having four different coloured beads that code for an instruction according to how they are arranged. For example, we could have a “green-green-green” combination to mean “start”, and a “red-red-red” arrangement for “stop”.

While the genetic code is in the nucleus, cell activities take place in the cytoplasm. To get the information from the nucleus to the cytoplasm, the DNA makes a copy of the part of itself that is necessary for the instruction, in a form called ribonucleic acid (RNA).
RNA carries instructions from which the DNA can be “read” in the cytoplasm. The RNA is then translated into a new action by the cell.

**Figure 1.1 The cell**

![Cell diagram](image)

2. **The immune system**

The immune system protects the body against diseases. It is our **defence system**. It is made up of two main systems:

**The physical system:** This includes the skin and the germ-trapping linings of our respiratory and digestive passageways. The clotting of the blood is also a physical defence mechanism to seal wounds. When the physical system is broken, such as when the skin is broken by a cut or abrasion, foreign organisms can easily cross into the inside of the body.

**Internal defence system:** When physical barriers are broken and unwanted organisms get into the body, we have another process that takes over the defence task. The **white blood cells** are the main part of this mechanism. The organs involved include the **bone marrow** and **thymus gland**. Different white cells are produced in these areas. The cells are also in the **lymph nodes**, where they are usually stored. Lymph nodes are distributed throughout the body, and are the small lumps we feel under the armpits or in the groin area. White cells are also found in the **blood**.
2.1 White blood cells in the immune system

Figure 2.1 The white blood cells

We can draw comparison with a country’s defence system to explain the immune system. Usually, the first point of a country’s resistance is the border. In the body, the skin is the border. Keeping watch at the border are the soldiers that scout around to detect intruders. In the case of the body, a similar function is performed by white cells called phagocytes.

The second group of white cells are the macrophages, which act as security guards. They will intercept intruders and prevent them from coming any further into the body, much in the same way a security guard will stop intruders from entering the house if they get past the gate. Sometimes the soldiers acting as security guards are overwhelmed and the country needs to mount a full scale battle. War is sounded and coordinated by the General. In the immune system, the CD4 cell acts as the General. It stimulates the rest of the “body soldiers” to go to war. The General is therefore a crucial member of the defence system.

There are two key types of “body soldiers”. The killer T-cells could be likened to the infantry that is involved in hand-to-hand combat with the enemy. These are the destroyer cells. A second type of cells, called B-cells, produce substances called antibodies. These can be likened to the chemical arsenal and rockets that are released to neutralise the enemy.
The antibodies are specific to the type of organism they neutralise. For example, antibodies for polio virus will specifically act against polio. The antibodies for HIV are specific to HIV. We can detect and measure antibodies against a particular organism. When testing if someone is HIV-positive, we usually check for the presence of antibodies against HIV.

After the invading organism has been destroyed, the body must stop the soldiers from continuing to fight. Otherwise, they will start destroying the body’s own cells. The suppression is done by suppressor T-cells, which we can call the peacemakers. The body must also get rid of all the debris. A second type of macrophage engulfs the garbage that is then taken out of the body.

Having gone through the war, the body now knows the enemy. The immune system keeps what are called memory T and B cells, which store the information about the organism that it has fought. Should the organism enter the body again, the memory cells will very rapidly mount an appropriate attack to remove the invader.

It is this ability of the immune system to “remember” that is usually triggered in vaccination processes. A sample of the disease-causing organism (prepared so that it cannot actually cause a disease) is introduced into the body, which then stimulates the production of T and B cells. Next time the body comes into contact with the real bad organism, it quickly recognises and destroys it. But if the disease-causing organism changes (mutates), the body may not recognise it next time. It is therefore difficult to prepare vaccines for organisms that mutate quickly. HIV is one such organism.

We are always surrounded by organisms that can cause us serious disease. However, so long as the immune system is functioning well, we do not fall sick as the organisms are destroyed on entry. If, however, the immune system is compromised, then the organisms take the opportunity to cause us diseases. HIV compromises our immune system.

3. Human immunodeficiency virus (HIV)

Compared with the human cell, the HIV is very simple. It has a viral envelope enclosing a nucleus surrounded by a protein coat. Within the nucleus is genetic material in the form of a single strand of RNA. The virus also carries three enzymes: reverse transcriptase, protease, and integrase. The virus has no machinery to produce energy or to manufacture protein.
3.1 Virus invasion and replication in human CD4 cell

The virus has on its membrane, a receptor that can interact and bind with the receptors on some cells in the body, especially the CD4 cells. Once the virus has entered the body, it binds with two receptor sites on the CD4 cell. This binding causes the fusion of the virus and the CD4 cell. The virus then penetrates (infests) the cell and empties its contents.

The viral replication starts when the viral DNA in the infected cell is “read” instead of the cell’s own DNA. The “read” viral DNA instructs the production of RNA, which then moves to the cytoplasm and causes the production of long chains of viral proteins. The long chains are cut into viral proteins by the protease and are assembled together to produce immature viral particles. Viral RNA is also produced.

The immature viral particles bud (push) out of the cell, taking also some of the cell membrane with it. A cell can produce hundreds of the viral particles and as they bud out, they destroy the cell membrane, leading to cell lysis and death of the CD4 cell.

In summary, the virus uses the body cell’s own machinery to replicate. The viral DNA is incorporated in the cell DNA. The release of viral particles leads to the death of the CD4 cell. Therefore, as viral quantity (viral load) in the body increases, more CD4 cells get killed and the immune system loses its ability to mount an effective defence mechanism. The immune system is compromised.
3.2 The physiology of the disease

The virus itself does not cause any disease, but because it destroys the immune system, it allows other organisms and cancer cells to cause diseases.

There is a progression from the asymptomatic stage (no symptoms) to minor opportunistic infections and then, as the body’s immune system gets more compromised, AIDS occurs where serious opportunistic infections and cancers occur.

When the immune system ceases to function, any part of the body can be affected. Accordingly, ailments affecting any part of the body – from the top of the head to the soles of the feet – can occur when AIDS sets in. This is why AIDS is referred to as a “syndrome” rather than a disease.

There are two periods when a person with HIV is most infectious. First, a person is very infectious (they have the most HIV in their blood) just after they have been infected themselves, while at the same time they are showing the least symptoms. Later, a person becomes more infectious again as their CD4 count falls as their immune system is overwhelmed. This is when ARVs are required for survival.
When the virus first enters the body, the immune system is stimulated. However, it takes some time before the B and T cells are able to effectively attack the virus. There is therefore an initial period during which the quantity of the virus (viral load) is increasing. In this period, it is possible to be tested for HIV and for the result to be negative. It means that the antibodies cannot be detected yet, but someone may still have the virus in their body.

That is the reason one is advised to repeat the test after three or six months. An HIV test can only show that a person did not have the virus between three and six months ago.

Eventually, T cells and B cells, and therefore antibodies, are produced. These attack the virus and bring the level down. This period, taking about three months, is called the seroconversion phase. The body is “converting” from an absence of HIV antibodies to having HIV antibodies.

The second phase is the asymptomatic phase. The viral load is low and the CD4 count, i.e. the count of the number of CD4 cells, can be high. During this period, the body’s immune system is mounting an effective fight against the virus and keeps the viral count low.
Meanwhile, more CD4 cells are getting infected and destroyed. Eventually the CD4 cells are destroyed to a level that they cease to be adequate to fight all the infections. The HIV infection therefore enters the **symptomatic phase**. In this phase, the body starts to experience some non-specific health problems such as weight loss, fevers, diarrhoea, and enlarged glands (lymph nodes). There may also be bacterial, fungal and viral infections referred to as opportunistic infections.

As the CD4 cell count falls **below 350**, more serious opportunistic infections and cancers attack the body in what is then referred to as **acquired immune deficiency syndrome** or **AIDS**. At this stage, the affected person may need to start taking antiretroviral drugs.

The decisions about treatment for people with HIV and AIDS should be guided by regular monitoring of the amount of HIV in the patient’s blood (viral load) as well as the number of CD4+ T cells - the immune system cells that fight infection.

### 3.3 Opportunistic Infections (OIs) and conditions

Once the immune system is compromised, the body is unable to mount effective defence against the organisms attacking it. The organisms therefore take the opportunity to invade the body, and that is why the resulting ailments are referred to as **opportunistic infections (OIs)**. The diagnosis and the treatment of OIs must be done by a clinician.

The most common OIs are tuberculosis, pneumocystic carinii pneumonia (PCP) and bacterial diseases like typhoid. Other diseases not necessarily caused by organisms but normally kept in control by the body also “take the opportunity” to attack the body. These include cancers such as Kaposi’s sarcoma. Below is a graphic explanation of some of the body parts often affected by OIs.
Figure 3.4 Some Opportunistic Infections associated with HIV

**The Head**
- OIs affecting the Central Nervous System (head, brain, spinal cord): Cryptococcal meningitis (severe headache and stiff neck); toxoplasms (fits and stroke) (organism from chicken and cat litter dust); meningitis; poor eyesight (cytomegalovirus); dementia (forgetfulness, cry and suck like a baby).

**Mouth and throat**
- Cold sores (by Herpes simplex); oral and oesophageal (Throat) thrush; Kaposi’s sarcoma (blister like cancer in mouth and throat); oral hairy leucopenia.

**The lungs**
- Tuberculosis, pneumocystic carinii pneumonia (PCP).

**The Stomach**
- Diarrhoea (caused by cytomegalovirus or disseminated TB), Kaposi’s sarcoma.

**The skin**
- Seborrhea dermatitis (start from head as dandruff and then to the rest of the body); Hairy leucopenia; shingles by herpes zoster (afflicting nerves on one side of the body causing painful blisters on the face, chest, waist or back).

**The legs and trunk**
- Thrombosis in the legs, peripheral neuropathy, (pins and needles sensation or numbness); swollen lymph glands (a sign that immune system is still working but can also be TB of the glands).
4. HIV counselling and testing

Knowing one’s HIV status is the first step to seeking medical attention and gaining access to effective treatment that can prolong life and delay the onset of AIDS. The earlier the start of treatment, the greater the delay in the onset of the serious complications associated with AIDS. Also, being aware of one’s HIV status enables the person to take the necessary precautions to prevent further spread of the virus to others and to future children.

The HIV antibody test should always include pre-test and post-test counselling. The counselling is to help one understand the test result, how to live positively (if infected), and how to avoid other infections. Testing for HIV is a central part of responding to the pandemic.

Testing and counselling is recommended for everyone. All of us need to know our HIV status. There are a number of reasons why church leaders should encourage counselling and testing. This is important. For example:

- The test result (positive or negative) helps the doctor to determine the cause and best treatment of the various illnesses one may have. These conditions are approached differently in HIV positive persons.
- Knowing one’s status helps to protect the spouse from infection or re-infection.
- It may help protect the unborn child from infection.

Church leaders should lead the way by encouraging the congregation and families to test for HIV and to seek treatment.

4.1 The meaning of HIV test results

**Negative result**

A negative result means that no HIV antibodies were found in the blood. The condition is called seronegative. This usually means that the person might or might not be infected, now and was not infected three months ago.

Almost all people who are infected develop HIV antibodies within three months, but it can take up to six months after infection in some people. To be sure that someone is negative, they must be re-tested at least three months after there was an action that could lead to the person being infected with HIV.

**Positive result**

A positive result means antibodies against HIV exist in the person’s blood. This means that the person has an HIV infection.

What should people do if they test positive for HIV?
Testing positive for HIV changes one’s life dramatically. Early medical attention and treatment can be the first step to a longer life and delaying the onset of AIDS. Leading a healthy lifestyle can help prevent life-threatening conditions. If a person tests positive, there are a number of important steps that they can take immediately to protect their health and that of others. These steps also play a key role in HIV treatment.

They include:

- Making behavioral changes to minimise transmission of the virus, such as practising safer sex with partners and not sharing needles;
- Seeing a doctor, even if one does not feel sick. Monitoring and appropriate medical action are the ways to slow the growth of HIV and delay the onset of AIDS;
- Informing family or friends. Telling people about your test result can be a very sensitive matter. The Church and the counsellor should assist such persons to deal with this challenge.

4.2 Counselling and testing for the youth

Peer counselling is an effective approach to HIV and AIDS education. Since the social and cultural issues that teenagers face in Africa may differ from the experiences of adults, young people may be more receptive to receiving information about HIV and AIDS from peers. It is beneficial for church leaders to encourage testing and counselling among the youth.
SUPPORTING INFORMATION B

THE ALL AFRICA CONFERENCE OF CHURCHES
COVENANT DOCUMENT ON HIV AND AIDS

Preamble

The Lord God is the creator of heaven and earth; the creator of all life forms in the earth community. He created all life and everything good. In this HIV and AIDS era, He sees the misery of His people, who are infected and affected by this disease. He has heard their cry on the account of this epidemic. He knows their sufferings and He has come down to deliver them from HIV and AIDS. So He calls to send us to the infected and affected, to bring His people, His creation, out of the HIV and AIDS epidemic. Now, therefore, this Assembly recognises God’s call to us and hence makes this covenant with God today:

Covenant 1: Life and HIV and AIDS prevention

We shall remember, proclaim and act on the fact that, the Lord our God created all people and all life and created life very good (Genesis 1–2). We shall, therefore, seriously and effectively undertake HIV and AIDS prevention for all people - Christians and non-Christians, married and single, young and old, women and men, poor and rich, black, white, yellow, all people everywhere, for this disease destroys life and its goodness, thus violating God’s creation and will.

Covenant 2: Love and HIV and AIDS care

We shall remember, proclaim and act on the fact that love is from God and everyone who loves is born of God and knows God. Those who say “I love God,” and hate their sisters and brothers are liars, for unless you love your sisters and brothers whom you see, you cannot love God whom you have never seen (I John 4:7–21). We shall, therefore, do all that is necessary and within our power to encourage both men and women to love, care, support and heal all those who are infected and affected by HIV and AIDS in our communities, countries, and continent.

Covenant 3: Treatment and HIV and AIDS drugs

We shall remember, proclaim and act on the fact that the earth and everything in it belongs to the Lord and that He has given it over to all human beings for custodianship (Psalms 24:1 and Genesis 1:29). We shall, therefore, openly and persistently undertake
prophetic and advocacy roles for all the infected who are denied access to affordable HIV and AIDS drugs, until antiretrovirals are available to all who need them.

**Covenant 4: Compassion, HIV and AIDS stigma and discrimination**

We shall remember, proclaim, and act on the fact that the Lord our God is a compassionate God, who calls upon us to be compassionate, to suffer with those who suffer, to enter their places and hearts of pain and to seek lasting change of their suffering (Luke 6:36; Matthew 25:31–46). We shall, therefore, have zero tolerance for HIV and AIDS stigma and discrimination and do all that is necessary to eliminate the isolation, rejection, fear and oppression of the infected and affected in our communities. We shall declare HIV and AIDS stigma and discrimination an unacceptable sin before God and all believers and in all our communities.

**Covenant 5: Poverty and HIV and AIDS**

We shall remember, proclaim, and act on the fact that the Lord our God created all the resources of the earth, blessed both women and men and gave them the resources of the earth for their sustenance (Genesis.1:28-29). We shall, therefore, work to empower all the poor and denounce all the cultural, national and international structures, laws and policies that have condemned billions to poverty, thus denying them their God given rights and, in the HIV and AIDS era, exposing them to infection and denying them quality care and treatment.

**Covenant 6: Gender inequalities and HIV and AIDS**

We shall remember, proclaim and act on the fact that the Lord our God created humankind in His image. In His image, He created them male and female, He blessed them both and gave both of them leadership and resources in the earth. He made them one in Christ (Genesis 1:27–29; Galatians 3:28–29). We shall, therefore, denounce gender inequalities that lead boys and men to risky behaviour, domination and violence; that deny girls and women leadership, decision making powers and property ownership thus exposing them to violence, witchcraft accusation, widow dispossession, survival sex – fuelling HIV and AIDS infection and lack of quality care and treatment.

**Covenant 7: Children and HIV and AIDS**

We shall remember, proclaim and act on the fact that, the Lord our God welcomes children. He has given His kingdom to them and He is the Father of all orphans (Mark 9:33–37;
10:13–16; Psalms 68:5 and Psalms 146:9). We shall, therefore, work to empower and protect all children and denounce all the national and international structures, cultures, policies, laws and practices that expose children to sexual abuse and exploitation, HIV and AIDS stigma and discrimination, dispossession and poverty thus exposing them to HIV and AIDS infection and lack of quality care.

**Covenant 8: The Church and people living with HIV and AIDS**

We shall remember, proclaim and act on the fact that we are one body of Christ and if one member suffers, we all suffer together with it; that the Lord our God identifies with the suffering and marginalised and heals the sick (1 Corinthians 14:26; Matthew 25:31–46). We shall, therefore, become a community of compassion and healing, a safe place for all PLWHA to live openly and productively with their status.

**Covenant 9: Human sexuality and HIV and AIDS**

We shall remember, proclaim and act on the fact that the Lord our God created human sexuality and created it good (Genesis 2:18–25). We shall, therefore, test for infection, denounce sexual violence, abstain before marriage, be faithful in marriage and practice protected sex to avoid HIV and AIDS infection and plunder on life, for all life is sacred and prevention should be seriously pursued to protect life.

**Covenant 10: Justice and HIV and AIDS**

We shall remember, proclaim and act on the fact that the Lord our God, sees, hears, knows the suffering of His people and comes down to liberate them (Exodus 3:1–12; Luke 4:16–22). We shall, therefore, declare the jubilee, and we shall proclaim liberty throughout the land and to all its inhabitants (Leviticus 25:10), for unless and until justice is served to all people in the world, until justice rolls down like waters and righteousness like an ever-flowing stream, HIV and AIDS cannot be uprooted.

*Source: All Africa Conference of Churches Covenant Document on HIV and AIDS*
NETWORKING, PARTNERSHIP AND RESOURCE MOBILISATION

HIV treatment can be an overwhelming activity even for the most prepared and well-funded churches. Finding appropriate opportunities for collaboration in order to complement work on HIV treatment is a good strategy. Church leaders are challenged to establish effective networks and collaborations with other treatment and care providers in order to strengthen their capacity.

1. Five Characteristics of an effective network

Most networks have some or all of the following characteristics:

- They are a group of organisations or individuals who come together to pursue common interests
- They share venues for social action through exchange and mutual learning
- They are sustained through some form of communication
- They are committed to a jointly developed structure and shared responsibility
- They are based on member ownership and commitment to shared objectives and means of action.

2. Guidelines to developing effective HIV and AIDS networks

Networking is a dynamic creative process of linking institutions and individuals for either joint endeavours or to share information and resources. It takes hard work, careful planning, management and occasional frustration to develop effective and efficient networks.

Although there is no known prescription for how churches can establish effective networks, it helps to consider the benefits and constraints of working with a partner. Following are some tips on how to establish church networks:

- Select a partner that your church wants to work with
- Establish the best and the worst attributes of the partner
- Discuss and list the positive and negative experiences that working with this partner can bring
Discuss the balance between pros and cons, and what your church can do to make the most of the benefits and to cope with the challenges.

Determine how working with this partner can affect the church’s relationships with other individuals and organisations.

Get to understand how working with this partner will affect the church’s programmes and relationships with the community.

3. Examples of partnerships

**International Network of Religious Leaders living with or personally affected by HIV and AIDS (INERELA+)**

*Web site: http://www.inerela.org*

INERELA+ is an interfaith network open to religious leaders living with or personally affected by HIV and AIDS. It aims to:

- Provide support without judgement
- Encourage people living with HIV to live positively, healthily and openly
- Fight stigma, denial, discrimination and inaction around HIV and AIDS.

INERELA+ conducts retreats that aim to build the capacity of participants to become advocates of hope and change in their own congregations, communities and countries. This rapidly growing network uses its members’ massive potential to challenge and overcome stigma, discrimination, denial and inaction frequently associated with HIV and AIDS.

Within INERELA+, a new model of responding to HIV has been developed. It is called SAVE, which stands for Safer practices, Available medication, Voluntary counselling and testing, and Empowerment through education. HIV prevention will never be effective without a care component. The SAVE model combines both prevention and care components, and provides messages to counter stigma.

In the life of churches, INERELA+ works towards breaking the silence surrounding HIV infection, including bringing the realisation to churches that HIV and AIDS affects them directly too. It demonstrates positive living by example. It assists in developing or modifying and implementing existing faith-based policies and declarations, and runs support groups.

**Zimbabwe Church Interdenominational AIDS Network**

Zimbabwe has formed an interdenominational AIDS network to enable churches to identify areas of need, and mobilise community resources to provide people living with
HIV with necessary support in their homes. The network gives home-based caregivers training in prevention and counselling.

The teams of caregivers are usually composed of a church worker, a nurse, and a driver, conducting their work under the supervision of qualified medical personnel. The teams, along with a pastor, are responsible for services such as:

- Emotional and spiritual support to the people living with HIV and their families
- Nursing services at home
- Financial support when possible
- Health education for family members, schools, parent-teacher associations, and the community
- Training of caregivers.

As an extension of the home-based care services, churches in Zimbabwe have adopted a programme to identify and care for orphans left destitute by parents who have died of AIDS-related illnesses. The programme is a formidable challenge to the Church because the number of orphans grows each year, while the resources of the Church do not.

The Church has the added responsibility of educating the orphaned children and training them in occupations that can give them a sense of dignity and personal fulfilment. This outreach of the Church is worthy of support from people everywhere.

Ecumenical HIV and AIDS Initiative in Africa (EHAIA)

Web site: http://www.oikoumene.org/programmes

EHAIA was set up in 2002 as a joint undertaking of African churches, Northern churches and agencies, and the World Council of Churches. The initiative enables churches in Africa to gain access to the information, training, networks, and funding they need to help deal with HIV and AIDS in their communities. EHAIA works to help churches in Africa become “AIDS-competent churches”. An AIDS-competent church is one:

- Whose teaching and practice indicate clearly that stigma and discrimination against people living with HIV is sin and against the will of God
- Which, along with its ecumenical partners, has a full understanding of the severity of the HIV pandemic in Africa
- Which reaches out and responds to collaborative efforts in the field of HIV and AIDS
- Which finds its role in prevention of HIV, taking into consideration pastoral, cultural and gender issues
- Which uses its resources and structures to provide care, counselling and support for those affected and/or infected with HIV.
The Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM)
Web site: http://www.theglobalfund.org
The Global Fund to fight AIDS, Tuberculosis and Malaria was created to dramatically increase resources to fight three of the world’s most devastating diseases, and to direct those resources to areas of greatest need.

As a partnership between governments, civil society, the private sector, and affected communities, the Global Fund represents an innovative approach to international health financing.

The Global Fund was founded on a set of guiding principles as follows:

- Operate as a financial instrument, not an implementing entity.
- Make available and leverage additional financial resources.
- Support programmes that reflect national ownership.
- Operate in a balanced manner in terms of different regions, diseases and interventions.
- Pursue an integrated and balanced approach to prevention and treatment.
- Evaluate proposals through independent review processes.
- Establish a simplified, rapid, and innovative grant-making process and operate transparently, with accountability.

The United States President’s Emergency Plan for AIDS Relief (PEPFAR)
Web site: http://www.pepfar.gov
PEPFAR is the US president’s emergency plan started in 2003 as a multi-faceted approach through which US$15 billion were committed to combat HIV and AIDS around the world. In the countries where the United States is combating HIV and AIDS, the Emergency Plan:

- Encourages bold leadership at every level to fight HIV and AIDS;
- Applies best practices within bilateral programmes in concert with host governments’ national HIV and AIDS strategies;
- Encourages all partners to coordinate, adhere to sound management practices and harmonise monitoring and evaluation efforts.
SUPPORTING INFORMATION D

CONTACTS AND RESOURCES
Ecumenical Pharmaceutical Network (EPN)
P.O. Box 73860–00200 Nairobi, Kenya
Tel: +254 20 4444532/4445020
Fax: +254 20 4441090/4440306
Email: info@epnetwork.org

International Network of Religious Leaders Living with or personally Affected by HIV and AIDS (INERELA+)
5th Floor JCC House, 27 Owl Street Milpark, Johannesburg, South Africa
Tel: +27 114829101
Fax: +27 114829107
Email: info@inerela.org
Website: www.inerela.org

Network of African People Living with HIV/AIDS (NAP+)
PO Box 9389 - 00200, Nairobi, Kenya
Tel: 254 20 273 4677, Fax: 254 20 273 6418
Email: info@napafrica.co.ke
Website: http://www.rapnap.org/indexf.html

The Global Network of People Living with HIV and AIDS (GNP+)
GNP+ Central Secretariat
P.O. Box 11726 - 1001 GS, Amsterdam
The Netherlands
Tel: +31 20 423 4114
Fax: +31 20 423 4224
Email infognp@gnpplus.net
Website: www.gnpplus.net
Ecumenical Advocacy Alliance
150 route de Ferney
P.O. Box 2100, CH-1211 Geneva 2, Switzerland
Tel: + 41 22 791 6723
Email: info@e-alliance.ch
Website: http://www.e-alliance.ch

World Council of Churches
150 route de Ferney
P.O. Box 2100, CH-1211 Geneva 2, Switzerland
Tel.: (+41 22) 791 6111
Fax: (+41 22) 791 0361
Website: http://www.oikoumene.org

Ubuntu Education Fund
Zwide Township Headquarters
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REFERENCES AND RESOURCE MATERIAL


WHAT A CHURCH LEADER NEEDS TO KNOW TO SUPPORT ANTIRETROVIRAL TREATMENT

**What is known about HIV and AIDS and its terrain (knowledge)**
- Causes and prevention
- Treatment
- Care and support
- Responses to stigma and discrimination, etc.

*Everything to the glory of God*

**HIV and AIDS reality**
- Deaths
- Suffering
- Orphans
- Loss of dignity and hope
- Spiritual breakdown

*My people perish for lack of knowledge*

**Bridging the gap – Action by church leaders**
- Promote and uphold the basic rights of people living with HIV
- Advocate for comprehensive antiretroviral treatment and HIV care
- Counselling and spiritual support
- Awareness of social, theological and technical issues of HIV and AIDS
- Fight stigmatisation and discrimination in all areas
- Participate in antiretroviral treatment advocacy programmes
- Involve people living with HIV in programmes
- Networking
- Provide care and support
- Create opportunities for public interaction between church leaders and people living with HIV
- Encourage people to know their HIV status
- Support antiretroviral treatment literacy in the community
- Care for children and orphans

*I was hungry and you gave me food*

**Desired situation**
- Hope and protection of human dignity
- Church as the centre of love
- Drugs and treatment available for all
- Justice shown to the vulnerable and marginalised

*Imago dei – made in the image of God
Church upholding human dignity*