

# HIV AIDS

## Treatment Literacy Guide for Church Leaders





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# FOREWORD



It is with great pleasure that I present this document, the EPN Treatment Guidelines for Religious Leaders. This comprehensive resource is the culmination of extensive research, collaboration, and the collective efforts of healthcare professionals, church leaders, and community members dedicated to addressing the complex challenges posed by HIV and AIDS.

HIV and AIDS continue to affect millions of individuals worldwide, leaving a profound impact on individuals, families, and communities.

In the face of this global health crisis, it is crucial that we join forces, bridging the gap between medical expertise and spiritual guidance, to provide comprehensive care and support to those living with HIV.

This resource serves as a guidebook for churches and religious institutions, outlining strategies to promote awareness, address stigma, and provide effective support for individuals living with HIV. It offers valuable insights into the role of faith communities in promoting HIV testing, facilitating access to antiretroviral therapy (ARVs), and fostering an environment of compassion, understanding and love.

This document presents real-life case studies that shed light on the challenges faced by individuals living with HIV, their families, and the broader community. These stories emphasize the critical need for education, advocacy, and holistic care that integrates medical, emotional, and spiritual support. By recognizing the interconnections of these elements, we can empower individuals to embrace positive living, adhere to treatment, and promote healthy behaviors.

The HIV and AIDS Treatment Guideline also highlights the importance of collaboration between churches, healthcare facilities, and community organizations. Through partnerships, we can amplify our impact, pool resources, and create a united front in the fight against HIV and AIDS. By working together, we can bridge gaps in knowledge, ensure access to treatment and support, and dismantle the barriers of stigma and discrimination that hinder progress.

I commend the dedicated individuals and organizations involved in the creation of this document. Their commitment to the well-being of those affected by HIV and AIDS is commendable, and their tireless efforts to promote compassion, education, and empowerment are an inspiration to us all.

May this document serve as a catalyst for change, fostering a culture of acceptance, inclusivity, and love within our churches and communities. Together, let us embrace the challenge, dispel myths and misconceptions, and work hand in hand to build a future free from the burden of HIV and AIDS.

**Rev. Dr. Fidon Mwombeki**

General Secretary of All Africa Conference of Churches (AACC)

# FOREWORD



Presenting the EPN Treatment Guidelines for Religious Leaders, a transformative resource that stands as the culmination of a concerted effort between religious communities, and passionate advocates striving to confront the challenges posed by HIV and AIDS. This pivotal document not only provides practical insights into fostering awareness and mitigating stigma within religious institutions but also underscores the vital role of faith-based organizations in advocating for comprehensive care and support for individuals living with HIV. By highlighting the importance of an all-encompassing approach that integrates medical, emotional, and

spiritual assistance, this guideline underscores the need to create a nurturing and empathetic environment for those impacted by this global health crisis.

Moreover, the document emphasizes the collective impact achievable through shared resources, amplified advocacy, and a unified front against the persistent challenges associated with HIV and AIDS. Through concerted efforts, this guideline aims to dismantle prevailing barriers of misinformation, discrimination, and limited access to treatment, paving the way for a future where communities can break free from the shackles of stigma.

I extend my heartfelt appreciation to the dedicated individuals involved in crafting this indispensable resource. Their unwavering dedication to promoting empathy, education, and empowerment sets a commendable example for collective action and progress in the global battle against HIV and AIDS. May this document serve as a beacon of hope, fostering an atmosphere of inclusivity, empathy, and support within communities and beyond.

In conclusion, let us view the EPN Treatment Guidelines for Religious Leaders as more than just a compilation of recommendations. It symbolizes a profound commitment to the well-being of individuals impacted by HIV and AIDS, emphasizing the critical need for a collaborative and compassionate approach in addressing this ongoing global health challenge. By recognizing the interconnected nature of physical, emotional, and spiritual well-being, this guideline encourages religious leaders to become ambassadors of empathy and understanding, driving positive change and eradicating the stigma associated with HIV. It is imperative that we continue to build upon the foundations set by this document, fostering a culture of acceptance, education, and support within our communities and empowering individuals to live fulfilling lives despite the challenges posed by this relentless epidemic.

**Rev. Dr. Charles Odira**

St. Arnold's Nyalienga Catholic Parish, Homa Bay. INERELA+

Kenya Board Member

# PREFACE



In the annals of human history, certain moments arise that compel us to reflect deeply on our shared humanity. The HIV and AIDS epidemic is one such moment—an unyielding challenge that has tested our resolve, compassion, and capacity for transformation. As we gather collective wisdom and experiences within the pages of the EPN Treatment Guidelines, we embark on a profound exploration of faith, health, and the boundless potential of our interconnections.

This book stands as a testament to the tireless efforts of individuals, communities, and organizations around the world who have dedicated themselves to the intersection of faith and HIV care. It is a culmination of their wisdom, their struggles, and their unwavering commitment to alleviate the suffering caused by this devastating pandemic. Through these guidelines, we seek to illuminate a path forward—one grounded in compassion, knowledge, and the profound teachings of our faith traditions.

The stories contained within these pages are both heartrending and inspiring. They reveal the resilience of individuals living with HIV and the transformative power of faith communities to create safe spaces, foster understanding, and provide holistic support. They remind us that HIV is not merely a medical condition; it is a social, cultural, and spiritual phenomenon that demands a comprehensive response. One that acknowledges the interconnectedness of our physical, emotional, and spiritual well-being.

The EPN Treatment Guidelines delves into the complexities of the HIV epidemic within the context of faith communities. It explores the multifaceted challenges faced by individuals living with HIV, the deep-seated stigmas that perpetuate their marginalization, and the urgent need for education, awareness, and compassionate care. It is a call to action—an invitation for faith leaders, healthcare providers, policymakers, and community members to come together and address this global crisis with unwavering commitment and collective responsibility.

While these guidelines provide a framework for action, they are not prescriptive. Rather, they serve as a starting point, a canvas upon which each faith community can paint its unique tapestry of healing, support, and advocacy. It is through our shared commitment to empathy, inclusivity, and justice that we can foster environments where individuals living with HIV are embraced, empowered, and treated with the dignity they deserve.

**Dr. Richard Neci**

Executive Director,

Ecumenical Pharmaceutical Network (EPN)

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The publication includes updated information from various sources, including organizations, institutions, books, and reports, we are grateful to all the contributors whose work is quoted in this guide. We would particularly like to acknowledge the work of INERELA+ Kenya whose expertise with regard to religious leaders was very helpful. We would also like to extend our heartfelt appreciation to all the partners who have reviewed the treatment literacy guide. Your expertise, insights, and valuable feedback have been instrumental in shaping the guide and making it accessible and relevant to a wider audience. Your commitment to improving the health and well-being of individuals and communities is truly inspiring. We are honored to have worked with you and look forward to continuing our partnership in the future.

Nonetheless, a selected group deserves a mention for their special contribution: Judith Asin, Programs Officer - EPN, and Rev. Jane Ng'ang'a, National Coordinator at INERELA+ Kenya, for spearheading the process of developing this guide.

The technical working group included Umazi Fanjo (EPN), Sharon Odeo (EPN), Austine Opiata (EPN), Hezron Kiptalam (EPN), Mary Muchoki, Grace Kariuki, Kelvin Thuku, Annet Macharia of INERELA+ Kenya. Membership of Faith Leaders - Bishop. Dr. John Warari Wakabu, Rev. John Gatu, Bishop. James Okombo, Rev. Mulinge Mutuse, Pst. Lydia Muiruri, (Partners) Philip Nyakwana- MMA, Esthther Papa, and Patricia Macharia from NASCOP, Brian Otieno from Alfajiri, Dinah Mombo from ACC, Bonface Opayo and Kelvin Kariuki from Kenya Students' Christian Fellowship (KSCF).

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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

**Ecumenical Pharmaceutical Network (EPN) Secretariat**

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# ABBREVIATIONS

<b>AACC</b>	All Africa Conference of Churches
<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ANC</b>	Antenatal Care
<b>ARV</b>	Antiretroviral
<b>ART</b>	Antiretroviral Therapy
<b>FBO</b>	Faith Based Organisation
<b>GF</b>	Global Fund
<b>HIV</b>	Human Immunodeficiency Virus
<b>IEC</b>	Information Education and Communication
<b>MTCT</b>	Mother to Child Transmission
<b>OIs</b>	Opportunistic Infections
<b>PEP</b>	Post Exposure Prophylaxis
<b>PEPFAR</b>	President's Emergency Fund for Aids Relief
<b>PLHIV</b>	People Living with HIV
<b>PMTCT</b>	Prevention of Mother to Child Transmission of HIV
<b>STI</b>	Sexual Transmitted Infections
<b>TL</b>	Treatment Literacy
<b>UN</b>	United Nations
<b>USAID</b>	United States Agency for International Development
<b>VCT</b>	Voluntary Counseling and Testing
<b>WCC</b>	World Council of Churches
<b>WHA</b>	World Health Assembly
<b>WHO</b>	World Health Organization



# ORIGIN OF THE BOOK

In 2010, EPN developed a HIV literacy guide with the main aim of enabling religious leaders 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. However, there has been remarkable advancement in HIV treatment over the years with new formulations approved for HIV treatment to address issues such as adherence, toxicity as well as new prevention approaches. There was a need to therefore review and update the existing information to ensure that Church leaders are able to take action and promote antiretroviral treatment awareness, drug availability and adherence to new treatment practices in their daily work.

This guide focuses specifically on ARVs because they have not been sufficiently addressed by the Church while they are essential in controlling HIV and enabling HIV-positive people to live longer and healthier lives. There are also new and recent ARVs developed 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.

There are many treatment literacy programmes for patients, but very few 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 current antiretroviral treatment and related organizational management issues in African countries.

# CHAPTER ONE: THEOLOGICAL BASIS FOR CARE

I am the Lord that heals you. (Exodus 15:26(b))

By the end of this chapter, the readers should be able to:

- 1) Describe the biblical view on health and healing.
- 2) Apply scriptures to provide hope and healing people.
- 3) Identify and use scriptures to confront misconceptions on health and healing.  
Describe the role of religious leaders in promoting health and healing

## God and Health

The theme of health is woven throughout scripture. It is present at creation and is also present at the end of all things. This chapter provides an overview of the Bible's view of health. In so doing, it will give a justification for both concern and action on the part of religious leaders and the faith communities they lead on matters of health in general and HIV and AIDS in particular.

There is no better way to start this discussion than with God's own words with regard to health. In Exodus 15:26, God identifies himself as the God who heals.

I am the God that Heals You (Exodus 15:26)

This self-declaration by God affects our view of health in a few different ways. First, it suggests that following the instructions of God can lead to good physical health. God promises that obeying Him will have better health outcomes for Israel than they experienced in Egypt. This is an encouragement for God's people to seek out and follow His teachings as a way to take care of their bodies and promote well-being.

In the Old Testament, God provided His people with specific dietary and hygiene guidelines to ensure that they remained healthy and vibrant. There were also protocols for diagnosis and treatment of different health challenges. There is nothing in the Bible that suggests God has changed His view on health. While these dietary and hygiene laws have been replaced by modern scientific information, the principle of God's concern about health remains relevant even today.

The second implication of this declaration provides hope for the sick. God is the healer. There are many examples of God providing healing for different kinds of people. It is important to note that God chose very diverse methods of healing people. For some people, a simple decree delivered the needed relief. For others, there were more elaborate protocols, including the use of medicine as was the case with Hezekiah in Isaiah 38.

This view of health is further illustrated by the biblical concept of shalom. This Hebrew word is often translated as "peace", but it encompasses a much broader range of meaning than simply the absence of conflict or strife. Shalom refers to a state of completeness, wholeness, and well-being that encompasses all aspects of life, including physical, emotional, social, and spiritual health. It is a state of harmony and right relationship with God, others, and the world around us.

## Shalom

In the Bible, shalom is often associated with God's presence and blessings. For example, in the book of Isaiah, the prophet speaks of a time when "the wolf and the lamb will feed together, and the lion will eat straw like the ox, and dust will be the serpent's food. They will neither harm nor destroy on all my holy mountain," (Isaiah 65:25) which is a depiction of shalom on earth.

In this sense, the concept of shalom is closely related to health and well-being. When we are in a state of shalom, we live in harmony with God, others, and the natural world, which can promote physical, emotional, and spiritual health. At the same time, seeking shalom and striving to live in right relationship with God and others can also be a source of healing and wholeness in and of itself.

Shalom encompasses not just the absence of disease or physical ailment, but also the overall well-being of an individual. It encompasses not just the body, but also the mind, the emotions, and the spirit. It also includes the well-being of relationships and community, which can have a significant impact on an individual's health and happiness.

## Abundant Life

The concept of "abundant life" in the New Testament is closely related to the Hebrew concept of shalom. The term "abundant life" is used in the New Testament to describe the full and holistic life that Jesus came to bring to people. This life is characterized by blessings and prosperity in every area of life, including physical health, emotional well-being, and spiritual vitality. It is a life of joy, peace, and purpose, and it is available to all who believe in Jesus and follow him.

In John 10:10, Jesus says, "I have come that they may have life, and have it to the full." This passage asserts that Jesus came to bring abundant life. It is a life that is full of blessings and prosperity, and that is characterized by shalom, or wholeness and well-being, in every aspect. Abundant life includes healthy living. This is demonstrated by the numerous miracles that Jesus performed during His ministry on earth.

In 3 John, the apostle John writes to a man named Gaius, praising him for his love and hospitality towards believers and encouraging him to continue in these good works. In 3 John 2, John writes, "Dear friend, I pray that you may enjoy good health and that all may go well with you, even as your soul is getting along well." This passage shows that good physical health is something that God desires for believers. Health should be a quality that is promoted alongside spiritual wellbeing.

## Health at Creation

Let's go back to the beginning. The story of creation, as told in the book of Genesis, reveals several things about God's view on health. First, it shows that God created the world and all that is in it, including the human body, and that he declared everything he made to be "good." This suggests proof that God values the human body and considers it to be a good and important part of his creation.

Second, the story of creation illustrates that God intended for humans to live in a world that was conducive to their health and well-being. He provided them with nourishing food to eat, a beautiful and varied environment to live in, and the means to take care of their bodies and maintain their health.

The story of creation also teaches that God intended for humans to live in harmony with one another and with the rest of creation. When everything was in its proper place and functioning as it should, there was shalom, or wholeness and well-being, in the world. God values healthy relationships and a healthy environment as important contributors to overall health and well-being.

The Garden of Eden reveals important aspects related to health and wellness. It was a place of perfect harmony and well-being, where everything was in its proper place and functioning as it should. There was no sickness or suffering, and humans were able to live in perfect health and vitality.

In this sense, the Garden of Eden can be seen as a kind of “ideal state” of health and wellness, in which humans were able to live in perfect harmony with God, with one another, and with the rest of creation. This again shows that God values health and well-being and desires for his people to experience these blessings.

At the same time, it’s important to note that the Garden of Eden was a unique and special place, and that the conditions described there are not necessarily the norm for human experience. The Bible teaches that humans have fallen from this state of perfect harmony and that they now live in a world that is broken and imperfect, where sickness, suffering, and death are a part of life. However, it also teaches that God is still at work in the world, and that he is able to bring about healing and restoration in the lives of those who trust in him. So the Garden of Eden serves as an example of the kind of health and wellness that God desires for his people, even though it may not be fully attainable in this present world.

## Health and Redemption

The Bible teaches that Jesus came to redeem the human race from the fall and reverse the effects of the fall. In the Book of Isaiah 53:1-5, Jesus is portrayed as the “Man of Sorrows”. This passage makes direct reference to healing by stating that “By His stripes, we are healed”. This occurs alongside other redemptive processes like “being wounded for our transgression”, “bruised for iniquity” and “chastised for our peace”. The New Testament makes reference to this passage severally.

First is to show that the healing work of Jesus was a direct fulfillment of this prophecy (Matthew 8:17) and secondly to provide hope for believers that Jesus already provided for their healing (I Peter 2:24). Anyone, then preaching the good news of Jesus Christ will be confronted with the reality that His redemptive work includes healing and restoration of peace (shalom). This should inspire action on our part.

## Health and Eschatology (End Times)

As the Bible draws to a close, it describes a city that is called The New Jerusalem. This city is depicted as a kind of “heaven on earth,” a place of perfect harmony and well-being that is free from all the brokenness and imperfection of this present world. In this sense, it can be seen as a kind of fulfillment of the kind of health and wellness that God desires for his people, similar to the way that the Garden of Eden is often understood as an “ideal state” of health and wellness. In this city “there will be no more death or mourning or crying or pain, for the old order of things has passed away” (Revelation 21:4). This suggests that in New Jerusalem, there will be no sickness or suffering, and that people will experience perfect health and vitality. It also describes the city as having the “glory of God” and being “radiant with the glory of God,” which means that it will be a place of great beauty and splendor.

There is also another aspect of health in Revelation 22. The Bible says that “the river of the water of life, as clear as crystal, flowing from the throne of God and of the Lamb” will be for the healing of the nations. This shows that the river of life, which flows from the throne of God and of the Lamb, has a special power to bring healing to people. It is described as being “clear as crystal,” which suggests that it is pure and uncorrupted, and that it has the ability to cleanse and purify those who drink from it.

The river of life is often understood to be a symbol of the life-giving power of God and of the salvation that is available to all who believe in him. In this sense, the fact that it is described as

being for the healing of the nations suggests that it has the ability to bring not just physical healing, but also spiritual healing and restoration. It is a source of life and vitality that is able to bring about transformation in the lives of those who receive it.

## Common Misconceptions about Health

In spite of the above discussion about health in the Bible, sections of the Christian faith community hold some beliefs and attitudes towards health that are incompatible with this information. The list below outlines some common misconceptions held by some individuals and organizations:

1. **That good health is always a result of following God's commands, and that illness is always a result of disobedience.** This is not always the case, as health is influenced by a variety of factors including genetics, lifestyle choices, and environmental factors.
2. **That faith in God alone is sufficient to heal all physical ailments.** While faith in God can bring emotional and spiritual comfort and can sometimes lead to physical healing, it is not always the case that physical healing will occur.
3. **That Christians should not seek medical treatment or use medication.** While faith in God can be an important part of the healing process, it is not always wrong to seek medical treatment or use medication. In fact, the Bible teaches that God has given us the means to care for our bodies and promote well-being (Isaiah 38).
4. **That all physical suffering is a result of sin.** This is not always the case, as suffering can come as a result of a variety of factors including genetics, accidents, and natural disasters.
5. **That Christians should not be concerned with their physical health or appearance.** While it is important to prioritize spiritual health, it is not wrong to take care of one's physical health or to be concerned with one's appearance. In fact, the Bible teaches that our bodies are temples of the Holy Spirit and that we should take care of them (1 Corinthians 6:19-20).

## The Role of the Religious Leader in Healthcare

The foregoing discussion has implications on the response of religious leaders to health issues. This response finds its basis in the pages of scriptures. Here are a few suggestions:

### 1. Compassion

Matthew 9:35-36: "Jesus went through all the towns and villages, teaching in their synagogues, proclaiming the good news of the kingdom and healing every disease and sickness. When he saw the crowds, he had compassion on them, because they were harassed and helpless, like sheep without a shepherd."

Matthew 14:14: "When Jesus landed and saw a large crowd, he had compassion on them and healed their sick." Mark 1:41: "Moved with compassion, Jesus reached out his hand and touched him. 'I am willing,' he said. 'Be clean!' Immediately the leprosy left him and he was cleansed."

Jesus' compassion can help us in our view of health in several ways. First, it can remind us that God cares about our physical as well as our spiritual well-being. Throughout his ministry, Jesus demonstrated a deep concern for the physical needs of others, and he performed many miracles of healing in order to demonstrate the power of God to bring about physical restoration. This can give us hope and encouragement when we are facing health challenges, knowing that God cares about our physical well-being and that he has the power to bring about healing.

Second, Jesus' compassion can remind us that God's love and care for us is not dependent on our health or circumstances. Jesus loved and cared for people regardless of their physical condition or social status, and he demonstrated this love through his actions, his words, and his willingness to sacrifice himself for others. This can help us to see that our worth and value as individuals is not

based on our health or our circumstances, but rather on the fact that we are loved and valued by God.

Finally, Jesus' compassion can inspire us to care for the physical needs of others in a similar way. As followers of Jesus, we are called to imitate his compassion and love for others, and this can involve caring for their physical needs as well as their spiritual needs. This can help us to see the importance of being involved in caring for the physical well-being of others and can inspire us to take action to make a positive difference in their lives.

## 2. Care

The story of the Good Samaritan, as told in Luke 10:30-37, teaches us several important lessons about helping the sick.

First, it teaches us that we have a responsibility to care for the physical needs of others, regardless of their background or social status. In the story, the Good Samaritan shows compassion for a man who was sick and in need, even though the man was from a different social group and was considered an outsider by the Samaritan. We should be willing to care for the physical needs of others, regardless of who they are or what they have done. Second, the story teaches us that we should be willing to go out of our way to help those in need. In the story, the Good Samaritan takes the time and effort to care for the man's wounds and to provide for his needs, even though it means going out of his way and incurring some cost to himself. This suggests that we should be willing to put ourselves out for others and to make a sacrifice in order to help those who are sick.

Finally, the story teaches us that we should be willing to do more than just provide for someone's physical needs. In the story, the Good Samaritan not only cares for the man's physical needs, but he also takes him to an inn and pays for his care there. We must show the willingness to go beyond just providing for someone's physical needs and to provide ongoing support and care for those who are sick.

In Matthew 25:36, Jesus says, "I was sick, and you looked after me." This passage, along with the story of the Good Samaritan, teaches us that caring for the sick is an important aspect of following Jesus and living out his commands. Caring for the physical needs of those who are sick, we are serving Jesus and showing love and compassion to him.

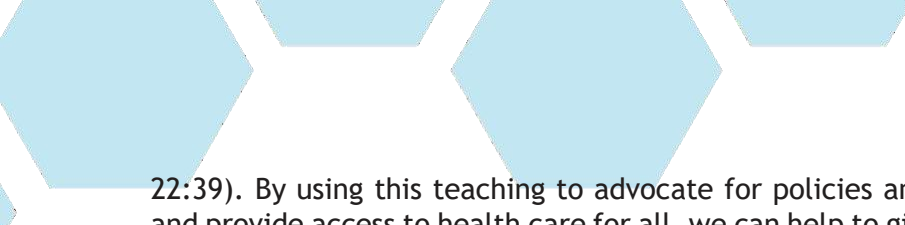
This passage also reminds us that caring for the sick is not just a matter of fulfilling a duty or obligation, but rather it is an opportunity to show love and compassion to others in a very practical and tangible way. By taking the time and effort to care for the physical needs of those who are sick, we are demonstrating the love of Jesus to them and offering them hope and comfort.

## 3. Provide a Voice for the weak

We can learn from the Bible to give a voice to those who cannot access good health by speaking out on behalf of those who are marginalized and disadvantaged. This means using the Bible's teachings about justice and compassion to advocate for change on behalf of those who are being denied access to good health.

One way to do this is to use the Bible's teachings about justice and compassion to speak out against systems and structures that contribute to health disparities. For example, the Bible teaches that God cares for the poor and disadvantaged (Psalm 146:7) and that he calls his people to defend the rights of the poor and to speak out against injustice (Proverbs 31:8-9). By using these passages to speak out against systems and structures that contribute to health disparities, we can help to bring about change and to give a voice to those who are being denied access to good health.

Another way to use the Bible to give a voice to those who cannot access good health is to use it to advocate for policies and programs that promote health equity. For example, the Bible teaches that we are to love our neighbors as ourselves and to care for the physical needs of others (Matthew



22:39). By using this teaching to advocate for policies and programs that promote health equity and provide access to health care for all, we can help to give a voice to those who are being denied access to good health.

#### 4. Be a Trusted Source of Information on Health Matters

Malachi 2:7 is a verse that speaks to the role and responsibilities of religious leaders, specifically priests in this case. It states, “For the lips of a priest ought to preserve knowledge, because he is the messenger of the Lord Almighty and people seek instruction from his mouth.”

This verse shows that priests have a responsibility to preserve and share knowledge, and that people look to them for instruction and guidance. In the context of health, this could mean that priests have a responsibility to be knowledgeable about health-related matters and to be proactive in sharing this knowledge with their congregants.

For example, priests might teach their congregants about healthy lifestyle habits, such as the importance of regular exercise, a healthy diet, and stress management. They might also provide guidance on how to access medical care and other health resources or offer spiritual counsel and support to those who are facing health challenges.

By fulfilling these responsibilities, priests can serve as a source of information and instruction on health-related matters for their congregants and can help to promote health and well-being within their communities.

#### Conclusion

It is clear from this chapter that religious leaders have a reason to act when it comes to health issues. Apart from having the reasons to act, religious leaders also have ways or approaches they can use to address health. While the religious leaders might not be able to do everything, there is always something they can do. That action, however small, can save lives. It also advances God’s purpose on earth.

# CHAPTER TWO: HIV AND AIDS ; THE BASICS

My people perish for lack of knowledge (Hosea 4:6)

By the end of this chapter, the reader should be able to:

- 1) Explain the basic facts of HIV and AIDS
- 2) Deal with common misconceptions about HIV and AIDS
- 3) Provide leadership and example in testing and advocacy

## What is HIV and AIDS?

HIV (Human Immunodeficiency Virus) is a virus that attacks and weakens the immune system, making it more difficult for the body to fight off infections and diseases. HIV is primarily spread through sexual contact but can also be transmitted through the sharing of needles or from mother to child during childbirth, breastfeeding, or pregnancy.

AIDS (Acquired Immune Deficiency Syndrome) is a condition that occurs when the immune system is severely damaged and is unable to fight off infections and diseases. AIDS is the most advanced stage of HIV infection and is typically diagnosed when the immune system is so weakened that the person is at high risk for life-threatening infections and diseases.

HIV and AIDS are not the same thing. HIV is a virus that can lead to AIDS, but not everyone who is HIV-positive will develop AIDS. With proper treatment and care, it is possible for people living with HIV to live long and healthy lives without progressing to AIDS.

HIV can have a significant impact on the body. When HIV is left untreated, it can weaken the immune system, making it more difficult for the body to fight off infections and diseases. HIV can also lead to serious health complications, such as:

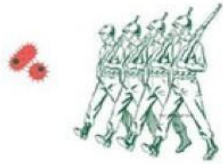
- **Opportunistic infections:** HIV-positive individuals are at increased risk of developing opportunistic infections, which are infections that occur more frequently or are more severe in people with weakened immune systems. Some examples of opportunistic infections include pneumonia, tuberculosis, and candidiasis (a yeast infection).
- **AIDS-related cancers:** HIV-positive individuals are also at increased risk of developing certain cancers, such as Kaposi's sarcoma, lymphoma, and cervical cancer.
- **Neurological disorders:** HIV can also lead to neurological disorders, such as HIV Associated Neurocognitive Disorder (HAND) and HIV-associated dementia.

HIV and AIDS can also have a significant impact on mental health. HIV-positive individuals may experience a range of emotions, such as fear, worry, and stigma, which can affect their mental well-being. PLHIV individuals may also face challenges related to their HIV status, such as disclosure to sexual partners, stigma and discrimination, and difficulties accessing healthcare, which can contribute to mental health issues. PLHIV individuals may also experience high levels of stress and may be at risk of developing post-traumatic stress disorder (PTSD).

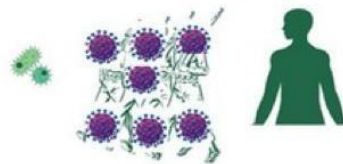
It is important for PLHIV to take care of their mental health and to seek support if needed. This may involve seeking therapy or counseling, joining a support group, or finding other ways to manage stress and improve mental well-being. They should also be aware of the potential for HIV-related stigma and discrimination to affect their mental health and seek support if needed to manage these challenges.



## HIV MECHANISM



In a healthy individual, the body has a defence mechanism (White Cells) that can fight any invading disease causing organism, thereby keeping the body healthy.



HIV Attacks the body's defence



Without the defence, disease causing organisms can now attack and cause a sickness

## History of HIV and AIDS

The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have had a significant impact on the global population since they were first identified in the 1980s. In 1981, the first reported cases of HIV and AIDS were in the United States, when a cluster of men who had sex with men were diagnosed with a rare form of pneumonia. In 1983, scientists identified the virus that causes AIDS, which was later named HIV. HIV and AIDS quickly spread beyond the United States and became a global pandemic, with cases reported in Africa, Asia, Europe, and Latin America. In the 1990s, antiretroviral therapy was developed, which effectively suppresses the HIV virus and allows people living with HIV to live long and healthy lives. Despite significant progress in the treatment and prevention of HIV and AIDS, the disease continues to have a significant impact globally, with millions of people living with HIV and AIDS and new cases being reported every year.

## Modes of Transmission

HIV is transmitted through the exchange of certain bodily fluids, such as blood, semen, vaginal fluids, and breast milk. HIV can be transmitted in the following ways:

1. **Sexual contact:** HIV is primarily transmitted through sexual contact, including vaginal, anal, and oral sex. The virus can be transmitted when infected bodily fluids come into contact with mucous membranes or damaged tissue, or when infected blood comes into contact with broken skin.
2. **Sharing needles:** HIV can be transmitted through the sharing of needles or other equipment used to inject drugs.
3. **Mother to child:** HIV can be transmitted from a mother to her child during pregnancy, childbirth, or breastfeeding.

HIV cannot be transmitted through casual contact such as shaking hands or sharing food and drinks.

## Methods of Prevention

1. **Condoms:** Using condoms consistently and correctly during sexual activity is one of the most effective ways to prevent the transmission of HIV. Condoms create a physical barrier that can help to prevent the exchange of infected bodily fluids.
2. **Pre-exposure prophylaxis (PrEP):** PrEP is a daily pill that can be taken by HIV-negative individuals to reduce their risk of HIV infection. PrEP is most effective when taken consistently and as prescribed.

- 3. Post-exposure prophylaxis (PEP):** Post-exposure prophylaxis (PEP) is an antiretroviral (ARV) treatment regimen that may prevent some HIV infections if it is started soon after a potential exposure to HIV. Potential exposures to HIV include unprotected sex, needle-sharing among injection drug users, or a needle stick or other sharp object injury in a healthcare setting. PEP should be initiated as soon as possible, preferably within the first 24-72 hours after potential exposure. PEP is not a substitute for regular safer sex practices and ongoing HIV testing. The medications for PEP are different than those for pre-exposure prophylaxis (PrEP) and should be taken for 28 consecutive days.
- 4. Antiretroviral therapy (ART):** HIV-positive individuals can take antiretroviral medication to suppress the virus and reduce the risk of transmission to others. When taken consistently, ART can reduce the amount of HIV in the body (known as the viral load) to very low levels, which makes HIV transmission much less likely.
- 5. Avoiding sharing needles or other injection equipment:** Sharing needles or other injection equipment can increase the risk of HIV transmission. To reduce this risk, it is important to use new, sterile needles and other injection equipment each time.
- 6. HIV testing and treatment:** Getting tested for HIV and seeking treatment, if necessary, can help to reduce the risk of transmission to others. HIV-positive individuals who are aware of their status and are receiving treatment are much less likely to transmit the virus to others.
- 7. Abstaining from sexual activity is one way to completely eliminate the risk of HIV transmission through sexual contact.** However, abstinence is not a realistic or desirable option for everyone, and it is not always a practical or effective method of HIV prevention.
- 8. Having multiple sexual partners can increase the risk of HIV transmission.** When an individual has multiple sexual partners, the risk of exposure to HIV increases, as they may be more likely to have sexual contact with someone who is HIV-positive or at high risk of HIV infection. It is important to note that HIV can be transmitted through sexual contact with just one infected partner, and having multiple sexual partners does not necessarily mean that an individual will definitely contract HIV. However, having multiple sexual partners does increase the risk of HIV transmission, and it is important for individuals to consider this risk and take steps to protect themselves and their partners.

## Discordant Couples

Discordant couples are couples in which one partner is HIV-positive and the other is HIV-negative. Discordant couples may face unique challenges and considerations related to HIV transmission and prevention.

It is important for discordant couples to understand the risks of HIV transmission and to take steps to protect their HIV-negative partners. This can involve the HIV-positive partner taking antiretroviral medication to suppress the virus and reduce the risk of HIV transmission and using condoms consistently and correctly.

Discordant couples may also need to consider issues related to reproduction and parenting, as there are options available for HIV-positive individuals to have HIV-negative children. It is important for discordant couples to discuss these issues with a healthcare provider and to make informed decisions about their options.

Discordant couples may face unique challenges related to HIV transmission and prevention, and it is important for them to seek guidance and support from a healthcare provider to address these challenges and make informed decisions about their health and well-being.

## Mother to Child Transmission

Mother-to-child transmission (MTCT) of HIV refers to the transmission of HIV from a mother to her child during pregnancy, childbirth, or breastfeeding. MTCT is a significant mode of HIV transmission, particularly in countries with high rates of HIV infection.

There are several steps that can be taken to prevent MTCT of HIV:

1. **HIV testing:** It is important for pregnant women to get tested for HIV so that they can receive appropriate care and treatment if necessary. This can involve seeking out HIV testing at a healthcare facility or using self- test kits.
2. **Antiretroviral therapy (ART):** HIV-positive pregnant women can take antiretroviral medication to suppress the virus and reduce the risk of HIV transmission to their children. ART can be taken during pregnancy, childbirth, and breastfeeding to reduce the risk of MTCT.
3. **Safe delivery practices:** It is also important to use safe delivery practices, such as avoiding unnecessary medical procedures that may expose the baby to HIV-infected blood, and avoiding breastfeeding if the mother is HIV-positive.
4. **Infant feeding:** HIV-positive mothers who are unable to take ART or who choose not to breastfeed can use infant formula to feed their babies.

## HIV Testing

HIV testing is an important tool in addressing HIV and AIDS. HIV testing allows individuals to learn their HIV status and can help to identify those who are HIV-positive so that they can access treatment and care.

HIV testing is important for several reasons:

- ❖ **Early detection:** HIV testing can help to detect HIV infection in its early stages, which is when treatment is most effective. Early treatment can help to suppress the virus, improve the immune system, and reduce the risk of HIV-related complications.
- ❖ **Prevention:** HIV testing can also help to prevent HIV transmission, as HIV-positive individuals who are aware of their status can take steps to protect their partners, such as using condoms consistently and correctly, and taking antiretroviral medication to suppress the virus.
- ❖ **Stigma reduction:** HIV testing can also help to reduce HIV stigma, as it allows individuals to learn their HIV status in a confidential and non-judgmental setting and can help to reduce the fear and stigma surrounding HIV testing.

There are several reasons why one should consider getting tested for HIV:

1. **To know your HIV status:** HIV testing allows you to learn your HIV status, which is important for your own health and well-being. Knowing your HIV status can help you to make informed decisions about your health and to take steps to protect yourself and your partners.
2. **To access treatment and care:** If you are HIV-positive, HIV testing allows you to access treatment and care that can help to suppress the virus, improve your immune system, and reduce the risk of HIV-related complications.
3. **To prevent HIV transmission:** HIV testing can also help to prevent HIV transmission, as HIV-positive individuals who are aware of their status can take steps to protect their partners, such as using condoms consistently and correctly and taking antiretroviral medication to suppress the virus.
4. **To reduce HIV stigma:** HIV testing can also help to reduce HIV stigma, as it allows

individuals to learn their HIV status in a confidential and non-judgmental setting and can help to reduce the fear and stigma surrounding HIV testing.

HIV testing is an important tool for your own health and well-being and can help to prevent HIV transmission and reduce HIV stigma. It is important to consider getting tested for HIV, and to seek testing if necessary.

In addition to services offered by professionals in clinical settings or other testing centers, HIV self-testing kits allow individuals to test for HIV without the need for a healthcare professional. These kits use a simple finger prick method and a small amount of blood to provide immediate results at home. This is particularly useful for individuals who are unable to access regular HIV tests due to financial or other constraints. HIV self-testing kits may also be beneficial as they can facilitate early diagnosis, leading to more effective treatment and a better prognosis for the person's overall health. Furthermore, these kits can provide greater privacy and help reduce the stigma associated with HIV testing.

## HIV and AIDS Stigma

HIV stigma refers to negative attitudes, beliefs, and behaviors towards people living with HIV and AIDS. HIV stigma can take many forms, including prejudice, discrimination, and social exclusion. HIV stigma can be based on misinformation, fear, or a lack of understanding about HIV and how it is transmitted.

HIV stigma can have serious consequences for people living with HIV, including:

- **Lack of willingness to access healthcare:** HIV stigma can prevent people from seeking testing, treatment, and other healthcare services out of fear of discrimination or rejection.
- **Social isolation:** HIV stigma can lead to social isolation and exclusion, as people living with HIV may fear rejection or discrimination from friends, family, and other community members.
- **Difficulty finding and maintaining employment:** HIV stigma can also make it difficult for people living with HIV to find and maintain employment, as they may face discrimination from potential employers or coworkers.
- **Poor mental health:** HIV stigma can also have a negative impact on mental health, as people living with HIV may feel shame, guilt, or stress as a result of stigma and discrimination.

HIV stigma is a serious issue that can have serious consequences for people living with HIV. It is important to combat HIV stigma and promote understanding, compassion, and acceptance towards those living with HIV and AIDS.

## Vulnerable Groups

1. **Men who have sex with men:** Men who have sex with men (MSM) are at increased risk of HIV transmission through sexual contact and are particularly vulnerable to HIV due to stigma and discrimination.
2. **People who inject drugs:** People who inject drugs are at increased risk of HIV transmission through the sharing of needles or other injection equipment.
3. **Sex workers:** Sex workers, particularly those who work in informal or underground settings, are at increased risk of HIV transmission due to the nature of their work and the potential for stigma and discrimination.
4. **Transgender individuals:** Transgender individuals may be at increased risk of HIV transmission due to stigma, discrimination, and a lack of access to healthcare and other resources.
5. **People living in certain geographical areas:** HIV disproportionately affects certain

geographical areas, including sub-Saharan Africa, where around two-thirds of people living with HIV are located.

6. **People with low income or education:** People with low income or education may be at increased risk of HIV transmission due to a lack of access to education, resources, and healthcare.

It is important to recognize that HIV and AIDS can affect anyone, and to work to reduce stigma and discrimination and increase access to education, resources, and healthcare for all populations.

## The SAVE Toolkit

The International Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (INERELA) uses a model known as SAVE. This is an acronym for

**S**- Safer Practices

**A**- Access to Medication

**V**- Voluntary Testing

**E**- Empowerment.

The safe practices include abstinence, correct and consistent use of condoms, being faithful to one's partner, preventing mother-to-child transmission, using sterile needles, voluntary male circumcision, ensuring the safety of blood transfusions, and taking ARV therapy for those living with HIV to reduce transmission risk. More information on the SAVE toolkit is available from the INERELA office closest to you or by using the contacts provided in the resources section of this book.



[https://drive.google.com/file/d/1vHSpmV6xSk\\_1E-rWA9A5Yi4PsUjxwtmX/view?usp=sharing](https://drive.google.com/file/d/1vHSpmV6xSk_1E-rWA9A5Yi4PsUjxwtmX/view?usp=sharing)

# CHAPTER THREE: ANTIRETROVIRAL TREATMENT

Is there no balm in Gilead; is there no physician there? Why then is not the health of the daughter of my people recovered? (Jeremiah 8:22)

By the end of the chapter, the readers should be able to:

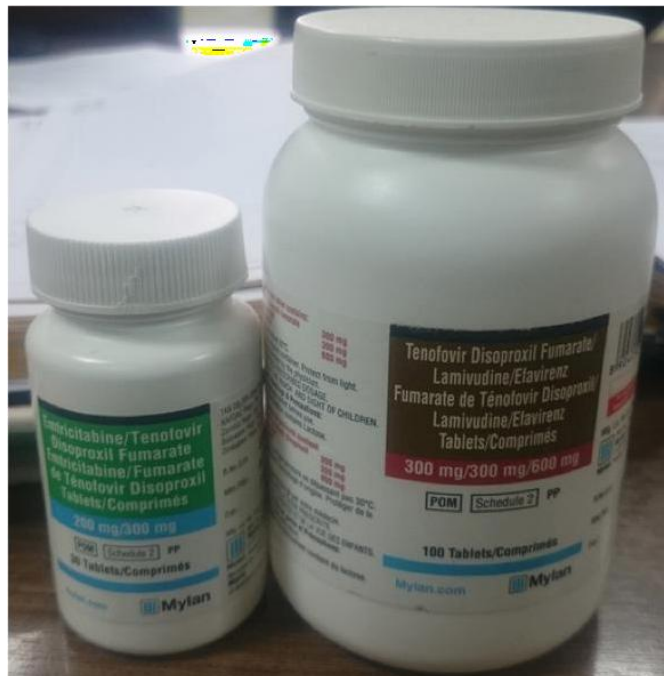
- To define what ARVs are, how they work and side effects
- To describe the importance of disclosure and adherence in promoting ART
- To explain the importance of nutrition with regards to ARV treatment

## What is Antiretroviral Therapy?

Antiretroviral (ARV) drugs are medications used to treat infections caused by retroviruses, particularly HIV. HIV attacks the immune system, making it difficult for the body to fight off infections and diseases. When someone has HIV, their immune system gets weaker over time. This makes them more likely to get AIDS (acquired immune deficiency syndrome). ARVs work by making it harder for the HIV virus to make copies of itself and spread through the body. This slows down the spread of HIV and keeps it from turning into AIDS. ARV treatment is known as antiretroviral therapy (ART), and it is typically taken for life. ART can effectively manage HIV and allow people with HIV to live long and healthy lives.

When it comes to ART, there are two things to keep in mind. One is HIV viral load, which is a measure of how much HIV is present in a person's blood. It is typically expressed as the number of HIV RNA copies in one milliliter of blood. HIV viral load can be used to check how well antiretroviral therapy (ART) is working and help decide how to treat someone. A high viral load could mean that the HIV virus is multiplying quickly, and that the person's immune system is under stress. On the other hand, a low or undetectable viral load may mean that ART is doing a good job of keeping the HIV infection under control. 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 transmitted in the blood to other people. This means that the person is still infectious and can still pass on HIV.

The other thing is the CD4 count, which is a measure of the number of CD4 cells in a person's blood. CD4 cells, also known as T cells, are a type of immune cell that helps fight off infections. HIV attacks and destroys CD4 cells, which can lead to a decline in the number of CD4 cells in the body. If a person has a low CD4 count, it could mean that their immune system is weak and that they could get opportunistic infections. The CD4 count is often used to track how HIV is getting worse and to decide how to treat it.



## The objective of ART is to:

- ❖ **Suppress HIV replication:** ART is designed to inhibit the replication of HIV in the body, which helps to slow down the progression of HIV infection and prevent the development of AIDS.
- ❖ **Restore immune function:** HIV attacks and destroys immune cells, particularly CD4 cells, which can lead to a decline in immune function. ART can help to restore immune function by reducing the number of HIV-infected cells and allowing the body to produce new immune cells.
- ❖ **Improve quality of life:** ART can help to reduce the symptoms of HIV infection and improve a person's overall quality of life. It can also reduce the risk of HIV transmission to others.
- ❖ **Prolong survival:** ART can help to extend the lifespan of people with HIV by slowing down the progression of the disease and reducing the risk of opportunistic infections.
- ❖ **Achieve viral suppression:** The ultimate goal of ART is to achieve viral suppression, which means reducing the HIV viral load to an undetectable level. This is important because it indicates that the HIV virus is being effectively controlled and that the person's immune system is not under stress.

Additionally, ART offers some benefits to individuals and communities. They include:

1. **Slowing down the progression of HIV infection:** ART can slow down the replication of HIV in the body, which helps to prevent the development of AIDS and prolong survival.
2. **Reducing the risk of HIV transmission:** ART can reduce the amount of HIV in the body to an undetectable level, which reduces the risk of HIV transmission to others through sexual contact or the sharing of needles.
3. **Reducing healthcare costs:** ART can reduce the need for hospitalizations and other costly medical interventions, which can lower healthcare costs in the long term.
4. **Improving productivity:** ART can help people with HIV to maintain good health, which may increase their ability to work and improve their employment prospects.
5. **Providing greater economic security:** ART can improve a person's ability to work, which can lead to greater economic security and stability.
6. **Improving social relationships:** ART can reduce the symptoms of HIV infection and improve a person's overall quality of life, which may enhance their social relationships and social support network.
7. **Increasing social inclusion:** ART can help to reduce the stigma associated with HIV and increase the social inclusion of people living with HIV.
8. **Enhancing sense of hope and well-being:** ART can give people with HIV a sense of hope and a sense of control over their health and well-being, which can have a positive impact on their mental and emotional well-being.

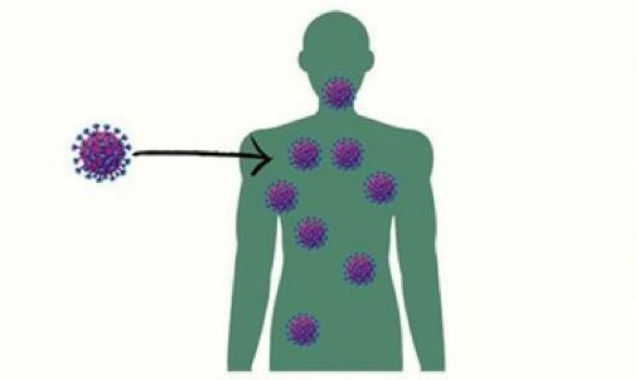
## Who should be enrolled in ART?

Antiretroviral therapy (ART) should be given to everyone who has HIV, according to the current guidelines. This is because ART can significantly improve the health and well-being of people living with HIV and reduce the risk of HIV transmission to others. In general, people with HIV should start ART as soon as possible after their diagnosis, regardless of their CD4 count (a measure of immune function) or the severity of their HIV infection. Early ART can help keep the immune system working and lower the risk of HIV complications.

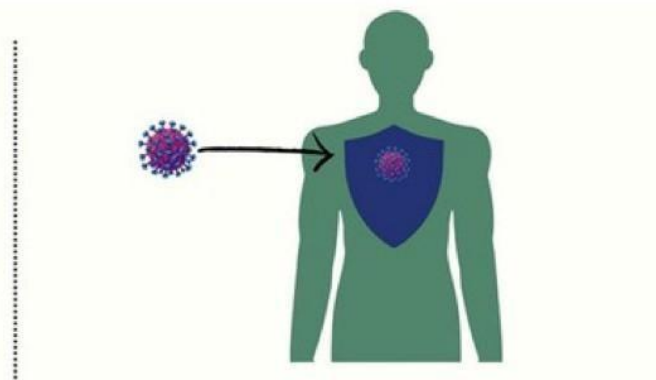
## Anti-Retroviral Drugs

There are some exceptions to this recommendation. For example, people with HIV who have advanced HIV disease or who have AIDS-defining illnesses should receive ART as soon as possible, even if their CD4 count is relatively high. Similarly, pregnant women with HIV should start ART as soon as possible to reduce the risk of HIV transmission to their newborns.

In some cases, people with HIV may choose to delay starting ART, either due to personal preference or because they do not feel ready to commit to lifelong treatment. In these cases, it is important for the person to have access to HIV care and support to help them make an informed decision about when to start ART.



Once inside the body, HIV begins to replicate



ARVs Prevents HIV from replicating (making copies of itself)

There are different classes of ARV drugs, which operate under different brands. The classification of these drugs is done on the basis of the mechanism they use to deal with HIV. Here are the main ways in which they work:

There are different types of medicines that help fight HIV. These medicines work in different ways to stop the virus from growing in your body. Here are the main types:

1. **By blocking a special step**, the virus ceases to grow and thus keeping the virus from making more copies of itself.
2. **By keeping the virus from getting inside your body's cells**. This stops the virus from making more copies of itself.
3. **By stopping the virus from becoming part of your body's cells**. This keeps the virus from making more copies.

## What are the Side Effects of ARVs

Antiretroviral (ARV) drugs can cause a variety of side effects, some of which can be serious. The specific side effects of ARV drugs can vary depending on the specific drugs being used and the individual taking them. The table below contains some examples of ARV side effects.



SIDE-EFFECT	PRESENTATION / COMMENT
Hepatitis (inflammation of the liver)	Abdominal pain, rash, jaundice(yellow skin and eyes), nausea/vomiting
Pancreatitis (inflammation of the pancreas)	Abdominal pain that radiates to back, nausea
Rash	Can be severe e.g. blister, skin loss, or minor e.g. itching
Lactic acidosis (sensation of severe heartburn)	Fatigue, nausea, fever, abdominal pain, weight loss
Anaemia (low red blood cell count)	Fatigue, pale skin, fast beating of the heart
Diarrhea	Loose stools, mild abdominal pain
Nausea and abdominal pain	Many ARVs can cause mild nausea, vomiting and abdominal pain. Some may cause bloating and flatulence (gassiness). These symptoms pass with time.
Lipodystrophy	Transfer of fat to the abdomen and back of neck
Lipoatrophy	Loss of fat in the arms and legs
Peripheral neuropathy	Numbness, tingling, painful burning sensation in toes/ fingers, symmetric (left and right)
Dizziness/sleepiness/bad dreams	Dizziness, nightmares, feeling sleepy. In severe cases symptoms of mental illness, hallucinations, depression, mania. Some may have suicidal tendencies. However, this is rare
Kidney problems	Usually no symptoms; maybe fatigue, tiredness

## Resistance

Antiretroviral (ARV) drugs work by inhibiting different stages of the HIV lifecycle, which helps to slow down the replication of the virus in the body. However, over time, the HIV virus can develop resistance to certain ARV drugs, which means that the drugs are no longer effective at controlling the virus.

There are several factors that can contribute to the development of ARV drug resistance, including:

1. **Poor adherence to treatment:** Taking ARV drugs consistently and as prescribed is important for maximizing their effectiveness and minimizing the risk of resistance.
2. **Genetic mutations:** HIV is a rapidly mutating virus, and certain genetic mutations can lead to the development of ARV drug resistance.
3. **Drug interactions:** Some medications, supplements, and herbal products can interfere with the effectiveness of ARV drugs and increase the risk of resistance.
4. **Previous exposure to ARV drugs:** People who have previously been exposed to ARV drugs, either through treatment or through HIV transmission, may be at higher risk of developing resistance to certain ARV drugs.

If HIV develops resistance to one or more ARV drugs, it may be necessary to switch to a different ARV regimen in order to effectively control the virus. If your treatment doesn't work or if the HIV virus becomes resistant to your current ARV drugs, your healthcare provider can help you figure out what to do next.

## Drug Interactions

There are several drug interaction issues that people should be aware of when taking antiretroviral drugs (ARVs). Many drugs, including over-the-counter medications, prescription medications, and herbal supplements can interact with ARVs. Some medications can reduce the effectiveness of ARVs, while others can increase the risk of side effects or toxicity. It is important to talk to a healthcare provider about any medications or supplements being taken, including over-the-counter drugs, before starting ARV treatment. Healthcare providers can help to identify potential drug interactions and adjust medications as needed to ensure that ARV treatment is effective and safe.

## Adherence

ARV adherence means that a person takes their antiretroviral (ARV) drugs as prescribed and consistently. Adhering to treatment, or sticking to a treatment regimen, is important for several reasons:

1. **To maximize the effectiveness of ARV drugs:** ARV drugs work best when they are taken consistently and as prescribed. Taking ARV drugs irregularly or missing doses can reduce their effectiveness and increase the risk of treatment failure.
2. **To prevent the development of drug resistance:** If ARV drugs are not taken consistently, the HIV virus may develop resistance to the drugs, which means that they are no longer effective at controlling the virus.
3. **To reduce the risk of HIV transmission:** ARV drugs can help to reduce the amount of HIV in the body to an undetectable level, which reduces the risk of HIV transmission to others through sexual contact or the sharing of needles.
4. **To improve quality of life:** Adhering to treatment can help to reduce the symptoms of HIV infection and improve a person's overall quality of life.

There are many factors that can affect ARV adherence, including the complexity of the treatment regimen, side effects of the drugs, stigma associated with HIV, and access to healthcare. It is important for people with HIV to work with their healthcare provider to find an ARV regimen that is suitable for their individual needs and to develop strategies to ensure that they are able to adhere to treatment.

## ART Disclosure and Privacy Issues

People living with HIV may face a number of privacy and disclosure issues related to their antiretroviral (ARV) treatment. Some of the privacy and disclosure issues that people with HIV may face include:

1. **Stigma and discrimination:** People with HIV may be concerned about disclosing their HIV status due to the stigma and discrimination that still exists around HIV.
2. **Confidentiality:** People with HIV may be concerned about the confidentiality of their medical information, including their ARV treatment.
3. **Employment:** People with HIV may be concerned about disclosing their HIV status to their employer or potential employer due to concerns about discrimination in the workplace.
4. **Insurance:** People with HIV may be concerned about disclosing their HIV status to their insurance company due to concerns about discrimination or coverage.
5. **Relationships:** People with HIV may be concerned about disclosing their HIV status to sexual partners or potential partners due to concerns about rejection or stigma.

It is important for people with HIV to be aware of their rights and to seek support if they are facing any privacy or disclosure issues. In many cases, there are legal protections in place to prevent discrimination against people with HIV, and there are also resources available to help people with

HIV navigate these issues. It can be hard and personal to decide whether or not to tell someone you have HIV, and there is no one way to do it. Here are a few things to consider when deciding whether and how to disclose your HIV status:

1. **Think about your reasons for disclosing:** There may be a variety of reasons why you might want to disclose your HIV status, such as wanting to be open and honest with your sexual partners or wanting to reduce the stigma and discrimination associated with HIV. It can be helpful to think about your reasons for disclosing and what you hope to achieve by doing so.
2. **Consider your personal comfort level:** Disclosing your HIV status is a personal decision, and it is important to do so in a way that feels comfortable and safe for you. Take the time to think about your own feelings and concerns before disclosing your HIV status to others.
3. **Choose a safe and supportive environment:** Disclosing your HIV status can be easier if you do so in a safe and supportive environment. This might be with a trusted friend or family member, or with a healthcare provider or counselor who can provide guidance and support.
4. **Be prepared for a range of reactions:** Disclosing your HIV status can be unpredictable, and you may encounter a range of reactions from others. It is important to be prepared for this and to have a plan in place for how to handle negative reactions.

## 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 diarrhea. In these conditions, the body gets less energy and goodness from the food that is eaten. When someone loses weight while ill, they may be losing fat or lean body weight such as 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 well-balanced diet rich in protein and whole grains, as well as some sugar and fat, and regular exercise programs will help you build and maintain muscle.

Closely related to this is the question of access to clean water. This is critical for the success of ART treatment for people living with HIV and can improve overall health outcomes and quality of life.

Firstly, people living with HIV who are taking ART medication require adequate hydration to avoid side effects and ensure the medication is effective. Drinking clean water is essential for hydration and can also help to prevent other infections that may compromise the immune system, such as diarrhea or other waterborne illnesses.

Secondly, clean water is essential for proper sanitation and hygiene, which are important for preventing the spread of HIV and other infections. People living with HIV who have compromised immune systems are more susceptible to infections, and poor sanitation can increase the risk of infection and disease progression. Access to clean water can help to prevent the spread of infections and improve overall health outcomes.

Thirdly, clean water is needed for the preparation and administration of ART medication. The medication must be taken at specific times and in specific doses, and it is often taken with water. Without access to clean water, it may be difficult or impossible to take medication as prescribed, which can compromise the effectiveness of treatment.

Finally, clean water is important for the overall well-being of people living with HIV, who may already be facing stigma, discrimination, and other challenges. Access to clean water can improve quality of life and help to reduce the burden of living with a chronic illness.

## Children and ARVs

HIV infections in children can be significantly decreased where antiretroviral medications and good prenatal care are available. The majority of HIV infections in children occur during pregnancy, at birth, or through breast milk when they are breastfed, especially when the mother's HIV status is unknown, and no precautions have been taken. The infection could spread to other kids through blood transfusions or sexual abuse.

HIV in children needs special consideration 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 pediatric 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.

## 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.

In recent years, the rate of HIV being passed from mother to child (MTCT) has gone down a lot, thanks to the wide use of antiretroviral (ARV) drugs and other preventive measures. But the exact rate of MTCT depends on a number of things, such as how common HIV is in a certain area, whether or not there are ways to prevent it, and how easy it is to get and how good the care is.



According to the World Health Organization (WHO), the global rate of MTCT of HIV declined from 15% in the mid-2000s to around 4% in 2019. However, there are still regions of the world where the rate of MTCT is much higher due to a lack of access to preventive measures and HIV treatment.

It is important to note that the rate of MTCT can be further reduced with the use of ARV drugs and other preventive measures that include antiretroviral prophylaxis given to mothers during pregnancy and labour and to the infant in the first weeks of life, and the use of appropriate delivery practices. 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 thing is to make sure that the mother gets ARVs to stop her from giving HIV to her child and that she and any other family members are tested to see if they need antiretroviral treatment.

Many women do not see a doctor or attend health services when they are pregnant because it is too expensive. Every woman who is pregnant should go to an antenatal clinic so that she can be checked for any risks to herself or her baby. They should be encouraged to give birth in hospitals or by skilled medical personnel. 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, labor 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.

# CHAPTER FOUR: INCREASING ACCESS TO TREATMENT

In all these things we more than conquerors... (Roman8:37)

By the end of this chapter the reader should be able to:

- 1) Identify the barriers to access to treatment
- 2) Explain the relationship between stigma and ART
- 3) Describe ways of reducing HIV stigma at the congregation and community levels

## Increase Uptake of Testing Services

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. 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 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.

## Challenging 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.

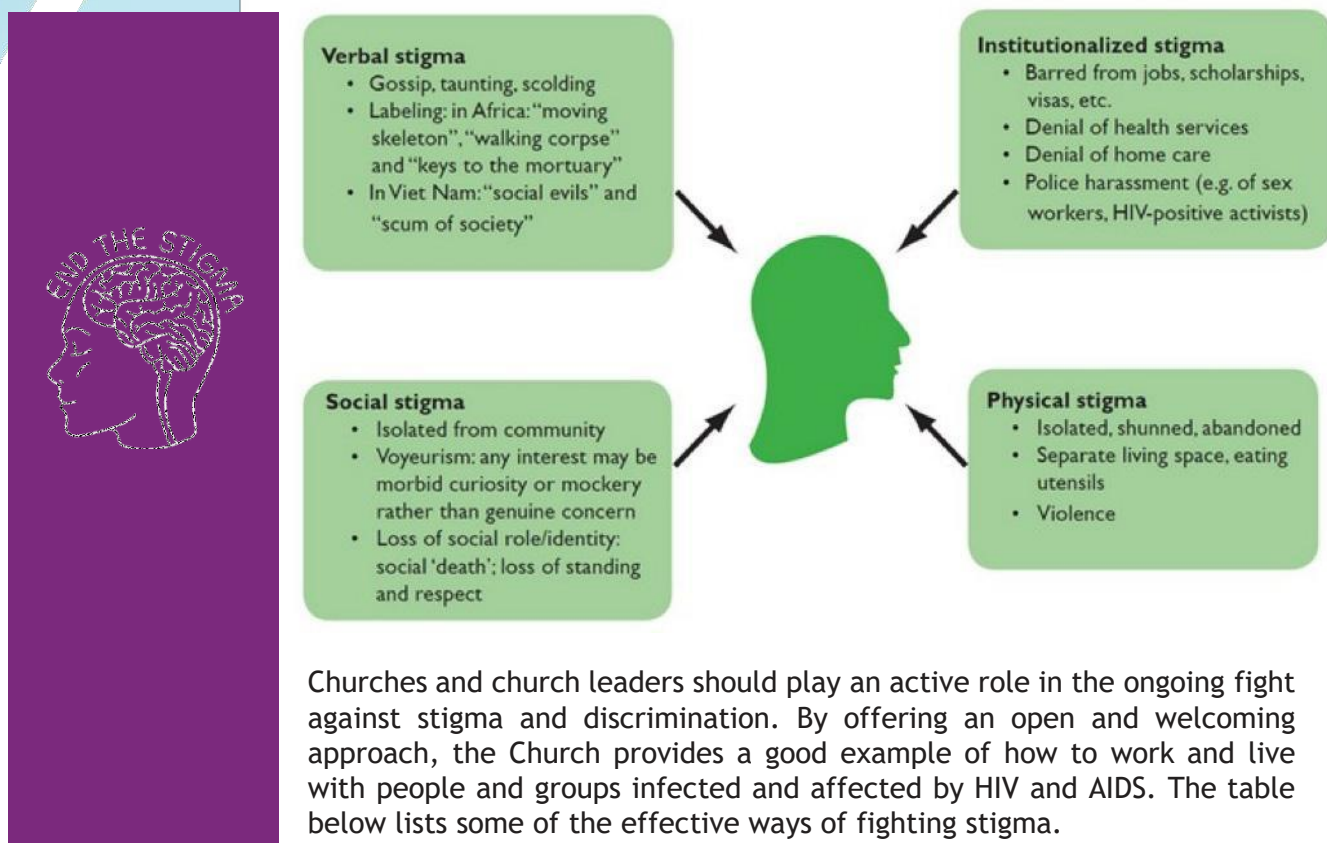
People living with HIV are often held responsible for their own infection. In a religious context, HIV is sometimes perceived as punishment for immoral behaviour. In addition, fear of infection and lack of knowledge about HIV increases stigma.

Stigma can be divided into four, loosely defined groups, namely: physical, social, verbal and institutional stigma (see Figure 3.1).<sup>3</sup> In some religious settings, the perception of HIV as punishment or curse from God because of immoral behavior has led to stigma.



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).

## Forms of Stigma



## Effective responses to stigma

INTERVENTION AREA	ACTIONS TO REDUCE STIGMA
Education and Information	<ul style="list-style-type: none"> <li>• Educate the desegregation on HIV prevention and treatment.</li> <li>• Use public education opportunities to put a human face on HIV.</li> <li>• Involve people living with HIV in public education Show antiretroviral drugs as an opportunity for giving glory to God.</li> <li>• Encourage families to get information about HIV and its treatment, and to visit people living with HIV.</li> <li>• Understand that HIV is not sin nor a result of sin</li> </ul>
Policy Development	<ul style="list-style-type: none"> <li>• Involve the clergy and congregations in programme design, development, and evaluation.</li> <li>• Demonstrate the church policy by involving people living with HIV in church activities (those who volunteer to do so)</li> <li>• Support and engage the Church in promoting confidentiality and non-discrimination.</li> <li>• Promote community development and mobilization</li> </ul>
Statutory/ regulatory environment	<ul style="list-style-type: none"> <li>• Familiarize yourself with applicable laws and regulations of your country.</li> <li>• Initiate or support actions to advance or strengthen protection of people living with HIV in your community</li> </ul>



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. Build capacity by networking with other agencies

## Facilitating 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 regarding reducing the cost of ARVs mainly due to competition from generic versions, simplification of regimens, scaling up of treatment through decentralization and increased involvement of communities. However, there are still many challenges, including:

- People unable to reach health care facilities because of stigma. Sometimes people choose to go to facilities that are far from their homes so that they can avoid being seen by people they know.
- Lack of funding for health staff and affordable antiretroviral treatment services by national and local governments
- 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 with community support, income generation activities or childcare. Remember that access to food is also an important aspect of taking ARVs. Another key action for religious leaders is sustained advocacy efforts with state and non-state actors.

## Encouraging and Supporting 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 about food intake.



Figure 1: 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.

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

## Factors Affecting Adherence to HIV Treatment

FACTORS	REASONS
Factors related to people living with HIV	<ul style="list-style-type: none"> <li>• Stigma and discrimination</li> <li>• Psychological reasons</li> <li>• Stress</li> <li>• Depression - giving up hope</li> <li>• Discouragement</li> <li>• Lack of knowledge/ misinformation</li> <li>• Low literacy</li> <li>• Lack of adequate drugs supply</li> <li>• Poverty: Lack of finance/ transport</li> <li>• Lack of social support</li> <li>• Drugs and Alcohol abuse</li> <li>• Dietary problems: Have not eaten</li> <li>• Personal discipline</li> <li>• Competing priorities: work, child e.t.c</li> <li>• Sharing drugs with others</li> <li>• Lack of faith</li> <li>• Non-disclosure</li> </ul>

Provider- based factors	<ul style="list-style-type: none"> <li>• Poor communication</li> <li>• Shortage of drugs supply</li> <li>• Lack of counseling skills</li> <li>• Lack of adequate personnel</li> <li>• Overwhelmed by the number of patients (High workload)</li> </ul>
Society- based reasons	<ul style="list-style-type: none"> <li>• Stigma</li> <li>• Cultural and social norms</li> <li>• Lack of knowledge/Misinformation</li> <li>• Displacement in emergency situation</li> <li>• Rigid or changing work schedules, such as hourly workers</li> <li>• Being homeless</li> <li>• Poverty</li> </ul>
Treatment and related factors	<ul style="list-style-type: none"> <li>• Characteristics of the medical regimen: The longer the regimen the poorer the adherence. More complex regimen for instance high number of tablets ( Pill burden) have been similarly associated with poor adherence</li> <li>• Side effects: ARVs can have some side effects that patients can find difficult to cope with. When this happens, some people living with HIV discontinue with medication</li> <li>• Long term treatment: ARVs are a lifetime commitment and one can not discontinue. Some patients get discouraged of taking drugs of life. This is dangerous, as it makes the viral load in the body to go up.</li> </ul>

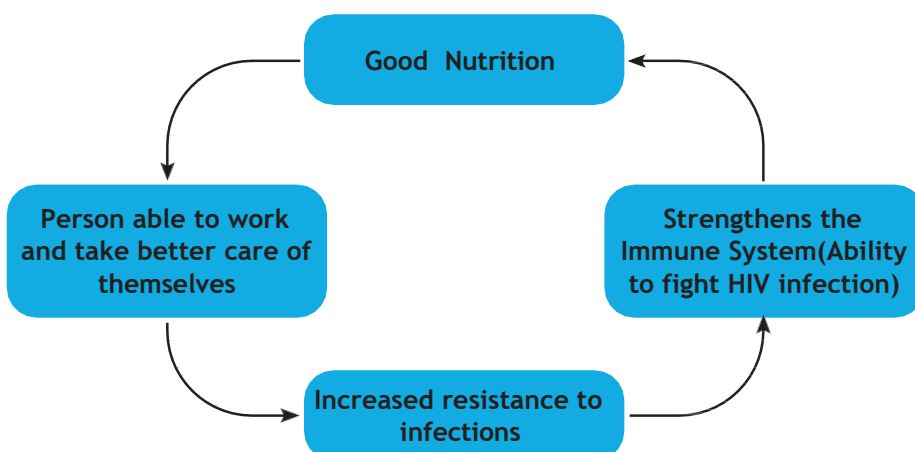
## Awareness and Support for Proper Food and Nutrition

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.

## 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, diarrhea, 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 dependents may also not be in a position to obtain food. This may lead to illnesses and exposures high-risk behavior. 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.

## Building Caring Communities

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 the 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 subsidize transport to cheaper shops or start income generating activities.

## Providing Care

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 centers 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.

## Addressing the Challenge of Faith Healing

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.

It is a generally accepted fact that God can heal in a miraculous way. He has done that throughout history. Psalms 107:20 says, "He sent out his word and healed them; he rescued them from the grave". In the New Testament, the Bible says in Matthew 14:14 that "When Jesus landed and saw a large crowd, he had compassion on them and healed their sickness." God can and does heal.

However, God's miraculous healing does not in any way contradict or exclude the use of medicinal products. In Jeremiah 8:22, the Bible asks "Is there no balm in Gilead? Is there no physician there? Why then is there no healing for the wound of my people?" God is seen here showing concern for the lack of medicine (balm) for the healing of the wounds of His people. This means that God approves the use of medicinal products. In Isaiah 38, prophet Isaiah in when delivering God's answer to King Hezekiah who was sick and about to die directed that medicinal herbs should be used to treat the King. The Apostle Paul advised his disciple Timothy to treat his "frequent illnesses" using a little wine with his food. Jesus affirmed that the sick need physicians. All these passages illustrate the point that use of medicine is part of God's plan. A more comprehensive explanation of this issue has already been dealt with in Chapter One.

## Challenging Unhelpful Culture Attitudes and Practices

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, culture influences attitudes and behaviors. 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 society, thereby re-enforcing the terrain in which HIV thrives and making treatment difficult.

## Addressing Structural Problems in the Society

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.

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 and 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 favors, 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 marginalized in society. Programmes to alleviate the impact of poverty and to support poor and marginalized groups should be on the Churches' agenda.

## Emergency Preparedness

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 stigmatize them if they find out.
- Home-based care is disrupted.
- Food and nutritional support are interrupted.
- In case of floods, the absence of clean water and basic hygiene exposes people living with HIV to infection.
- People develop new coping behaviors 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 behavior 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.

# CHAPTER FIVE: THE LEGAL FRAMEWORK ON HIV AND AIDS

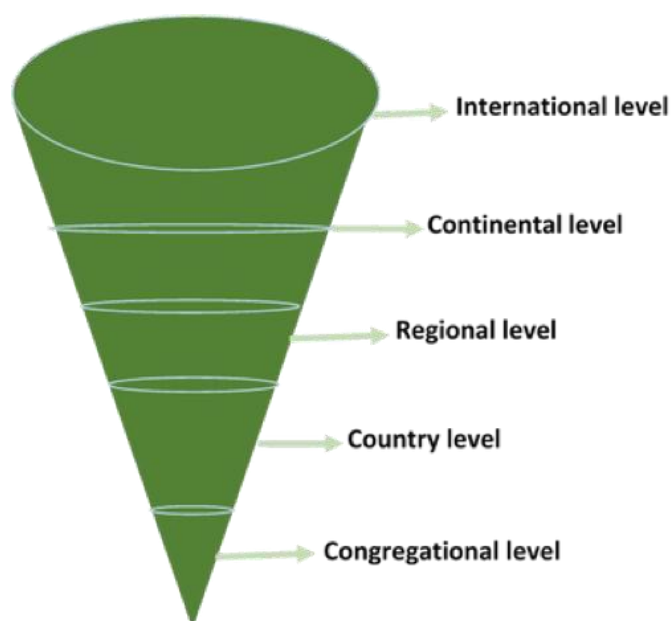
Let everything be done decently and in order (1 Corinthians 14:40)

By the end of this chapter, the reader should be able to:

- 1) Describe the legal framework that governs or affects ART
- 2) Develop a Congregational Policy on HIV and ART”

HIV and AIDS is governed by a framework of conventions, laws and policies, which apply at different levels. There exists a wide range of instruments that govern different aspects of HIV, and it is important for Religious Leaders to be aware of such.

This chapter provides an overview of these instruments. In this review a funnel approach has been adopted. This means that the chapter starts with the broader international level instruments and builds down to the congregational level.



## International Framework

### 1. The international covenant on civil and political rights

#### a) General overview

The United Nations International Covenant on Civil and Political Rights (ICCPR) ensures the protection of civil and political rights. It was adopted by the United Nations' General Assembly on December 19, 1966, and it came into force on March 23, 1976.

The ICCPR recognizes the inherent dignity of each individual and undertakes to promote conditions within states to allow the enjoyment of civil and political rights. Countries that have ratified the Covenant are obligated “to protect and preserve basic human rights and compelled to take administrative, judicial, and legislative measures in order to protect the rights enshrined in the treaty and to provide an effective remedy. There are currently 74 signatories and 168 parties to the ICCPR.

#### b) Applicable provisions

##### *Article 26:*

This provision provides for the right of every individual to equality before the law. It further provides for the right to freedom from discrimination and this right includes equal and effective protection from discrimination by the States.

#### *Article 10 (1):*

This provision contains the rights of persons deprived of liberty and it requires that there should be dignified and respectful treatment to the human dignity of the person.

#### *Article 6 (1):*

This provision contains the inherent right to life which should be protected by law. It requires that there should be no arbitrary deprivation to life.

#### *Article 17:*

This provision requires that there should be no subjection to arbitrary and unlawful interference with a person's right to privacy. It requires that the laws of states should protect this right.

#### *Article 23:*

This provision requires that the laws of states should protect an individual's right to marry. It requires that the states should protect this right by ensuring equality of rights, including those who should enter into marriage.

### **c) Enforcement**

#### *Article 2:*

This provision provides that all the rights in the ICCPR should be respected and protected. To do this, states should come up with legislation to enforce these rights and that they should further ensure that violations of the rights protected under the ICCPR are followed by effective remedies (enforcement procedures). Lastly, states should ensure that the rights are determined by competent administrative, judicial and legislative bodies.

#### *Article 3:*

This provision requires that all States Parties to the Covenant should undertake to ensure the equal right of men and women to the enjoyment of all civil and political rights set forth in the present Covenant.

## **2. International convention on economic, social and cultural rights**

### **a). General Overview**

The International Covenant on Economic, Social and Cultural Rights (ICESCR) is a multilateral treaty adopted by the United Nations General Assembly in 1966, through a General Assembly Resolution 2200A (XXI), and came in force from 3 January 1976. It commits its parties to work toward the granting of economic, social, and cultural rights (ESCR) to the Non-Self Governing and Trust Territories and individuals, including labour rights and the right to health, the right to education and the right to adequate standards of living. As of July 2020, the Convention has 117 parties. A further four countries, including the United States, have signed but not ratified the Convention. The ICESCR is part of the International Bill of Human rights, along with the Universal Declaration of Human rights (UDHR) and the ICCPR. Its implementation is monitored by the United Nations Committee on Economic, Social and Cultural Rights.

### **b). Applicable provisions**

#### *Article 12:*

This provision contains the right to the "enjoyment of the highest attainable standard of physical and mental health". "Health" is understood not just as a right to be healthy, but as a right to control one's own health and body (including reproduction) and be free from interference such as torture or medical experimentation. Each state must protect this right by ensuring that everyone,





within their jurisdiction, has access to the underlying determinants of health, such as clean water, sanitation, food, nutrition and housing, and through a comprehensive system of healthcare, which is available to everyone without discrimination, and economically accessible to all.

Article 12.2 particularly requires that states must take specific steps to improve the health of their citizens, including reducing infant mortality and improving child health, improving environmental and workplace health, preventing, controlling and treating epidemic diseases, and creating conditions to ensure equal and timely access to medical services for all. This right also requires that the reproductive rights of women should be respected, and this includes not limiting access to contraception, or intentionally misrepresenting or withholding information relating to sexual health. States should also ensure that women and girls are protected from harmful traditional practices, such as Female Genital Mutilation.

#### **c). Enforcement**

##### *Article 2:*

This provision requires that states should adopt legislation to enforce the rights in this Convention and further that the enforcement should be done without discrimination of any kind, including on the basis of HIV status.

##### *Article 3:*

This provision requires that states should ensure the equal right of men and women to the enjoyment of all economic, social and cultural rights set forth in the present Covenant.

### **3. The convention on the rights of the child**

#### **a). General Overview**

The Convention on the Rights of the Child (CRC) was adopted to enforce the right to growth and well-being

of a child, as a fundamental part of the family unit. The preamble affirms (in sum) the following objectives: Recognizing that the child, for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding.

Considering that the child should be fully prepared to live an individual life in society, and brought up in the spirit of the ideals proclaimed in the Charter of the United Nations, and in particular in the spirit of peace, dignity, tolerance, freedom, equality and solidarity.

Bearing in mind that the need to extend particular care to the child has been stated in the Geneva Declaration of the Rights of the Child of 1924 and in the Declaration of the Rights of the Child adopted

by the General Assembly on 20 November 1959 and recognized in the Universal Declaration of Human Rights, in the International Covenant on Civil and Political Rights (in particular in articles 23 and 24), in the International Covenant on Economic, Social and Cultural Rights (in particular in article 10) and in the statutes and relevant instruments of specialized agencies and international organizations concerned with the welfare of children;

Bearing in mind that, as indicated in the Declaration of the Rights of the Child, “the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth

## **b). Applicable provisions**

### *Article 1:*

This provision defines a child as a person under the age of 18 years. This means that the protections in the Convention extend to persons within this age bracket.

### *Article 3:*

This provision affirms the fundamental principle of the best interests of the child. This principle requires that decisions pertaining to children ought to be made only to the extent that they are for the benefit of the child in all aspects of their existence. This means that the provision of all services relating to children, including mental and health services, should be formulated to enforce the principle of the best interests of the child.

### *Article 16:*

This provision mandates that no child should be subjected to arbitrary or unlawful interference with their right to privacy. Additionally, states are required to enact laws that protect this right.

### *Article 19:*

This provision requires that states should take all appropriate legislative, administrative, social and educational measures to protect children from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child. Additionally, these protective measures should include effective procedures for the establishment of social programmes which will provide support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement.

### *Article 24:*

This provision requires that states should recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. From this obligation, no child should be deprived of their right of access to such health care services.

This obligation specifically entails the following commitments: To ensure provision of necessary medical assistance and healthcare for all children, to ensure appropriate pre-natal and post-natal health care for mothers and to abolish traditional practices which are prejudicial to the health or children.

### *Article 27 (1):*

This provision requires that states should recognize the right of every child to a standard of living which is adequate for their physical, mental, spiritual, moral and social development.

#### *Article 39:*

This provision requires that states set up all appropriate measures to promote physical and psychological recovery and social reintegration of a child victim of any form of neglect, exploitation, or abuse; torture or any other form of cruel, inhuman or degrading treatment or punishment; or armed conflicts. The reintegration of a child victim should take place in an environment which fosters the health, self-respect and dignity of the child.

#### **c). Enforcement**

##### *Article 2:*

This provision provides for the implementation of the rights under the CRC and requires that this be done without any form of discrimination.

##### *Article 4:*

This provision requires that all legislations and judicial and administrative procedures which are aimed at enforcing these rights should be guided by the principle of the best interests of the child.

## **4. Convention on the elimination of all forms of discrimination against women**

### **i. General Overview**

This convention was adopted in 1979 by the UN General Assembly and is often described as an ‘International Bill of Rights for Women’. It essentially defines what constitutes discrimination against women and sets up an agenda for national action to end such discrimination.

The Convention’s Article 1 defines discrimination against women as “...any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.” As a general rule, the Convention requires that states should embody the equality of men and women in the legislative framework.

### **b). Applicable provisions**

##### *Article 5:*

This provision requires that states should modify cultural patterns regarding the conduct of men and women in order to eliminate harmful practices.

##### *Article 12:*

This provision contains the obligation for states to take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, they all have access to health care services, including those related to family planning. More specifically, this obligation requires that states should ensure that women have appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation.

### **c). Enforcement**

##### *Article 3:*

This provision requires states to take action, particularly in the social, economic, political and cultural field, to ensure that legislation and other measures fully realize the full development and advancement of women. This is important so that women may fully enjoy the rights protected in this Convention.

## East African Legislative Assembly passed the EAC HIV and AIDS Prevention and Management Act (2012)



### A) General Overview

- This Act provides a more exhaustive legal framework on education targeted at promoting HIV-safe practices, in comparison with domestic laws such as the Kenyan HIV/AIDS Prevention and Management Act.
- It provides a broader framework in general, with an emphasis on information sharing and creating awareness about HIV/AIDS safe practices.

### b) Substantive provisions

Part II of the Act focuses on HIV and AIDS Information, Education and Communication. More specifically, the Act requires that EAC Member states should promote public awareness on the nature, cause and modes of transmission of HIV and AIDS. This information should be available, accurate and offered without discrimination against persons.

The Act requires that information sharing be based on available scientific evidence and in this regard, recognizes the need to promote advocacy to address social, religious and cultural attitudes, beliefs and practices and unequal gender relations. In conducting the education and information campaigns, EAC Member states are required to involve all relevant public, civil society and community based and private stakeholders, for effective participation.

Part III of the Act addresses HIV and AIDS Prevention measures, practices and procedures. In line with this, it requires that states should encourage practices that reduce the risk of HIV transmission, and this includes ensuring the availability, affordability and accessibility of protective methods and devices, including quality female and male condoms, particularly to vulnerable groups.

Secondly, the Act regulates the process of blood donation and requires that donors should provide informed consent to test for HIV. Prior to such testing, they should undergo pre-test counselling, and after the exercise, they shall undergo post-test counselling. This information should hold in confidence.

With regard to the objective of reducing the risk of mother-to-child transmission of HIV, the Act requires that states should provide comprehensive information to the relevant groups. Provide HIV counselling and testing for all pregnant women and develop programs on the prevention of mother-to-child transmission of HIV, which should be integrated into the reproductive health services available to pregnant women.

Part IV of the Act provides for HIV and AIDS counselling and testing and requires that all testing facilities provide pre-test and post-test counselling to a person undergoing a HIV test. It also requires that there should be informed consent of the person undergoing the test, or from their guardian, as the case may be.

The Act, however, excuses the requirement for consent where it is needed for HIV testing in the best interests of the child, but is being withheld by the guardian. It also requires that personnel providing HIV and related services should be trained to provide the services to the required standards. Additionally, the Act expounds on the requirements for pre-test counselling to include information on the nature of HIV and AIDS as well as the services that are available in the case of either a negative or a positive result. Regarding the requirements for post-test counselling, this includes: the test results and the implication, the importance of further testing and the continuing necessity of taking protective measures to avoid HIV infection. The Act mandates that the results of the HIV testing shall be confidential and directly communicated to the person concerned, or to their guardian, as the case may be.

Importantly, the Act cautions against compelling another person to undergo HIV testing as a precondition for the continued enjoyment of employment, marriage, admission into an educational institution or the provision of healthcare or insurance.

Part V of the Act covers the general protection of the rights of persons living with or affected by HIV. The Act guarantees everyone living with or affected by HIV the right to enjoy all human rights, without any form of discrimination. Persons living with HIV are entitled to the right to privacy and confidentiality in the handling of all their information, employment, and access to educational institutions, the freedom of abode, lodging or travel within the EAC and the right to seek an elective or other public office. The Act limits the instances in which information about a person living with HIV may be disclosed, including by virtue of a court order.

## Country Level

Different countries have different frameworks. It is important to check with the legal experts in specific countries to ensure that:

- Every action taken in response to HIV and AIDS is done within the law.
- The rights of people living with or affected by HIV and AIDS are realized.
- Efforts to advocate for important laws or eliminate bad laws are put in place.

A study was done compare national Human Immunodeficiency Virus (HIV) policies influencing access to HIV testing and treatment services in six sub-Saharan African countries. It reviewed national HIV policy documents and guidelines published in Kenya, Malawi, South Africa, Uganda, the United Republic of Tanzania and Zimbabwe between 2003 and 2013. The study found that national HIV policies in six sub-Saharan African countries were generally consistent and adhered to policy indicators such as providing free testing services and provider-initiated testing and counseling. However, there were variations in indicators related to quality of care, coordination of care, and patient support. For example, only South Africa and Zimbabwe guaranteed anonymous HIV testing and only Kenya and the United Republic of Tanzania had policies limiting the number of testing sessions that counselors could perform per day.

The study also found that all countries adhered to WHO's 2010 protocols on PMTCT and had explicit policies on the need for CD4 testing.

The table below provides a summary of findings by country.

COUNTY	FINDINGS
KENYA	Policies were consistent with policy indicators, with explicit policies enabling minors to access testing without parental consent. Anonymous HIV testing was not guaranteed, and names could be recorded in registers to facilitate patient management. There were explicit policies limiting the number of testing sessions that counselors can perform for a day.
MALAWI	Was the only country with no policy targeting testing among high- risk group? Repeat testing intervals for negative and repeat testing during pregnancy and labor or after delivery were not clearly defined in policy. The country stipulated that pretest HIV counseling be conducted either individually or in groups, and all sites providing ART should be able to initiate ART.
SOUTH AFRICA	Had explicit policies enabling minors to access testing without parental consent, and anonymous HIV testing was guaranteed. The country stipulated that pretest HIV counseling be conducted individually or in a group.
UGANDA	Had explicit policies enabling minors to access testing without parental consent. Names could be recorded in the register to facilitate patient management. Anonymous HIV testing was not guaranteed. Repeat testing intervals for negative and repeat testing during pregnancy, labor or after delivery were not clearly defined by policy.
TANZANIA	Did not define the high risk groups. Names could be recorded in registers to facilitate patient management. Anonymous HIV testing was not guaranteed. There were explicit policies limiting the number of testing sessions that counselor can perform per day. Policies influencing coordination of care and patient tracking were ambiguous in the country, with no clear policy on repeat testing intervals for negative or on repeat testing during pregnancy, labor or after delivery.
ZIMBABWE	Anonymous HIV testing was guaranteed. Policies influencing coordination of care and patient tracking were not clearly in the country.

The above study was done in 2015, and a lot may have changed in these polices and framework. Seeking current information is therefore advisable so that one can review information contained in the source documents used in this study.

Having said that it is important to note that national frameworks generally provide for the following:

- 1. Testing:** Many laws and policies provide for the availability of HIV testing and counseling services and may also include provisions for mandatory testing in certain situations, such as for certain groups of people at high risk of HIV, or for individuals charged with certain crimes.
- 2. Treatment:** Many laws and policies provide for the availability of antiretroviral therapy (ART) and other treatments for individuals living with HIV and AIDS, as well as for the provision of care and support services for people living with HIV and AIDS.
- 3. Prevention:** Many laws and policies include provisions for the promotion of harm reduction strategies such as condom distribution and needle exchange programs, and for the promotion of education and awareness campaigns to reduce the spread of HIV.

4. **Stigma and discrimination:** Many laws and policies include provisions to protect individuals living with HIV and AIDS from discrimination in areas such as employment, education, and healthcare, as well as provisions to address the stigma and discrimination associated with HIV and AIDS.
5. **Coordination and planning:** Many laws and policies also include provisions for the establishment of government agencies or councils responsible for coordinating the national response to HIV and AIDS, and for the development of national strategic plans for addressing HIV and AIDS.
6. **Confidentiality:** Many laws and policies include provisions to protect the confidentiality of individuals' HIV status and related medical information and may also include penalties for unauthorized disclosure of such information.
7. **Grievance mechanisms:** Some laws and policies may provide for the establishment of grievance mechanisms, such as tribunals, ombudsman or complaint procedures, for individuals to raise concerns or complaints related to HIV and AIDS
8. **Non-discrimination:** Many laws and policies include provisions that prohibit discrimination on the basis of HIV status in areas such as employment, education, and healthcare.

This list is by no means exhaustive, but it provides the main areas covered by HIV and AIDS framework. Again, it is important to be conversant with the laws that are in operation in one's area of work.

## Congregational Policies

Religious organizations or individual congregations can develop their own church HIV and AIDS policies. A Church HIV and AIDS policy is a set of guidelines or principles that a church or religious organization adopts to address HIV and AIDS and to protect the rights of people living with HIV. Church HIV and AIDS policies typically address a wide range of issues related to HIV and AIDS, including HIV testing and counseling, HIV prevention, treatment, and care services, and measures to address HIV-related stigma and discrimination.

The importance of congregational HIV policies lies in the fact that many religious organizations have significant influence and reach within communities and are often considered to be trusted sources of information and support for their members. A Church HIV and AIDS policy can help to ensure that religious organizations are providing accurate and up-to-date information about HIV and AIDS, and that they are taking steps to address HIV-related stigma and discrimination within their congregations.

Such a policy can also help to ensure that religious organizations are providing appropriate support and care to people living with HIV. This can include providing counseling and support services to people living with HIV, as well as connecting them with appropriate medical and social services.

In addition, church HIV policies can also play an important role in promoting HIV prevention and in supporting HIV education and awareness campaigns. This can be done by providing accurate information about HIV prevention and encouraging the use of HIV prevention methods such as condom use and promoting the knowledge about HIV testing and early diagnosis.

Instead of going into the trouble of giving details of an HIV and AIDS policy, a sample policy may be more beneficial. It can provide guidance on how a congregation may develop their own policy.

## Here is such a sample policy:

HIV and AIDS Policy for \_\_\_\_\_ Church

We, the community of \_\_\_\_\_,

Aware of the impact of HIV and AIDS in our community, Sensing our call to respond to the HIV and AIDS epidemic with compassion and responsibility in accordance with Matthew 25:36, Luke 10

Recognizing that HIV and AIDS affects people of all ages and backgrounds, Accepting that HIV and AIDS is a complex and multifaceted issue, acknowledging that the HIV epidemic continues to have a devastating impact on individuals, families and communities.

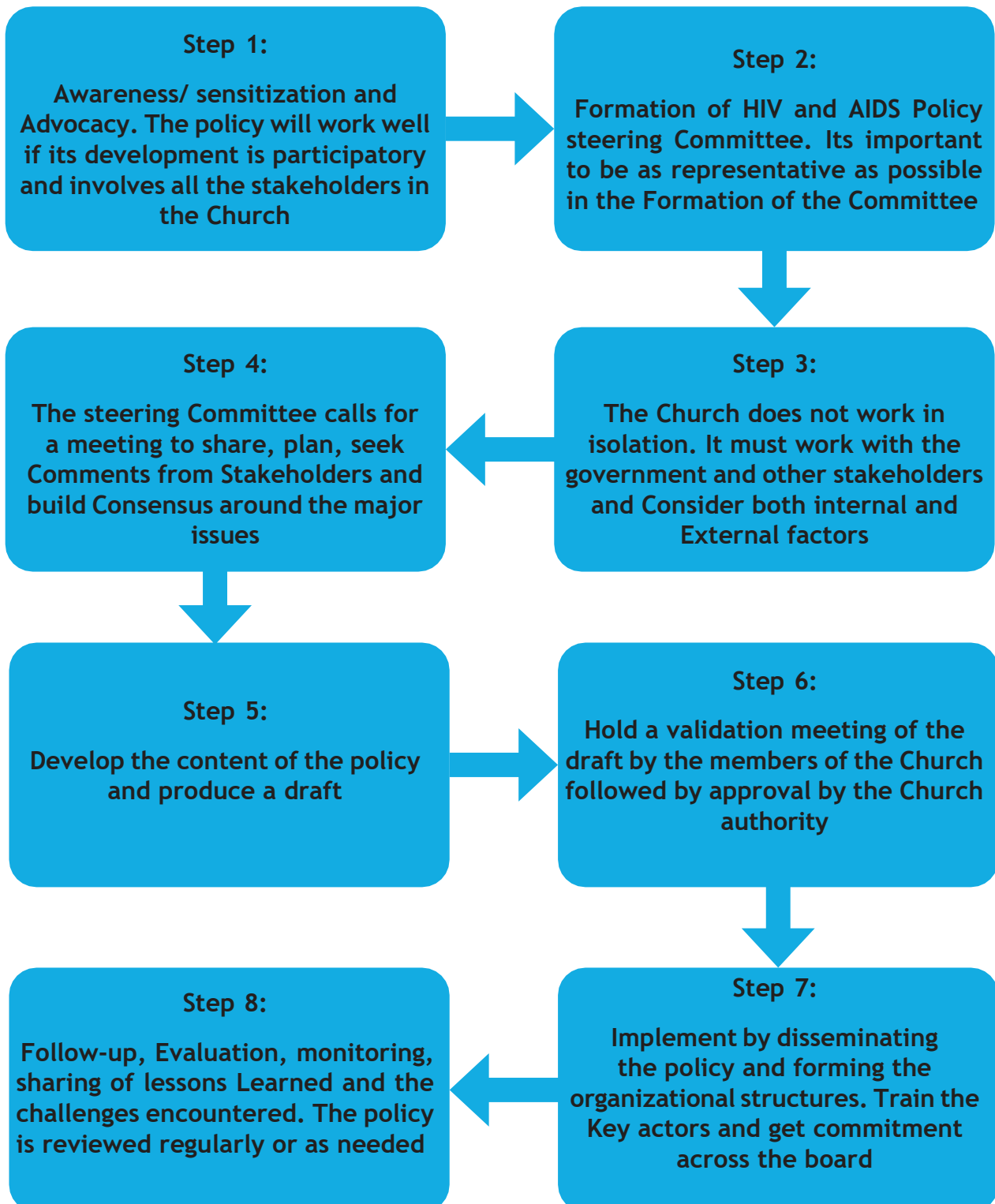
Through this policy, we commit ourselves to taking action to address the HIV epidemic and to support the rights and well-being of people living with HIV.

1. Purpose: The purpose of this policy is to provide a comprehensive response to the HIV and AIDS epidemic within our church community, and to ensure that people living with HIV are treated with dignity and respect.
2. Education and Awareness: The church will provide regular education and awareness campaigns to congregants on HIV and AIDS, including information on prevention, testing, treatment, and care. Church leaders and volunteers will also receive training on HIV and AIDS to ensure they are equipped to respond to the needs of people living with HIV.
3. Testing and Counseling: The church will provide access to HIV testing and counseling services, and will work to eliminate barriers to testing, such as stigma and discrimination.
4. Prevention: The church will promote evidence-based HIV prevention methods, including abstinence, fidelity, condom use and pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP).
5. Care and Support: The church will provide counseling and support services to people living with HIV and will connect them with appropriate medical and social services. The church will also provide spiritual support to people living with HIV.
6. Confidentiality: The church will ensure that the personal information and health status of people living with HIV will be kept confidential and will not be disclosed without the individual's consent.
7. Non-discrimination: The church will provide an environment free of HIV-related stigma and discrimination. In this regard HIV status will not be used to determine whether a person may receive services or not. Similarly, there will be no requirement for HIV testing as a condition for solemnization of marriage.
8. Human Rights: The church will respect the human rights of people living with HIV and will not discriminate against them based on their HIV status.
9. Partnership and Collaboration: The church will actively seek partnerships and collaborations with community-based organizations, government agencies, and other stakeholders to enhance its efforts to address HIV and AIDS.
10. Monitoring and Evaluation: The church will monitor and evaluate the implementation of this policy and conduct such reviews as may be from time to time needed.



## Policy Development Process


The process of developing a church HIV and AIDS policy follows the following general steps. This process is just provisional and may be adjusted to suit the needs of the organization. See the process flow below.



# APPENDICES

## Appendix 1 : Key messages

1. HIV and AIDS can affect anyone, regardless of their background or lifestyle. It's important to educate ourselves and spread awareness to help prevent its spread.
2. Antiretroviral therapy (ART) is a crucial treatment for those living with HIV and AIDS. It helps to suppress the virus and prevent its progression to AIDS.
3. We must support and care for those living with HIV and AIDS, and not discriminate
4. Getting tested for HIV is important for both your own health and the health of those around you. Testing is quick, easy and confidential.
5. Prevention is key in the fight against HIV and AIDS. This includes practicing safe sex, avoiding sharing needles, and getting tested regularly.
6. HIV and AIDS can be managed and treated, but it's important to catch it early. Regular testing and early diagnosis can make all the difference.
7. It's important to talk openly about HIV and AIDS and break down the stigma surrounding it. Only by educating ourselves and others can we help end the epidemic.
8. HIV and AIDS affect not only the individual but also their loved ones and community. Let's come together and support those affected by this disease.
9. Education is key to preventing the spread of HIV and AIDS. Let's work together to spread accurate information and dispel myths about the disease.
10. It's important to remember that HIV and AIDS is not a death sentence. With proper treatment and care, those living with HIV can lead long and healthy lives.
11. Adherence to antiretroviral therapy (ART) is crucial for those living with HIV. Taking the medication as prescribed helps to suppress the virus and prevent its progression to AIDS.
12. Missing doses or stopping ART can lead to the development of drug-resistant strains of HIV, making it harder to treat the virus in the future.
13. It's important to work with healthcare providers to find a medication regimen that works for you and to make sure you understand the importance of adherence to ART.
14. Sharing ART medication is dangerous as it can lead to harmful drug interactions and resistance.
15. Sharing ART medication puts yourself and others relying on it at risk and it's important to keep medication to yourself and follow the prescribed regimen.
16. Use of over-the-counter medication can cause serious harm and should be avoided
17. ART can cause side effects, but they are generally manageable with the help of healthcare providers.
18. Common side effects of ART include nausea, diarrhea, fatigue, and headaches, usually temporary, can be managed.
19. ART can have long-term side effects, but the benefits of ART in suppressing the virus and preventing its progression to AIDS outweigh the potential side effects.

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20. While antiretroviral therapy (ART) can suppress the virus and prevent its progression to AIDS, it doesn't completely eliminate the risk of infection.
  21. It's important to continue practicing safe sex and avoiding sharing needles even while on ART to reduce the risk of infection.
  22. Good nutrition is important for people taking ARVs.
  23. New Choices available for HIV testing: with life at its best, you choose how to test. Individuals have more choice, privacy, and control over where and how they are tested. Self-testing: HIV self-testing is safe, accurate and easy to use. An HIV test may help you and your family stay strong and live well! Make sure you and your partners and children get tested.
  24. New Treatment: with HIV medication you can live a long, healthy life. Treatment options are easier, better, and safer than ever before:
    - a. Fewer pills -often a single pill once a day, fewer clinic visits - once every 3 to 6 months for patients who are stable.
    - b. Fewer side effects and medication continues to work for faster viral load suppression and preventive TB medication - just once a week for 12 weeks with)
    - c. New Timing: start anti-retroviral treatment (ART) immediately for all individuals testing positive for HIV. Everyone who is diagnosed HIV positive should start treatment immediately whether they feel completely well or ill. Early treatment allows people living with HIV to live long and healthy lives and to protect their partners
    - d. New Hope: stay on treatment and you will not spread HIV to people you care about. A long healthy life is possible with HIV medication. An undetectable viral load will prevent progression to AIDS.
    - e. Undetectable viral load = untransmissible HIV (U=U): when taking HIV medication as prescribed, a person will not transmit the virus to their partner. U=U means that people living with HIV will no longer feel like a threat to those they love.

# Appendix 2: Exercises

## Exercise 1: Knowing The Facts

### Ideas for using the facts

You might want to use these facts as a leaflet; on a noticeboard; 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 people's 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 receive 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 them?

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.

### Preventing Mother to Child Transmission

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.

## Exercise 2 : 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 based on facts.

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 be 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.

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. If someone came to them and asked about ARVs, what questions would they dread being asked?
- 6. What do you think neighbours should know about ARVs?
- 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?
- 10. 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).

## Exercise 4 : 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.

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.

### Ideas for use

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 center of love (Mark 12:31, John 15:12, Rom 12:9).
The Church as an embracing family (Ephesians 2:18-19).
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 2:3-46).
We are all members of the body of Christ; if one member suffers, we all suffer together (Corinthians 12:26).

### 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-retroviral drugs 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.” - Attawell K, Mundy J, 2003. Provision of ART in resource-limited settings: a review of experiences up to August 2003. DFID/Health Systems Resource Centre.

“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 : Thinking about What We Would Say

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 to see 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?

## Exercise 6: Learning from those who know

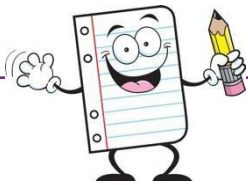
In this exercise there are some quotes from people who know what living with HIV is really like and they have described how they feel about ARVs, and their experiences of their churches.

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 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

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.

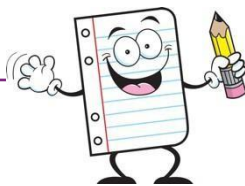
The problem is people only really go for VCT if they are going to get married or their partner or child has died.

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 3

I don't believe that my church is judgmental, 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 4

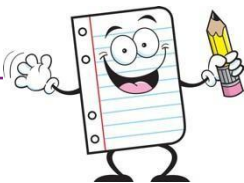
“I set out to develop a programme for nine areas. My first problem was stigma. Initially, HIV and AIDS was seen as proof and punishment of sin, but most churches have since changed their attitude, but I am not sure what this means in terms of actions. They do some work to increase VCT, but at the moment 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 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 centers, 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 centers and use the Catholic hospital as an example on nutrition and VCT, but it is very difficult to work with our hospitals.”



## Story 5

“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.”

## Exercise 7: Getting People to Know Their Status

### Ideas 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.
3. Shame.
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.”

## Exercise 9: Taking Action, Looking at Our Church

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.

DO WE HAVE ANY OF THESE PROBLEMS?	YES	NO
1. This 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.		
2. It has been largely accepted that doctors inform patients on ARV's and that this is enough.		
3. Church leaders have not been trained to talk about ARV's.		
4. In general, Churches do not focus on the development of support groups for support people living with HIV, which can have a number of roles, including personnel witness; income generation, advocacy for access to ARV's for members; community literacy; encouraging adherence etc.		
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.		
6. Church leadership of HIV testing is lacking and we don't understand how the availability of ARV's can encourage people to know their status.		
7. The link between ARV's and responsible behavior is not understood so we don't help people understand that even when someone is on ARV's they infect others.		
8. The materials we have to help us talk with our congregation are out of date and don't include any messages on ARV's.		
9. The church schools are missing out on enormous opportunities that young people represent in the fight against HIV and AIDS and support taking ARV's, and we don't look at recreating invigorated church-based activities in these schools.		
10. 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 free ARV's); with their strong media connections, congregation, and community work, can have a powerful and successful impact.		
11. We don't talk to our congregation about PMTCT and the importance of this treatment for protecting babes.		
12. We never try to deal with the myths that the people think are true about HIV and AIDS or ARV's.		
13. The church and church hospitals in this area do not work together.		
14. The churches don't know where to get ARV's nor how people can get them and there is institutional resistance. These are medical issues, and the church is not sure of its role.		



## Exercise 10: 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 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 hospitalized, 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 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
- Parents
- Schools
- 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!





## PARTNERS

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