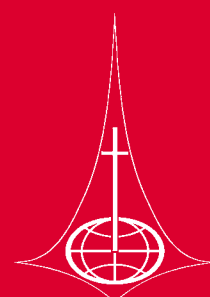


Grace, Care and Justice



A handbook for HIV and AIDS work

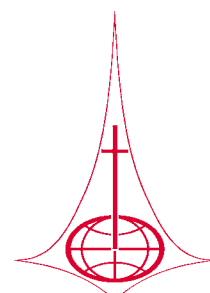
The Lutheran World Federation



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A handbook for HIV and AIDS work

The Lutheran World Federation



**Patients and caregivers are advised
wherever possible and appropriate to seek
the advice of medically trained personnel.**

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For additional copies, please contact
sni@lutheranworld.org

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Foreword

Since the 1980s, the Lutheran World Federation (LWF) has been addressing the crisis of HIV and AIDS. The LWF Action Plan, *Compassion, Conversion, Care: Responding as Churches to the HIV/AIDS Pandemic*, was launched in 2002, and HIV and AIDS have become strategic priorities in LWF field programs in areas affected by the virus, and continue to be global priorities of the LWF as a whole. Many of the LWF member churches have become increasingly active in addressing this challenge, and regional consultations have been held in Africa, Asia, Europe, and Latin America. It has become increasingly urgent to address the importance of preventive measures to protect life.

In the midst of these ongoing activities, it has become evident that there is a need to bring together, in one place, the theological and pastoral perspectives shaping how as a Lutheran communion of churches we should approach those living with and affected by HIV and AIDS. In this basic primer, we have included medical, preventive, home-based care, advocacy, and other guidance for those in local settings who are working on this challenge. We are aware that much more could be said about these and other aspects of the pandemic, and hope to update and provide additional material later to complement what is here.

This handbook was developed with input from a large number of persons who have been actively involved in this work. This included a December 2005 theological consultation near Lausanne, Switzerland and, in June 2006, a consultation in Nairobi, Kenya, for church leaders, doctors, nurses, social workers, counselors, and others pursuing this important work. Together they have provided substantial input for the various chapters. A staff team did most of the subsequent writing and editing of the material. We are grateful to all who have been involved in this participatory process.

We hope this will be a helpful resource, not only for Lutheran churches and their related programs, but also for those from other Christian traditions. Although its Christian grounding is obvious, many of the perspectives and recommendations are shared with those of other faiths and with secular organizations. It is a Lutheran contribution to ongoing ecumenical and interfaith efforts. The LWF remains deeply committed to working collaboratively with ecumenical, interfaith, governmental, and civil society partners.

Ishmael Noko
General Secretary

Introduction
**Why Local
Churches Must
Be Involved**



We cannot ignore the impact HIV and AIDS are having on our world. The pandemic affects our communities, our families, our churches, our friends, and us personally. This is certainly the case if we, or those we relate to, are living with and affected by HIV and AIDS. We have seen or experienced the fear and suffering caused by those who keep their distance from or exclude people living with and affected by HIV and AIDS. We may have accompanied those who have died of AIDS, or perhaps we were afraid to do so. We may have remained silent, or concealed the real cause of their death. Hopefully, we have been moved by compassion to reach out and help those who are affected. We may also have advocated for them to receive the medication and care they require to live, and for preventive measures to protect the lives of others.

There are many reasons why people of many different religious persuasions and walks of life have become involved in this work. It is crucial that we work with

"I was afraid to go to church, because I feared being judged by God. I feared being looked at by others and being judged by them also. But I went ... None of the stuff happened that I thought would happen. No one looked at me funny. No one moved over in the pew. Everyone hugged me. And I heard that Jesus loved me."

ELCA News Service,
22 November 2006,

at WWW.ELCA.ORG/NEWS/RELEASES.ASP?A=3489

those who may not share our particular faith or convictions without trying to convert them to ours. Nonetheless, it is important that we are clear as to why as local churches and church-related organizations we are involved. Most centrally, this is so because we are ***called by God to be inclusive communities of God's grace, as we know it in Jesus Christ.***

Lutheran Christians understand the church to be where the Word of God is preached and the sacraments are rightly administered. We come to receive God's grace, forgiveness and new life, while being mindful of all those ways

in which we continue to be in bondage to sin. Through the bread and wine of Holy Communion, God's grace can be touched and tasted. Here we receive God's saving and healing presence. We are strengthened, empowered and transformed to be Christ's body in the world. Christ welcomes us at his Table; all the baptized are welcome. In stark contrast to those systems and practices in our world that exclude on the basis of who people are, or what they do, the Lord's Supper is inclusive of all those who believe.

The church is bound to be "countercultural" by including those who are excluded from society. It is here, among the stigmatized, that the crucified God is

found. We meet the resurrected Christ in the breaking of the bread (Lk 14:13–35), and are formed into a communion. We become one with those whom others might consider “unclean,” “dangerous,” or “scandalous.”

Through baptism, we become part of the body of Christ. We belong intimately to Christ and thus to one another, as brothers and sisters in Christ. Whether we are living with and affected by HIV and AIDS or not, we belong to the same body and participate in the same communion. In this sense, *the body of Christ has HIV and AIDS*. Christ is present for us in Holy Communion; we are called to be present with those who are infected and affected by HIV and AIDS.

“for I was hungry and you gave me food, ... thirsty and you gave me something to drink, ... a stranger and you welcomed me, ... naked and you gave me clothing, I was sick and you took care of me, ... Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me” (Mt 25:35–40).

Diakonia (service) is part of the very being of the body of Christ. It is the church’s body language, how it bears witness in the world: compassionately reaching out to be with and serve all those who are suffering, especially those living with and affected by HIV and AIDS, and advocating with and for them. Christ’s unconditional love is

“the true spirit of diakonia—living with, walking with, touching, understanding, sharing, caring, and ‘struggling alongside’.”¹ This includes the church’s prophetic calling to pursue justice, equality and liberation for those infected and affected by HIV and AIDS. The church should be a place for spiritual support and social healing, where hope for the future is proclaimed and lived out.

As part of its diaconal calling, the church throughout history has reached out to those affected by various diseases. But, why do so many churches hesitate to do so in the face of the HIV and AIDS pandemic? Here, churches and Christians have often been the problem, especially when their attitudes and practices stigmatize (label a group of persons in a negative way), and exclude those who are affected and infected. Those with other diseases are not stigmatized and excluded in the same way as those known to be living with and affected by HIV and AIDS.

Tragically, local congregations are often places where such persons feel most excluded, stigmatized, or unwelcome. Sometimes they have been denied Holy Communion, or drinking from the common cup. According to St Paul, the

¹ *One Body: North-South Reflections in the Face of HIV and AIDS* (The Nordic-FOCCISA Church Cooperation, 2005), vol. 1, p. 30, at WWW.NORGESKRISTNERAD.NO/DOC/ONEBODY-VOL1-ENG.PDF

church is the body of Christ. However, as one person who later died of AIDS

declared, “I sometimes get the impression that some...are the teeth, while I am part of the slime that the body wants to get rid of!”² This is a scandal because Christians are called to bear witness to and live out God’s boundless love as revealed in Jesus Christ.

Why have many congregations failed to be “salt” and “light” in these situations? Is it out of ignorance? Fear? Because of what we have heard or been taught in the past? Is it because churches feel too overwhelmed? Why has it taken so long for many churches to respond?

This handbook is intended to help people from all walks of life to be more active and effective in accompanying persons who are living with and affected by HIV and AIDS, and in so doing

to bear witness to God’s grace, care and justice for all people.

² *Ibid.*, vol. 2, p. 7.

Chapter 1: Medical Facts and Prevention



Because of the many myths, assumptions and moral judgments surrounding HIV and AIDS, it is important for Christians to consider the findings of medical science. We believe in God, the Creator, whose creation is known and enhanced through medical science and those who work in the medical field. We begin with a straightforward discussion of the medical facts and proven prevention strategies for HIV and AIDS, because *“HIV is a virus, not a moral condition.”*³

What are HIV and AIDS?

Acquired Immune Deficiency Syndrome (AIDS) is a disease state caused by a virus called the Human Immunodeficiency Virus (HIV). HIV attacks and destroys the body’s immune or defense system, which normally protects the body against infections. The white blood cells are like the soldiers of the immune system; they fight to protect the body against attacks by germs (bacteria, viruses and other organisms that cause disease). HIV attacks a particular type of white blood cell, called the CD4 lymphocytes (a particular T-cell subtype), which plays a very important role in the immune system.

HIV “hijacks” the CD4 cell, inserts its own reproductive material into the cell and selectively destroys it. In other words, HIV takes over the CD4 cell, and uses it to reproduce more of its own kind. When the CD4 cell is destroyed, large numbers of new virus particles are released into the blood stream. This process is repeated in even more CD4 cells, gradually depleting the number of CD4 cells in the body.

Subsequently, the body’s ability to resist and fight infections is decreased, eventually reaching the critical point where the person infected is said to have AIDS. In healthy adults, a normal CD4+ count is usually between 600 and 1,800 per cubic ml. of blood. When the count drops to 500, the person begins to suffer from minor infections. When it falls below 200, signs and symptoms of AIDS appear.

How the virus attacks the CD4 cells

HIV belongs to a class of viruses called retroviruses. All bacteria and viruses have an outer coat, called an envelope, composed of proteins specific to each

³ Rev. J. P. Heath, African Network of Religious Leaders Living with or Personally Affected by AIDS (ANERELA+), in an address to the United Nations General Assembly Special Session on HIV and AIDS, June 2006.

particular type of organism. HIV is very clever in shedding or removing its outer coat before entering the CD4 cell. As a result, HIV is not recognized as a foreign organism and is “accepted” by the CD4 cell. HIV can therefore exist within a person’s CD4 cells for several years without any noticeable problems.

How is HIV transmitted?

HIV is present in the blood, sexual fluids and breast milk of those who are infected with the virus. It is passed from one infected person’s bodily fluids into those of another person.

Sexual activity

HIV is sexually transmitted by having unprotected intercourse (without using condoms) with an infected person. HIV can enter the body during sex through the mucous membranes of the vagina, penis (urethra), anus, or mouth, as well as through fresh cuts, sores and abrasions on the skin. Unprotected anal and vaginal sex are the riskiest sexual activities.

The risk of transmitting the virus increases in a person with a sexually transmitted infection (STI), because the presence of sores or broken skin makes it easier for HIV to enter. Prompt treatment of STIs is one way of reducing the risks of HIV transmission.

“Dry sex” is practiced in some parts of the world: a substance is put into the vagina to cause it to become dry. This creates more friction during intercourse, which some men find pleasurable. This practice results in lacerations to the delicate vaginal membranous tissue, making it easier for the HIV virus to enter. In addition, the natural antiseptic contained in the vaginal secretions is no longer available to combat STIs. Finally, condoms break far more easily due to increased friction.

Oral sex is much less risky than vaginal or anal sex, but cannot be considered as being entirely safe. The presence of mouth ulcers, severely inflamed or bleeding gums, sore throat, or practicing oral-vaginal sex with an HIV-infected woman during her menstruation contribute to the increased likelihood of HIV transmission.

Research has shown that male circumcision reduces the risk of HIV transmission by 60 to 70% because certain characteristics of the foreskin of the penis

make it easier for HIV to enter. Therefore, men who are not circumcised are at greater risk of being infected. When the foreskin is removed through circumcision, the likelihood of transmission is reduced.

Sharing needles or body piercing equipment

Sharing needles and syringes carries a high risk of HIV transmission. Sharing cookers (devices used to cook drugs to make them purer), cottons and water for mixing/bleaching can also transmit HIV, because of the small amounts of HIV-infected blood that can remain in them after use. This can then enter the bloodstream of the next user.

Being given a transfusion of infected blood

The risk of acquiring HIV through a transfusion of blood and blood products that have been tested for HIV is less than one in a million. The risk of acquiring HIV from an organ transplant is probably similar. Today, blood and organ banks screen out most potential donors at risk for HIV infection, and specimens of blood, blood products and organs for HIV and other blood-borne germs are tested extensively. Nevertheless, there is a remote possibility of someone donating blood without knowing they have the virus during the early weeks of infection, in the window period, when this is not yet revealed through testing (see “Knowing if a person is infected,” p. 15).

There is a very small yet real risk of health care workers contracting HIV from patients as a result of being pricked with a needle, or exposed to substantial amounts of blood. Persons who work in laboratories handling blood are also at risk, as are staff handling waste and soiled linen.

Mother to child transmission

HIV can be transmitted vertically from mother to child in the womb or through breastfeeding. Children born to an HIV-infected mother have a 20 to 30% risk of acquiring the virus. The transmission can occur in three ways: during pregnancy (antepartum transmission), during the birth of the baby (intrapartum transmission), and during breastfeeding (postpartum transmission). The highest risk of transmission is during the process of giving birth. Secretions of the birth canal contain high amounts of the virus, and the baby may develop small skin abrasions during childbirth through which the virus can enter. In postpartum trans-

mission, the infant can become infected through breastfeeding. An HIV-infected woman's breast milk contains the virus, and the longer the period of breastfeeding (more than 6 to 9 months), the greater the risk of transmission.

How HIV is not transmitted

Scientists and medical authorities agree that HIV does not survive well in the environment, making the possibility of environmental transmission very remote. Once the infected fluids have dried completely, the theoretical risk of environmental transmission is essentially considered zero.

HIV *cannot* be spread through/by:

- The air, coughing and sneezing
- Kissing, hugging, shaking hands, or massage
- Sharing dishes, glasses, or cutlery
- Contact with toilet seats
- Insect or animal bites (mosquitoes and bed bugs *cannot* transmit HIV)
- Swimming pools
- Eating food prepared by someone infected with HIV
- Sharing clothes or towels.

The difference between HIV and AIDS

Persons infected with HIV are considered HIV-positive; they may be healthy and show no symptoms of the illness. Such persons can live a long and active life with counseling, adequate nutrition, practicing a healthy lifestyle, following certain precautions, and if available and/or affordable, by taking antiretroviral (ARV) drugs.

A person who has reached the stage of AIDS is usually symptomatic, and often has to contend with many illnesses. Unless treated with ARV drugs, they will usually have a limited time left to live.

The difference between HIV and AIDS is an important one. In many parts of the world, HIV is now manageable. Life can be prolonged provided there is access to affordable treatment. The term HIV/AIDS should therefore be avoided and replaced with "HIV and AIDS," as they are two separate although linked conditions.

Stages of HIV infection

Primary infection

At the time of infection, the person is unaware of being infected. Within the first 6 to 8 weeks of infection, about half of those who contract HIV suffer flu-like symptoms which may include fevers, fatigue, rashes, sore joints, headaches, and swollen lymph nodes. Because these symptoms can be quite mild, they are often not noticed, and the person soon recovers. Yet, during primary infection the virus makes its way to the lymph nodes. This may take 3 to 5 days. Subsequently, HIV actively reproduces and releases new virus particles into the bloodstream. This HIV escalation usually lasts 2 to 3 months. During this stage, there is a large amount of HIV in the blood, and the immune system begins to react by producing antibodies. This process is known as seroconversion.

Asymptomatic infection

This stage lasts for an average of 10 years, during which a person is essentially free from major symptoms, although their glands may be swollen. Persons infected with HIV can continue to live and lead a healthy life for several years, on average 10 to 12 years, without antiretroviral treatment. This of course varies from person to person; in some instances the person can begin to show symptoms as early as 2 years from the day of infection, while others may take longer than 12 years to develop AIDS.

Symptomatic stage

As the immune system breaks down a person begins to experience many minor infections, such as sinusitis (inflammation of the sinuses), bronchitis (chest infection), occasional fevers, mild skin irritations and rashes, fungal skin, nail infections, mouth ulcers, and slight weight loss. In more advanced stages of HIV, they may also suffer from tuberculosis (TB), thrush (whitish eruptions in the mouth, throat, and tongue), and herpes blisters in the mouth or on the genitals.

The stage of AIDS

As the immune system becomes more damaged, it loses its capacity to fight disease. Persons may have severe diarrhea, severe weight loss, pneumonia, brain

infections, memory loss, etc. They become vulnerable to a series of “opportunistic infections,” caused by common bacteria, fungus and parasites. These would not result in disease in persons with normal immune systems, but in people with HIV these microbial agents take the “opportunity” to flourish, and thus are known as opportunistic infections.

Knowing if a person is infected

One cannot tell by a person’s appearance whether or not they are infected with HIV. While a person who has HIV or even AIDS can appear completely healthy, anyone infected with HIV can infect other people, even if no symptoms are present. The only way to determine this is to have a blood test, the most common of which detects the HIV antibodies.

Antibodies are disease fighting proteins that are produced in a person’s body in response to foreign invaders such as bacteria and viruses. When a person is infected with HIV, the body starts producing specific HIV antibodies. While this antibody is not very effective in fighting the virus, its presence in the blood is a reliable indicator of whether someone is infected with HIV. Usually, the antibodies are produced about 12 weeks after infection. Nearly all people will develop antibodies within 6 months of infection.

In the first 12 weeks after infection, there are no antibodies in the person’s blood, so that in testing, the results will be HIV-negative. This is the critical window period, during which an infected person could even donate blood without the virus being detected. In very rare cases, the window period may be as long as 6 months. Similarly, a person may become infected during sexual contact with an HIV-infected person, but still test negative during this window period. This is why it is important for those who test negative to have a second test 3 months later.

The “viral load” is the number of virus particles per ml. of blood. This level rises when the virus replicates rapidly in the bloodstream. The viral load is very high just before the person begins to produce antibodies during primary infection. During this period, the person is highly infectious, although they will still test negative for antibodies. The viral load then falls, remaining at a low level as the body regains control over the infection. If left untreated, after several years, the body becomes less able to control the virus and the viral load level begins to rise. As the disease advances the viral load increases while the CD4 count decreases.

ARV drugs

Since the start of the HIV and AIDS pandemic, a series of drugs have been developed that significantly prolong the lives of those who are HIV-positive (see appendix 2). These ARV drugs can block the replication of the virus and delay the onset of AIDS by slowing down the progression of the disease. They are not a cure. The most effective treatment is known as Highly Active Antiretroviral Therapy (HAART), a combination of three or more ARV drugs, aiming to slow down the rate at which the virus multiplies in the body.

The benefits of ARV drugs are that they:

- Reduce the rate at which the virus multiplies in the body, thereby decreasing the viral load
- Slow down the rate at which the disease progresses
- Preserve or restore the functioning of the immune system
- Make the person less infectious, thus reducing the risk of spreading HIV.

The risks of ARV drugs are that:

- Early treatment of HIV may reduce the quality of life because of the side effects and high cost of the medication
- Resistance to ARV drugs may develop, thus limiting future treatment options
- Therapy will probably need to be continued indefinitely.

Instructions for those taking ARV drugs

- **Strict adherence to the prescribed therapy:** Usually a combination of 3 to 5 different drugs, from at least 2 different drug classes, are prescribed at the same time (drug cocktail). If the person takes less than the prescribed quantity, or takes it irregularly, drug resistance, or tolerance will develop. This means that the drugs will stop working. As HIV changes its structure (mutates), some versions of the virus become resistant to drugs. The chances of keeping it in check are therefore much higher if several drugs are used.
- **Attention to adequate nutrition:** Taking drugs without proper and regular intake of food can cause gastrointestinal symptoms, anemia and nausea.

- **Patient education is extremely important:** This includes such topics as drug adherence, drug resistance, regular intake, adequate nutrition, toxicity, the continuing infectious status (some wrongly assume that under treatment they can no longer transmit the virus to others), monitoring blood counts, etc. Local volunteers can be recruited for these education efforts.
- **Drug resistance:** Patients usually start with the most basic combination of drugs (the first line regimen). After some years, these drugs are likely to stop working, and the person will need to be switched to a second line regimen, which is more expensive. Drugs need to be changed about every 3 years. Today, about 20 different drugs are on the market of which only a few are available in the developing world. The advanced regimens are usually expensive and therefore unaffordable for people living in these countries.
- **Regular monitoring:** It is important that CD4 counts, and if possible viral load counts, are measured every 3 to 6 months, which requires special equipment.

HIV prevention

Any method for preventing the spread of HIV and AIDS and thus protecting and preserving life needs to be taken into consideration. A method appropriate in one situation may not be effective in another. What must be borne in mind is the given context, a person's willingness or ability to use preventive measures, and the values prevalent in the community. The goal should be to save all human life, precious as it is in the sight of God.

Preventing sexual transmission of HIV

The transmission of HIV can be prevented by not having sex with anyone who is, or may be, HIV-positive, or by using condoms. If used properly and consistently, the male condom is essentially impermeable to HIV-sized particles, although no protective method other than abstinence is 100% safe. In the case of couples where one person is HIV-positive and the other negative, the use of condoms is crucial. Even if both are HIV-positive, condoms must be used because they may be infected with different strains of the virus. Each unprotected encounter with different strains of the virus increases the viral burden. Using condoms protects from HIV reinfection.

Female controlled methods of prevention

The female condom is a polyurethane sheath with rings at each end, which a woman can insert into her vagina up to 8 hours before sexual intercourse. It provides protection against pregnancy as well as STIs, and has no known side effects. Its biggest advantage is that it gives a woman control over her own sexual health. However, it is far more expensive than the male condom, and not yet widely available. Some negotiation and cooperation with the man are also necessary.

A microbicide would prevent the sexual transmission of HIV and other STIs when applied within the female genital tract. This may be available in a few years in the form of a gel, cream, suppository, film, sponge, or ring.

Preventing HIV transmission in intravenous drug users

The likelihood of injecting drug users becoming HIV-infected can be reduced by avoiding the sharing of needles. Usually it is very difficult for drug users to stop their addiction. Drug detoxification programs are required where intravenous drug users are gradually weaned from needles to avoid HIV infection. Programs providing clean needles in order to avoid HIV infection are known as “harm reduction” programs. As with condoms, the purpose is to protect from HIV and to preserve life.⁴

Preventing transmission from mother to child

Administering ARV drugs to HIV-positive mothers during pregnancy can prevent transmission. These drugs lower the viral load in the mother, and thus reduce the chances of the baby being infected. Delivery through Cesarean section to avoid transmission during childbirth is now practiced in most developed countries, but may not be feasible in places where resources are seriously limited.

The risk of the baby being infected through breast milk can be overcome by feeding infant formula. In many countries, this may be impractical, expensive, or culturally unacceptable. Clean, safe water to prepare the formula may not be available, and unsterilized bottles increase the possibility of intestinal infections.

⁴For more on how this is consistent with a Lutheran ethical approach, see chapter 2.

If it is not possible to substitute breast milk, it is advisable for HIV-positive mothers to wean their babies as soon as possible. Until then, it is advisable to breastfeed exclusively mother's milk and to avoid "mixed feeding" (breast and bottled milk), as this leads to increased chances of transmission.

Preventing transmission in health care settings

Health care providers need to protect themselves against HIV infection by following prescribed infection control protocols and universal precautions. There are methods for avoiding infection through needle injuries and mucous membrane splashes. Using protective gloves, impermeable aprons, protective footwear, eyeglasses, and masks also helps protect against such accidents.

If an accident occurs, the affected area must immediately be rinsed with soap and water. Then baseline HIV testing is conducted, both of the person who has been exposed as well as of the person from whom the blood or fluids have come. If the one who has been exposed tests negative (indicating they have not been previously infected), and the other person tests HIV positive, or is strongly suspected of being so, then the risks need to be assessed by an experienced expert. If the risks are high, ARV drugs are administered, preferably within 24 hours of exposure. This is known as post-exposure prophylaxis (PEP). In cases of rape, the same procedure can be followed, with follow-up tests for HIV 3 to 6 months later.

The "ABC" approach

One well-known approach to prevention is the **ABC** approach: **A**bstain (from sexual intercourse), **B**e faithful (to one sexual partner), and use **C**ondoms. ABC can be effective as a prevention tool, but for women it is limited, especially if promoted as the only means for protection.

Abstinence does not make sense for girls and women who are coerced into sexual activity or subjected to sexual violence, nor for women who are forced to marry and expected to bear children as part of their filial duty. Similarly, "being faithful" to one partner offers little protection to women whose husbands were infected before they married, or have other partners.

The major obstacle for the effectiveness of condoms in HIV and AIDS prevention is the power relationship between women and men. Often women are unable to get their male partners to use condoms. Many men who are opposed to

using condoms during sexual intercourse take it as an affront and as a statement of distrust or unfaithfulness when their female partner suggests the use of a condom. Moreover, condoms are a barrier to conception and the expectation to have children.

The “SAVE” approach

The African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (ANARELA+) has developed a model for a comprehensive response to HIV, called “SAVE.”

- **Safer practices:** This includes all means of prevention—abstinence, faithfulness, condoms, clean needles, the use of safe blood, preventing mother to child transmission, etc.
- **Available medications:** If treatment is available, it should begin as soon as indicated to avoid further infection, and for the sake of a better quality of life.
- **Voluntary counseling and testing (VCT):** Voluntary testing is crucial. VCT provides an important entry point for persons to learn about their HIV status, and the possibility to prevent further spread of HIV through responsible living.
- **Empowerment:** Persons living with the virus can be empowered to develop a positive attitude and outlook through counseling, prayer and other spiritual support. This is important in delaying the progress of the infection (see appendix 3).

Resources for this chapter

Averting HIV & AIDS, at WWW.AVERT.ORG

Bartlett, John, MD, *Pocket Guide to HIV & AIDS Treatment 2006* (John Hopkins AIDS Service), at WWW.HOPKINS-AIDS.EDU/PUBLICATIONS/POCKETGUIDE/POCKETGD0106.PDF

UK Department of Health, *HIV Post-exposure Prophylaxis: Guidance from the UK Chief Medical Officer's Expert Advisory Group on AIDS*, 2nd edition, at WWW.DH.GOV.UK/PUBLICATIONSANDSTATISTICS/PUBLICATIONS/PUBLICATIONSPOLICYANDGUIDANCE/PUBLICATIONSPOLICYANDGUIDANCEARTICLE/FS/EN?CONTENT_ID=4083638&CHK=qtPweH

UNAIDS, *Report on the Global AIDS Epidemic, 2006*, at WWW.UNAIDS.ORG/EN

UNAIDS, *Intensifying HIV Prevention. UNAIDS Policy Position Paper 2005*, at DATA.UNAIDS.ORG/PUBLICATIONS/IRC-PUB06/JC1165-INTENSIF_HIV-NEWSTYLE_EN.PDF

US Dept. of Health & Human Services, *AIDS Info Series*, at [HTTP://AIDSINFO.NIH.GOV](http://AIDSINFO.NIH.GOV)

Center for Disease Control, US Division of HIV/AIDS Prevention, at WWW.CDC.GOV/HIV/DHAP.HTM

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Chapter 2: Gender, Sexuality and Truth Telling



In the HIV and AIDS pandemic, faith-based convictions regarding the fundamental equality of women and men, the goodness of human sexuality and the obligation to tell the truth have been violated. This has had devastating effects. The risk and burden fall disproportionately on women and girls, and silence regarding sexual activity leads to death rather than life.

Women, girls and HIV and AIDS

In many areas of the world, more women and girls are infected with HIV and AIDS than men and boys. The rate of infection among women and girls is grow-

The huge difference in the levels of infection between girls and boys reflects deep gender biases and inequalities in our societies.

ing at alarming rates. Why is this the case? How does this affect the way in which we address this pandemic?⁵ Women are more susceptible to becoming infected because semen contains higher levels of HIV than the vaginal fluids, and the area of vulnerable tissue in the

vagina is much larger. The virus can enter the bloodstream through tiny tears in the tissue that occur during sexual intercourse. Genital sores create additional entry points for the HIV virus. Women are therefore more likely than men to contract HIV through sexual intercourse.

Lack of decision making power and economic dependency

For many women, financial, material, or culturally promoted dependence on men means that they have little or no power to make decisions regarding sexual activity. Far too often, girls and women are coerced to have sex. Furthermore, they cannot negotiate to minimize the risks of being infected, for example, by insisting that men use condoms. Discrimination of many kinds perpetuates gender inequality.

Poverty and HIV and AIDS are deeply intertwined.

Abject poverty can pressure women and girls to exchange sex for food or other material favors in order to ensure their daily survival. Some girls are ensnared by older men (known

as “sugar daddies”), who offer them attractive options, including financial help for their families, in exchange for sexual favors. A woman’s double burden is in-

⁵ See WWW.WHO.INT/MEDIACENTRE/NEWS/RELEASES/2004/PR_UNAIDS/EN/PRINT.HTML

tensified when the family is living with and affected by HIV and AIDS, because she is expected to provide care in addition to contributing to sustaining the household, while at the same time battling with her own infection.

Silence about sexuality

Social norms impose a dangerous ignorance on girls and young women, who are often expected to know little about sex and sexuality. In many societies, “good girls” do not or should not display any knowledge of sex. Their lack of knowledge greatly increases their risk of HIV infection since many young women do not know how to protect themselves against contracting HIV.

Lack of education

In many areas where HIV and AIDS are prevalent, women and girls have far fewer educational possibilities than men and boys. Completing secondary school can boost women’s social power, their employment opportunities, self-reliance, and reduce their risk of infection. With education comes increased awareness and knowledge, higher rates of condom use and greater communication between partners regarding HIV prevention.

Gender based violence

Violence against women and girls is one of the major factors contributing to their increased rate of infection. This includes such vicious crimes as rape and other forms of physical violence, as well such harmful traditional cultural practices as female genital mutilation. Much of this occurs within families. The following comprehensive definition by the United Nations refers not only to direct forms of personal violence, but also to the systems and structures that covertly perpetuate violence.

The term “violence against women” means any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life.⁶

When women and girls are raped, they run a much higher risk of becoming infected because of physical injury to their genitalia or anus. Rape occurs in the home or

⁶ The United Nations Fourth World Conference on Women, *Platform for Action* (Beijing, September 1995), para. 113, at WWW.UN.ORG/WOMENWATCH/DAW/BEIJING/PLATFORM/VIOLENCE.HTM

community, in police custody and in prisons, in situations of conflict and war. Fear and shame can deter women from seeking HIV information or from being tested and treated, even when they strongly suspect they have been infected.

For many women, marriage itself has proven to be a high risk situation. Young married women have significantly higher rates of HIV infection than their single, sexually active peers. This is so because married women are exposed to a greater risk if their partner is infected. There also are many instances when wives are forced by their HIV-infected husbands to have sex. Such forceful sexual acts result in greater chances of infection.

Denial of inheritance and property rights

Women are more vulnerable because of unequal property and inheritance rights, as well as such practices as dowry. Although this varies around the

In some countries, when a woman's male partner dies of AIDS, she is stripped of her property by his relatives. She is thus cast into deep economic insecurity.

world, gender inequalities are strikingly widespread. Usually, men own property, with women only occasionally acquiring property, mainly through marriage.

Lacking enforcement rights to own or inherit land and property, women and girls risk becoming destitute when their parents or husbands die. In turn, poverty and economic dependence leave them more exposed to sexual exploitation and violence.

Wife inheritance

This is the practice whereby a widow is taken as a wife by a close relative of her late husband. She is "inherited," sometimes by a polygamous family, and may even lose her children. Subsequent sexual activity is often coerced and unsafe. If either the wife or the new husband is already infected with HIV, this increases the risk of transmission, and thus the spread of the virus.

Female genital mutilation

Through the multiple use of unsterilized razors, knives and needles to cut off the clitoris and areas close to the vagina, this practice places women and girls at increased risk of HIV infection. Scar tissue that forms makes the genitals more likely to tear during intercourse, greatly increasing the likelihood of sex-

ual transmission of the virus from an HIV-positive male partner. Because intercourse becomes more difficult for the woman, she may resist the advances of the man, who may become more aggressive during the sexual act, thereby placing her at even greater risk of becoming infected.

False and dangerous myths and practices

In some circles, the myth prevails that having sex with a virgin will cure a male of HIV and AIDS. Some men also feel that having sex with young girls is safe, assuming they are less likely to be HIV-infected. This has resulted in many young women and girls being infected. In some parts of the world, the practice of “dry sex” (see chapter 1) also contributes to the spread of the infection.

Lack of access to treatment

Globally, men tend to have better access to care and treatment for HIV and AIDS when this is provided mainly through the private sector and drug trials. Access to voluntary counseling and testing still poses a significant challenge for girls and women, who do not usually use reproductive health services, as well as for men, who are generally less likely than women to use public health facilities. As treatment programs expand, there is growing concern that many women may miss out on opportunities to learn their status and receive treatment because they are afraid that if they discover that they are HIV-positive and their partners become aware of this, they may be subjected to further abuse.

The obstacles barring women from access to treatment and care must be identified and overcome. Part of the answer lies in strengthening primary and reproductive health services, and providing more points of access to treatment and care for women through improved referral systems. By integrating treatment services of STIs with primary health and family planning services, women’s fear of social censure could be reduced, and their access to services increased. We need more concerted efforts to reduce HIV-related stigma. Girls under the age of 18 should not be barred from voluntary counseling, testing and treatment because they lack their guardian’s consent or proper identification.

Childbearing and HIV and AIDS

An HIV-positive woman is likely to transmit HIV to her baby if the interventions discussed in chapter 1 are not undertaken. During pregnancy and deliv-

ery, HIV-positive women with advanced stage of infection are at risk of complications and need special health care because of their weakened immune systems. Some HIV-positive women are forced to terminate their pregnancies, others are sterilized. These procedures have a serious psychological impact on the women, scarring them for life. Lack of pre- and postnatal care and little or no maternity leave can leave women exhausted and at risk for opportunistic infections. This may also affect the infant and other family members.

If the infant is HIV-positive the mother sometimes feels responsible for this. Feelings of guilt may also be present in men who, once infected with HIV, can only consider having a child at the risk of infecting the mother, as well as the child who may be born with HIV. Pressure on men to prove their masculinity, or on women to prove their worth by having children, only compound the spread of HIV and AIDS.

Women as caregivers

Throughout the world, women are the main caregivers. HIV and AIDS have significantly increased this care burden. In countries hardest hit, up to 90% of the care for people living with and affected by HIV and AIDS takes place in the home (see chapter 5). The vast majority of women and girls who do this work receive little or no material or moral support. They receive no training or needed resources, and often have no means to pay for the care and education of their children. The combined physical and emotional burdens of caring for sick household members and others (such as orphans), and of providing enough food, medicine and income, inevitably force women to neglect their own health and well-being.

As more women living with and affected by HIV and AIDS are working outside the home to provide for their families, caregiving duties are increasingly shifting to older women and younger girls. On an unprecedented scale, older women are assuming responsibility not only for their children and grandchildren, but also for other children orphaned because of AIDS. In addition, HIV and AIDS frequently result in girls withdrawing from school to provide care and help compensate for lost family income, thus augmenting their risks of sexual exploitation and HIV infection.

Unsafe work environment

Certain types of work situations may increase the risk of HIV infection. These include: women who travel for their work or migrate to find work, spouses of migrant or mobile workers, women who are in a small minority at the workplace,

female domestic workers (especially those who live at their place of work), and female sex workers. Power imbalances in the workplace also expose women to the threat of sexual harassment.

Sexuality

Human sexuality was created for the purposes of expressing love and generating life, for mutual companionship and pleasure. God created us as sexual beings, and declared this to be good (Gen 1:27, 31, see also the Song of Songs). Yet, sexuality has also been marred by sin, which alienates us from God and others. This results in expressions of sexuality that harm persons and communities. Through sexuality, human beings can experience profound joy, purpose and unity, as well as deep pain.

We become most accessible and vulnerable through sexual activity and by fully giving ourselves to another person. Faithfulness to one sexual partner is important to enable this self-giving intimacy to flourish. God who loves us expects sexuality to serve the purposes of human love and sharing. This is why it is crucial that sexual relationships express mutual love, care and intimacy, rather than exploiting, harming, violating, or infecting another person. Love is expressed by honoring the dignity and safety of the other. In this sense, “making love” is very different from simply “having sex.”

What matters most is the quality of the relationship within which sexual expression occurs, and whether sexual acts build up and enhance, or harm and destroy other persons. Sexual relationships should be tender and loving, promoting personal and social flourishing. Sexuality can easily be misused to satisfy oneself at the expense of another, or to demonstrate power and control over another person.

Coercing another person to engage in sexual intercourse against their will is wrong. This can occur within marriage, as well as with other vulnerable family members; it can occur within same-sex as well as within heterosexual relationships.

It is necessary to get beyond idealistic platitudes associated with certain cultural ideals of sexuality and to focus on the actual effects on persons and families.... Attitudes and

“Responsible and respectful sexual behavior for both women and men must be a foundational belief and a key strategy in preventing the further spread of HIV and AIDS.”

One Body ...
op. cit. (note 1), p. 17

practices must be challenged when they harm or manipulate bodies for the sake of acceptance within a culture, or exclude some people from full participation in the church.⁷

Women must not be viewed as the property of men or as sex objects that can be used as men please. Men and boys need to be challenged to understand the relationship between male assumptions and behavior and the spread of HIV and AIDS, to accept the responsibility this brings, encouraged to do whatever they can to prevent the spread of HIV and AIDS, and care for those affected. It is wrong for a man who knows himself to be infected with HIV to pressure his intimate partner (whether she is his wife or not) to have unprotected sex with him. This is even more troubling when a woman is kept subordinate, unable to challenge the dominating power of the man who refuses to use a condom to protect her from being infected.

Truth telling about sexual practices

In many cultures, men and women do not normally discuss sexual practices. It is assumed that people will abstain from sexual activity before marriage, and be faithful to their spouses once they are married. However, this is often not the case. The silence must be broken, and the truth told about what is actually occurring.

“To be infected by someone who didn’t dare to tell the truth, was an overwhelming blow to my confidence in other people. How could I ever again dare to believe in anyone, when my trust was betrayed so totally that it had even given me a deadly virus?”

Preben Bakbo Sloth,
in op. cit. (note 1), p. 23.

As you read the following account from one African context, think of cultural practices in your own setting that need to be brought to light:

Men tend to have more sexual partners than women and men often do not use condoms consistently. Why do men behave that way? ... Many men and women think that it is “natural” for men to have more partners or that a man’s sex drive is so strong that it cannot be controlled. So boys grow up with the expectation that they have a “right” to have sex whenever they want it and some girls grow up expecting that it is their duty to satisfy men. Women who want to protect themselves often feel they cannot raise the subject with their partner.

⁷ Karen L. Bloomquist, “Embodiment Contextualizes Sexual Ethics,” in Karen L. Bloomquist (ed.), *Lutheran Ethics at the Intersections of God’s One World, LWF Studies 02/2005* (Geneva: The Lutheran World Federation, 2005), p. 84.

A terrible burden is imposed on men by gender roles that equate masculinity with sexual prowess, multiple sex partners, physical aggressiveness and dominance over women, a readiness to engage in high risk behavior. If men can be encouraged to behave in ways, which are in accordance with the scripture and which reduce their own risk of HIV transmission, then they themselves will emerge stronger, no longer stigmatized as drivers of the pandemic but enlisted as partners, as fellow leaders in finding a solution.

Current HIV/AIDS prevention strategies promote monogamy, fidelity and condom use ... [but] since these strategies have failed to address the underlying concepts of masculinity and high-risk or even violent practices of sexuality, they have proven to be insufficient and even harmful An effective strategy will take the gender questions seriously.⁸

Or consider this perspective from a Nordic context:

Sexuality expresses a person's innermost being ... In the North, we have encountered AIDS at a time when this experience of sexuality is in many ways splintered and shattered. Sexuality has become a commodity among many others, and we trade bodies in the strangest ways, with more and more elaborate symbols and rituals. ... Sexuality becomes a medium through which we hope to find what we are looking for: the assurance that we are loved, that we are more than the worthlessness that we can feel invading our soul. ... AIDS plucks away at strings in our deepest subconscious: fear of annihilation, fear of sexuality...fear of being humiliated by a disease that makes us powerless and out of control.⁹

What needs to be brought to light in your context? How might you encourage men, women and youth to tell the truth about what is occurring? How can men and women be helped to talk safely and more openly with one another about how to avoid becoming infected with HIV? What cultural practices need to be challenged?

⁸Japhet Ndhlovu, "Patriarchal Sins," in *op. cit.* (note 1), pp. 15-19.

⁹Elizabeth Knox-Seth, "Sexuality and Death," in *op. cit.* (note 1), p. 25.

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Chapter 3: Responding to Questions of Faith



Questions of faith often hold us back from reaching out to persons living with and affected by HIV and AIDS. Sometimes people respond in hurtful ways that only deepen other people's suffering. Much of what we have learned or assumed in the past may need to be questioned, rejected, or viewed in a new light. We need to reflect on whether our views are consistent with what is at the heart of our faith.

In the following, we shall consider some basic questions from a Christian perspective that is informed by the Lutheran tradition. We shall begin by looking at Jesus who was inclusive in how he reached out to people in need. Other faith traditions might provide different responses, yet in terms of basic values and approaches, much is shared and provides the basis for our working together-

What did Jesus do?

The human Jesus related to and met the people of his day in whatever their situation. He often challenged their cultural and religious assumptions with words such as, "You have heard it said, but I say to you..." He confronted his followers with alternative ways of relating to people, because of his deep compassion for them. He thereby turned people's expectations upside down. He continues to do so for us today.

We need not speculate about what Jesus *would do* today. We encounter what the earthly Jesus actually *did* in the gospels. Instead of identifying with those considered respectable or "holy," he reached out to people who were weak, sick, lowly, and socially outcast. This included those who were:

- Considered unclean and stigmatized because of their physical condition or disease (e.g., lepers)
- Looked down upon because of their gender or class (e.g., women and the poor)
- Scorned because of what they were suspected of doing (e.g., sex workers and adulterers).

Jesus reached out, touched and healed those whom society considered "outcasts." In doing so, he violated religious laws (that prohibited healing on the Sabbath) and social taboos (against those with questionable sexual histories). As a result, he and his followers were increasingly viewed with suspicion by the

religious and political authorities of his day. His radically inclusive, boundary-crossing love was more than they could tolerate.

It is this Jesus who embodies and most directly expresses what God is like. In Jesus Christ, the fullness of God is revealed: he is the Word of God made flesh (Jn 1). Jesus Christ is at the center. He is the key to how we are to read and interpret the rest of Scripture, as it witnesses to God’s grace and promise throughout biblical history. Through baptism, Christians are incorporated into Jesus: they *become* the body of Christ in the world today. Thus, to be “in Christ” is to do as Jesus did.

On this basis, we must challenge tendencies to be moralistic toward those living with and affected by HIV and AIDS. Judging, ostracizing, stigmatizing, and discriminating against them goes against what it means to treat others as Jesus did. If we profess our faith in Jesus Christ, then we must also stand with those who are marginalized or excluded because of their HIV status. We meet the God whom we know in Christ, not apart from, but in and through those living with and affected by HIV and AIDS.

What is God like?

Some people think of God as almighty and judgmental. However, in Jesus Christ God is revealed in ways that are contrary to what is commonly associated with divine power: through the vulnerability, weakness, suffering, and death inherent in what it means to be human. In other words, God is revealed through the opposite of what people tend to associate with God. This is referred to as the theology of the cross.

Does this understanding of God challenge what you have heard in the past? What difference would this make for persons living with and affected by HIV and AIDS?

When we feel abandoned and cry out with Jesus on the cross, “My God, why have you forsaken me?” there God is revealed. This is a God of compassion, who is touched by, accompanies and suffers with those who are living with and affected by HIV and AIDS. Usually, such persons are already burdened with a sense of being condemned. Yet, the good news is that God’s power is expressed through unconditional love—through grace and the gospel—rather than through judgment and condemnation. This unfailing love is at the very heart of our faith: nothing “will be able to separate us from the love of God in Christ Jesus our Lord” (Rom 8:39).

This kind of God is depicted in the Parable of the Prodigal Son (Lk 15:11–31), which is actually about God the loving parent. God shows unconditional love, without judging or analyzing the kind of life the son had lived. The father embraces and accepts the returning son before he has a chance to repent. The older son, who had lived an upright life, is left feeling resentful; his morally upstanding life did not earn him any special favors with the father.

God loves *this* world (Jn 3:16). In suffering love, God is profoundly involved in, with and for the world. God is overflowing with love, grace and mercy. The church has expressed this in terms of the relationships within the Trinity—as Father, Son and Holy Spirit. This relational God yearns to be in relationship with us. How the Triune God relates to us—creating, redeeming and sustaining us—grounds our relationships with one another.

Through the Holy Spirit we received at baptism we became children of God. Through Holy Communion, we enter into communion with the crucified and risen Christ in whom God’s Spirit is made visible and tangible.¹⁰

Human beings in relation to God

As human beings, we are created by God to live in relation to God and in community with one another. This human community is richly diverse. Rather than considering some to be better than others on the basis of such differences as gender, sexual orientation, or HIV and AIDS status, our relationships with each other should be equal, mutual and reciprocal.

Because all human beings are created in the “image of God” (Gen 1:26), human dignity is given by God equally to both men and women. God enables us to be the subjects of our lives, rather than objects controlled by others. When we do not honor this, such as when men exert dominating power over women (see chapter 2), the image of God is violated.

By caring for others and ourselves, God empowers us to act responsibly. This is our calling as Christians. It includes resisting and working to change what is unjust for the sake of living in just relationships with each other, and acting responsibly with regard to our bodies and sexuality.

¹⁰ *Study Book, “For the Healing of the World,” LWF Tenth Assembly* (Geneva: The Lutheran World Federation, 2002), p. 21.

Throughout much of church history, and in many cultures today, there is the mistaken tendency to think of the body as bad and the spirit as good. This goes against the central Christian conviction that in Jesus Christ, God became incarnate or embodied: “in him the whole fullness of the deity dwells bodily” (Col 2:9).

Consequently, our bodies are to be considered good, not inferior. Our bodies are “God’s temple” (1 Cor 3:16). They are sources of joy and delight, even though vulnerable to sickness, suffering, abuse, and death. In the Apostles’ Creed, we profess our faith in the resurrection of the body. This leads us to the central question, How do we take good care of our bodies, as an aspect of an ethics of embodied care?¹¹ This includes taking responsibility to avoid harm, realizing that unsafe and risky behavior lead to harmful consequences.

In the sixteenth century, a highly contagious, deadly plague struck many central European communities. When asked whether Christians should flee to avoid becoming infected, Martin Luther provided practical pastoral advice, based on faith in God’s promises. He urged them not to abandon those affected, “as Satan would tempt us to do.” Neither should we tempt God by failing to take the necessary precautions, which in our day would mean using preventive measures (e.g., condoms or clean needles). Luther wrote,

It is...shameful for a person to pay no heed to his own body and to fail to protect it against the plague the best he is able, and then to infest and poison others who might have remained alive if he had taken care of his body as he should have. He is thus responsible before God for his neighbor’s death and is a murderer many times over.¹²

In the face of HIV and AIDS, what similar advice would you give today?

What then is sin?

From a Lutheran Christian perspective, the reality of sin goes much deeper than certain acts. Rather than primarily emphasizing sin as something we do (or fail to do), it is important to see sin also as a state of bondage or domination

¹¹ Wanda Deifelt, in *op. cit.* (note 7), p. 54.

¹² Martin Luther, “Whether One May Flee from a Deadly Plague” (1527), in Timothy F. Lull (ed.), *Martin Luther’s Basic Theological Writings*, second edition (Minneapolis: Fortress, 2005), p. 487.

from which we cannot escape. Sin is a condition of being alienated from God, from the person God has created us to be, from other people, and from the rest of creation. We all are immersed in this together, whether we are HIV-positive or negative.

This bondage of sin is what leads to violations of the Ten Commandments, such as when we endanger or harm the lives of our neighbors and do not help and support them in all of life's needs (the Fifth Commandment: do not kill), or when we fail to love and honor our spouse (the Sixth Commandment: do not commit adultery).¹³

Martin Luther spoke of how we are at the same time saints (created and redeemed by God) and sinners (still prone to sin). The ongoing battle against sin continues within us, and in our world. Theologically, this bondage to sin is exposed through the law, which is intended to prevent or restrain evil.

But once the harm has been done, the law is powerless. The law cannot redeem. To apply the whip of the law to the infected and affected will do nothing to remedy the situation, but only make the situation worse.¹⁴

If we view sin primarily as a set of acts a society considers wrong or immoral, then some persons—especially those living with and affected by HIV and AIDS—are suspected of being worse sinners than others. This leads to people living with and affected by HIV and AIDS being stigmatized or discriminated against. Excluding such persons from communities is in itself an expression of sin. It is misleading and sinful to try to apportion blame. We must resist any attempt to distinguish between “guilty” or “innocent” carriers of HIV and AIDS.

As Jesus said, “Do not judge” (Mt 7:1; Lk 6:37). St Paul also rules out this kind of ranking. He insists that “all have sinned and fallen short of God’s glory,” and that we are “justified by God’s grace as a gift, through the redemption that is in Christ Jesus” (Rom 3:23–24).

Instead of condemning individuals on moral grounds, it is important to understand and address the underlying causes for the spread of the disease. The most perva-

¹³ Cf. Martin Luther’s explanation of the Ten Commandments in his *Small Catechism*.

¹⁴ Klaus Nürnberger, *Martin Luther’s Message for Us Today: A Perspective from the South* (Pietermaritzburg, SA: Cluster Publications, 2005), p. 298.

sive factor is that of systemic poverty, and all the deprivations that come with it. It is unsafe practices that need to be changed, such as unprotected sexual activity, contaminated needles for injecting drugs and contaminated blood supplies.

Certain cultural practices are abusive and dehumanizing of human beings, all of whom are created in God's image. Cultural practices that oppress or violate those who are most vulnerable, including such practices as female genital mutilation, the rape of virgins and other forms of violence perpetrated against women and children.

Patterns of inequality, discrimination and oppression based on gender, economic situation, ethnicity, sexual orientation, etc., are expressions of the domination of sin. So, too, are the ways in which sexual practices are governed by rules of "property" (e.g., a woman seen as a man's property) or of "purity" (certain behavior ruled out because it is considered unclean or taboo). This prevailed in biblical times, and continues in many societies today.

It is crucial that we recognize how Jesus continually challenged rules based on property or purity. He openly confronted those who for the sake of their tradition "make void the word of God" (Mt 15:6), and who cling to tradition rather than being open to God's new order as begun in Jesus Christ (Mk 7:1–13). In this new order, rather than men treating women as their property (see Mk 10:4–9), it is mutual commitments of love that are normative.

Often churches support or are silent regarding assumptions, behaviors, systemic injustices, and patterns of control that contribute to the spreading of HIV and AIDS. This includes failing to:

Repentance must begin within the churches themselves.

- Accompany those affected with compassion and effective care
- Address poverty as a breeding ground for the spread of HIV and AIDS
- Challenge patriarchal assumptions that men are entitled to have unprotected sex (without a condom), and that women must submit to their desires
- Be clear that abstinence is not the only strategy to counter HIV and AIDS.

While abstinence before and faithfulness in marriage might be what Christians should strive for, a faithful Christian response must be practical in relation to

“Therefore, we commit ourselves and call on member churches to: further awareness regarding prevention of the HIV/AIDS pandemic through education and information, including speaking-out against harmful, abusive and exploitative sexual practices, treating sexually transmitted diseases, promoting faithfulness in marriage and advocating effective means of prevention (e.g. abstinence, use of condoms, sterilized needles, clean blood supply).”

Resolution of the Tenth Assembly of the Lutheran World Federation, Winnipeg, 2003.

what is actually occurring, and the different ways in which the virus is transmitted. Amid the ongoing risks of HIV and AIDS, ethical priority must be given to what will effectively protect the life and well-being of real, not just ideal human beings.

In the face of suffering, yearning for healing

Suffering is often associated with sin. Persons going through any kind of illness have been encouraged to confess their sins so that they might be reconciled with God. The story of Job, however, challenges this: his misfortunes were not caused by his failing to live an up-

right life. We realize today that much suffering is due to social, economic and political factors.

Jesus lived and preached the Good News to a world that associated sickness with sin. When his disciples saw a man born blind (Jn 9:1–3), they asked, “Who sinned, this man or his parents that he was born blind?” Jesus answers, “Neither.” Once again, he turned their expectations upside down, and instead reminded them of God’s power. Although this man’s sight was restored, many people who were sick at the time were not healed physically.

God suffers with us.

God does not abandon us, even though we may experience deep loneliness in times of intense suffering. Jesus cried, “My God, my

God why have you forsaken me!” (Ps 22:1; Mt 27:46; Mk 15:34). God was there even when it felt as if God were absent. Suffering does not mean that God has forsaken us.

People often suffer because of the lack of a caring community. The HIV and AIDS pandemic offers humanity an opportunity to come together and live out God’s love toward those infected and affected. This occurs by reaching out to those who are suffering through prayer, actions, compassion, and care (see chapter 4).

What is healing?

From a biblical perspective, healing is about restoring right relationships—with God, ourselves and the rest of the community. Healing is God’s activity in which we participate. Healing is not the same as curing. In the case of HIV and AIDS, the virus remains, but what is transformed is how people are received as whole persons in the community.

Healing is closely connected with forgiveness—becoming reconciled with what has occurred in the past so that we are no longer haunted by it. This is the miracle God in Christ brings about in our lives through the power of the Spirit. Jesus implied that forgiveness was at least as amazing a miracle as was physical healing (Mk 2:5–12).

In their encounters with Jesus, persons who were sick were touched, transformed and empowered through his grace. “Jesus was often seen as a folk healer, one who took people’s need for healing at face value. He entered individual stories and experiences of suffering, bringing concrete experiences of liberation.”¹⁵ Likewise, the task of healing today is “to enable as many people as possible to live their lives in such a way that others can recognize the image of the living God in them, and so that they may live and remain truly human until death.”¹⁶

To “receive the Holy Spirit” is to see what God is doing, in and through the brokenness of our lives and world, to bring healing and wholeness. Although God is the ultimate healer, we human beings have a role to play. We do so in cooperation with God. God works, for example, through doctors, nurses and medical treatments.

Being created in God’s image means that whatever we do should be done in such a way that it gives glory to God. In Christ, God frees us to make responsible choices. HIV-positive people should not have to die of AIDS-related complications when the needed medications are available. Access to life-sustaining medication is a matter of basic justice. When this does not occur, the realities of suffering and sin are only aggravated.

“Just as Jesus told that woman who was bent over, ‘You are set free from your ailment,’ he said that to me. I was set free from my ailment, and it wasn’t the physical ailment that had me bent over, but the emotional ailment, the spiritual ailment.”

ELCA News Service,
22 November 2006,
at WWW.ELCA.ORG/NEWS/RELEASES.ASP?A=3489

¹⁵ *Study Book, op. cit.* (note 10), pp. 18–19.

¹⁶ *Ibid.*, p. 188.

What then makes us right with God?

What people do, how moral they are, the kind of life they lead—including keeping free from HIV—are not what makes people right with God. We are saved or made right with God not by what we do, or fail to do, but solely by faith in God's free grace as revealed in Jesus Christ. This amazing grace goes against our human assumption that what we do will earn God's approval.

Our faith in God is expressed in love toward others, in response to God's love. From the First Commandment flow all the others. Jesus gave us a new commandment: to love one another. This love overcomes all fear, including the fear that leads us to stigmatize others.

God does not need our good works, but our neighbors do.

In this sense, what we do *does* matter—to those who need our care, embrace, acceptance, and help. That is the kind of “holy living” that flows from God's gracious acceptance. It

includes taking care of ourselves so that we do not become infected, and seeking the necessary help if we do.

What will other people think?

What will others think if we reach out to those who are scorned, looked down upon in our societies, or not considered worthy of respect? If those from other churches, cultures, or faiths insist that you have to live according to certain moral rules in order to be accepted or saved, or have certain expectations of what it means to be a man or a woman, how will they view us?

“Woe to you when all speak well of you, for that is what their ancestors did to the false prophets” (Lk 6:26).

That is the risk Christians have often faced, beginning with Jesus' earliest disciples. Like Jesus, they mingled with the poor, the sick, women, and others whom society discriminated against.

As a result, the religious and political establishments increasingly viewed them with suspicion, even hostility. On the eve of Jesus' crucifixion, and all the times people die unjustly in our day, we are tempted to deny that we are Jesus' followers, just as Peter did (Mt 26:74; Mk 14:66–72). Christ's unconditional love is often too radical to accept. Nonetheless, this kind of embracing acceptance is what Christ calls us to, even when it risks our reputation.

Chapter 4: Ministry of Care and Counseling



Christian as well as other communities are called to bear each other's burden through caring presence. This ministry of care and counseling includes:

- Proclaiming the gospel of hope in the face of the HIV and AIDS pandemic
- Upholding the dignity of persons living with and affected by HIV and AIDS
- Advocating for and being in solidarity with people who suffer from the effects of the virus
- Encouraging, comforting and consoling those who are grieving the loss of their loved ones
- Accompanying persons who seek healing and search for life's meaning in these difficult circumstances.

These are responsibilities of all baptized Christians—men, women and youth—and not only of those who are ordained, consecrated, or specially designated. In many congregations, lay leaders have regularly provided care for individuals or families in times of sickness, distress, or grief, as well as people's ongoing practical needs. Sometimes they have also conducted funerals. All these activities are

part of "pastoral care," including the important home-based care discussed in chapter 5. In the face of HIV and AIDS, the church is called to increase and strengthen these activities, and include more people in this ministry of care.

Jesus said, "I came that they may have life, and have it abundantly" (Jn 10:10). Through faith in Christ, essential ministries of care and counseling are carried out in defiance of those many ways in which HIV and AIDS threaten life.

Most of those who provide spiritual care in this area are not formally trained in pastoral care. Therefore, this chapter provides general,

basic reference material to assist a wide variety of people to carry out these responsibilities in settings that vary greatly.

Care and counseling in the contexts of HIV and AIDS

The terms "care" and "counseling" are interrelated and sometimes used interchangeably. The ministry of counseling relates to the spiritual guidance of individuals in difficult emotional, psychological, social, and spiritual circumstances. These result in emotional, spiritual and psychological reactions that include fear and anxiety, feelings of loneliness and grief, and theological and spiritual questions.

“Care” includes having compassion for and comforting those afflicted, as well as providing physical assistance. It may also involve consoling, reconciling and healing. As an integral aspect of diakonia, it also implies pursuing justice and transforming the wider social environment of those affected and infected.

Any person can do counseling. What makes it “pastoral” is that it is done from the perspective of faith in Christ, trusting in the guidance of the Holy Spirit, the promised counselor. Christian counseling draws on spiritual resources such as biblical texts, prayer, songs, liturgical material, and the sacrament of Holy Communion for freeing, empowering and nurturing wholeness within the church as the body of Christ. (For further biblical resources see appendix 3.)

At the core of counseling is the good news of God acting in Christ, through the power of the Holy Spirit, to bring new life in the midst of human suffering. It is the encounter of ordinary human beings, walking together in mutual respect, in order to understand and clarify their situation, and to find wholeness in the midst of suffering. It is a sacred journey of sinful and weak human beings who are searching for answers, healing and restoration. Jesus Christ joins us on this journey, and reveals to us the hidden mysteries of God. In the conviction that this disease plagues us all, we accompany other human beings through distress, deep emotional and spiritual difficulties, anger, doubts, fears, and feelings of abandonment.

Pastoral care and counseling means moving **toward rather than away from our neighbors who are infected and affected by HIV and AIDS.**

Goals and objectives

The overall goal of this ministry is to make the good news revealed in Jesus Christ real or tangible. Thus, people become means of hope and strength for each other, while pointing to God as the source of help and healing.

In the story of Moses and the Israelites, the people were plagued by poisonous snakes in the wilderness. God did not take away the snakes, but commanded Moses to make a bronze serpent and set it on a pole so that in looking at the snake they would not die but live (Num 21:1–8). Similarly, Jesus was nailed on the cross, the symbol of death, and there defeated the powers of evil and suffering and won freedom from death for us all. This is the message that pastoral care proclaims and lives out (see Mt 8:16–17 and Mk 9:25–26). In this sense, the ministry of care is a human encounter through which we meet the crucified and risen Christ.

Key objectives of spiritual care and counseling in the contexts of HIV and AIDS:

- Ensure that human dignity is upheld and the sanctity and quality of life are promoted
- Strengthen human solidarity by providing all possible human support so that no one is despised or left alone because they are HIV-positive
- Console, strengthen and encourage people to place their hope in Jesus Christ who overcomes the powers of evil and death
- Encourage all persons to take the necessary preventive measures to avoid either spreading the virus (if they are carriers), or contracting the virus (if they are not infected).

What to avoid

The ministry of care and counseling is not about telling others what to do, giving directives, or prescribing answers. People living with and affected by HIV and AIDS require respect, acceptance, trust, and genuine compassion. These approaches open up space for suffering persons to be more open and to share their stories. Thus, both the one telling the story as well as the one listening are better able to understand the situation.

The ministry of care and counseling is not about talking but listening.

In providing care and counseling, we must not assume a stance of superiority or self-righteousness. Job's friends thought they were carrying out good pastoral care by insisting that Job was suffering because of his sin. They demanded that Job confess and repent (Job 4 and 11). The more they insisted, the more Job defended his innocence, thus creating a distance between himself and his friends. Their intentions were good, but their approach was wrong.

People who are suffering or grieving may want to repeat telling their stories; this requires patience and the ability to listen. It may occasionally be appropriate to share personal experiences in order to affirm the voices of those suffering, but the conversation should not center on such personal stories. Whenever counselors feel the need to be heard, they should seek assistance from others.

Preparing to provide care and counseling

- **Accurate, timely information:** The lack of correct information about HIV and AIDS has led to untold suffering. It is therefore important to review and, if necessary, update the medical facts in the first chapter of this handbook. Church members and others in the community must continue to educate each other on the ways in which the virus is transmitted, effective preventive measures, psychological, social, and theological issues related to the pandemic, and on how to respond. It is also important to understand the local situation facing persons living with and affected by HIV and AIDS, including the availability of medical care, counseling and testing centers, support groups and networks. Also relevant are specific economic, social and cultural factors that may complicate the impact of the virus.
- **Confronting our own fears and doubts:** Any lingering fears of being with or among persons living with and affected by HIV and AIDS must be dealt with beforehand, especially those that perpetuate stigmas and discrimination.
- **Prayer and spiritual reflection:** Mutual ministry in this area requires continuous reflection and meditation. This includes praying to God for guidance so that those suffering and those providing care may discover meaning in the situation.

Important qualities

- **Acceptance and warmth:** Provide a welcoming environment where everyone feels accepted, loved, safe, and free to share their stories. Conveying compassion builds trust. This encourages people to speak freely about the painful issues in their lives, and can foster healing, forgiveness, reconciliation, and restoration.
- **Build trust:** Nurture an open and trusting relationship for the sake of safe and confidential dialogue. This makes it possible for persons to open up, and to let others enter into their life story. Building a relationship of mutual trust involves defining the objectives of the relationship, its process, boundaries, and the expected outcome.
- **Confidentiality:** Maintaining confidentiality is a basic principle in counseling. People open up their lives to others, trusting that their stories will

not be shared or become the subject of gossip. When people are not sure that their concerns will remain confidential, they are likely to close the doors to their lives. Exceptions to this include life threats, violent abuse, when a person is suicidal, or in danger. In these cases, the person should be informed of the need to bring the matter to the attention of others for further assistance.

- **Sensitivity to language:** Language and non-verbal expressions should convey respect and dignity for others and create confidence rather than distance between people. Avoid using language that reinforces stigma and discrimination. Keep abreast of the changing terminology and understandings regarding HIV and AIDS.
- **Self-awareness:** Be aware of your own strengths, weaknesses and limitations and your ability to manage your grief and emotions. Being open to learning and growing strengthens mutual trust. The quality of care we provide is affected by our personal fears, prejudices, assumptions, level of comfort with those living with the virus, how well-informed we are about the virus and our understanding of faith.
- **Focus on the other person:** It is important to differentiate between the disease and the person affected by the disease. The campaign is not against persons, but against the virus and its related challenges. Keep the focus on the person and how they would like to move on.
- **Compassion:** Being compassionate does not mean feeling sorry for or pitying others. It implies a loving presence, a deep sense of care and the hope that healing and wholeness will come about. Compassion is a willingness to be a channel of God's grace while standing alongside people who are hurting. It is expressed through gentleness, kindness, acceptance, and love.
- **Affirm the dignity and worth of all people:** In Jesus' day, persons suffering from leprosy were considered ritually impure and socially excluded. Consequently, when Jesus touched those affected by leprosy, he made himself ritually impure. Still today, people living with and affected by HIV and AIDS are sometimes treated as if they too had leprosy. Instead, like Jesus we need to affirm the dignity and worth of all persons, as loved by God.

Stigma and discrimination must be confronted

Being infected with HIV is commonly associated with sexual immorality, commercial sexual activities, sexual promiscuity, intravenous drug abuse, and in some contexts with homosexual, bisexual, or other non-heterosexual activity. Because of these associations, those living with and affected by HIV and AIDS are stigmatized and subjected to discrimination or exclusion. Some even consider people living with and affected by HIV and AIDS as having been punished by God for their sins. When stigma and discrimination lead to people refusing to shake hands with HIV-positive persons, or to share the Holy Communion cup with them, this becomes a form of apartheid that must be confronted and vigorously rejected.

Stigmas related to HIV and AIDS build upon and reinforce existing prejudices and social inequalities based on gender, sexual orientation, or race. Stigmas cause some groups to be devalued and others to feel morally superior. Stigma and discrimination breach fundamental human rights: often people lose their jobs, or are rejected by family and friends. Families sometimes blame relatives who are infected for bringing shame or dishonor upon the family.

A climate is created in which people become more afraid of being stigmatized and discriminated against than they are of the disease itself.

Transforming stigma and discrimination

Turning stigma and discrimination into care and counseling is one of the greatest challenges. Experiences and perspectives of those living with and affected by HIV and AIDS must be heard and drawn upon in countering stigma. Only when the church has changed its attitude with regard to persons living with and affected by HIV and AIDS, and raises its voice against discriminatory attitudes, will its witness in this area be credible.

Any interpretation and representation of biblical texts that encourage stigma and discrimination must be challenged and reinterpreted. Look again at Jesus'

Stigma and discrimination together constitute the greatest barrier to combating the epidemic, and continue to fuel it globally.

"I had to love myself first. I had to get rid of my own stigmas first, before I could deal with the stigma of others."

ELCA News Service,
22 November 2006,

at WWW.ELCA.ORG/NEWS/RELEASES.ASP?A=3489

encounters and acceptance of persons who were stigmatized and treated as impure or sinners:

- To a person suffering from leprosy and thus treated as an outcast, Jesus “stretched out his hand and touched him” (Mt 8:3)
- To a despised Samaritan woman at the well, Jesus said “Give me a drink” (Jn 4:7)
- To Levi, a tax collector, considered one of the worst sinners, Jesus said “Follow me” (Mk 2:14)
- To a woman suffering from menstrual bleeding and thus considered ritually impure, Jesus said “Take heart, daughter; your faith has made you well” (Mt 9:22).

In light of these examples, the church, as the body of Christ today, must also embrace and stand with human beings who are suffering from any illness. Talking openly about its harm can break the cycle of stigma and discrimination. Therefore,

- Urge people to think about how they have experienced discrimination and stigma and how they felt about it
- Ask persons living with and affected by HIV and AIDS to share how stigma and discrimination have affected their lives
- Ask how they have coped with stigma and discrimination. What was or was not helpful?
- Explore how stigma and discrimination related to HIV and AIDS can be eliminated from society.

The importance of being tested for the virus

Out of fear of being stigmatized, people often prefer to ignore their actual or possible HIV status. This leads to further progression and spread of the virus. People are deterred from getting tested, or from disclosing their positive status, or from taking action to protect others, or from seeking treatment. They may also stigmatize themselves, lose their sense of self-worth, curse themselves, or completely cut themselves off from the community.

Individuals and families are strongly encouraged to go for testing, but they do not have to disclose their status to others. Those who are HIV-positive should not be

required to announce publicly that they are infected. People who discover that they are HIV-positive need to be accompanied as they deal with related emotions, seek the treatment they need and take precautions against spreading the virus to others.

Drug use and addiction

Spiritual care for persons addicted to drugs and living with and affected by HIV and AIDS requires understanding the dynamics of addiction and the pain experienced by those struggling with drug abuse. For some people, drug abuse may constitute a way of resolving personal struggles related to social, familial, or personal issues. It is therefore helpful to try to enter their world, to listen to their stories and to understand their perspectives in order to discover a way forward through dialogue.

Sexual lifestyles

Persons providing spiritual care and counseling are expected to be welcoming of all, including those leading different lifestyles. A loving presence, a willingness to accompany persons and to clarify their situation and to dialogue in search of possible solutions are crucial. Some of the issues surrounding their lifestyles may also need to be addressed, but the ministry of care and counseling is not about judging someone on the grounds of their lifestyle. Rather, all persons are to be seen in the first place as children of God. Just like heterosexuals, homosexuals or bisexuals are persons of sacred worth. They deserve the same ministry of care and counseling in their struggles for human fulfillment, as well as the spiritual and emotional care of the church community that nurtures positive relationships with God, with others and with self.

Cultural practices need to be reassessed

Culture is an aspect of human social identity and solidarity. Nevertheless, it can be a stumbling block to responding to the challenges of HIV and AIDS, especially when culture reinforces stigma and contributes to the spread of the virus. Some of the cultural factors (see chapter 2) include: gender inequality, sexual violence, sexual exploitation of women and girls, female genital mutilation, multiple sexual partners (including polygamy), sex as proof of “manhood,” and the alarming and false belief that sex with a virgin can cure HIV-infected

All cultural values need to be evaluated in terms of whether or not they preserve life.

persons. These practices must be challenged and confronted by the church's witness to the gospel of liberation and abundant life for all.

In some cultures, talking about sexual matters is a taboo subject. Parents have difficulty talking to their children about sex. According to some traditions, a widow mourning the loss of her husband has to be "cleansed," meaning that a brother or another close male relative of the deceased has to have sex with her. Cultural customs such as these must be challenged and reinterpreted, especially in the contexts of HIV and AIDS.

The sanctity and dignity of human life are more important than the preservation of cultural values. It is for this that Christ suffered and died. In the Parable of the Lost Sheep (Lk 15:1–10), Jesus taught us that one endangered human life is so important that God would leave the 99 others to search for and restore the one lost and in danger.

Alienation

Persons living with and affected by HIV and AIDS often experience isolation and alienation from others as a result of stigma, feelings of guilt and condemnation from both church and society. Some may separate themselves from the church and community. Too often, persons living with and affected by HIV and AIDS are avoided out of fear, prejudice, or moralistic interpretations of the disease, as are their families, relatives and close friends. The entire Christian community is responsible for challenging judgmental attitudes, and for breaking down walls cutting us off from others (Eph 2:14).

Feeling alienated from others can lead to feelings of being alienated from God. The church must reach across the walls of fear and moral judgment and bear witness to Christ's reconciliation. As St Paul wrote, "in Christ God was reconciling the world to himself, not counting their trespasses against them, and entrusting the message of reconciliation to us" (2 Cor 5:19).

Shame and guilt

Persons may blame themselves for becoming infected, or attribute their suffering to divine punishment. This then is compounded by judgmental attitudes in church

and society. Consequently, people living with and affected by HIV and AIDS can be tormented or torment themselves with feelings of guilt and being damned.

Crucial here is the gospel of God's grace. People who feel guilty and responsible for becoming infected need to hear and experience God's mercy and forgiveness. This is at the center of spiritual care, offering release from shame and guilt and the promise of a new life in Christ.

This does not mean ignoring a person's deeper spiritual struggles. Recognizing and talking about the source of the shame and guilt will enhance the significance of forgiveness. Otherwise, grace might be applied as a balm rubbed on a wound without first cleaning or caring for the depth of the wound.

Why has this happened to me?

Emotional and spiritual distress may cause persons living with and affected by HIV and AIDS to ask, Is my HIV-positive status a result of sin and punishment of God? or, What have I done? There are no easy answers to these questions. The biblical story of Job shows how the "why" questions became more complicated when Job's friends tried to give the right answer.

While human choices or decisions have consequences, inferring that people suffer from HIV and AIDS because of their sin is likely to increase stigma and discrimination, and to impede efforts to respond to those living with and affected by the virus. Therefore, pastoral care should focus on Jesus' promise to forgive and to heal, rather than trying to answer the question of "why."

Funerals as opportunities for counseling and care

On occasion, funeral services for people known to have died of AIDS have been arranged differently, and in some instances pastors have not worn the same clerical garb as for other funerals. Such discriminatory practices heighten fear, isolation and alienation and must therefore be challenged.

In some communities, the impact of HIV and AIDS is especially evident in the number of people dying. Because of the overwhelming number of funerals that

had to be carried out in some congregations, church leaders have had less time and energy to carry out their other ministerial responsibilities. Funerals provide important opportunities for pastoral care as friends and families need support, comfort and the message of hope in Jesus Christ.

The kind of language used in the funeral service is crucial. The church's liturgies should incorporate texts, songs and silence for people to express their grief and to cry out to God, as exemplified in the Psalms of lament. The liturgy should also encourage people to look beyond the grave to Christ who has overcome death.

In some places, a new culture of funeral practices has developed. A "proper funeral" means very expensive coffins, elaborate entertainment involving "special guests" and other extravagant expenses. Resources that could assist surviving widows, children and other dependents are wasted, literally buried with the dead, and survivors are left with huge debts. Christian communities need to reflect on what these practices mean for their faith in God and their love for the neighbor. What alternative practices could better express their love for the deceased and solidarity with those left behind? Are expensive funerals for the sake of the dead or the living? How can our love be expressed while people are still alive rather than after they have died?

Some counseling skills and techniques

Listening

Each person is accompanied by joys and sorrows known only to themselves. Too many spoken words can actually be an enemy to understanding. First, the real feelings and struggles of the person may be distorted or concealed through word games. Second, we may miss an important opportunity to be truly present to the other person. Third, too many spoken words may cloud or cover the presence of Christ who comes as a hidden, holy visitor.

Through listening, we journey with those whose lives have been affected by the HIV and AIDS pandemic, and facilitate healing and the restoration of human dignity. Attentive listening enables people to share their stories freely and to seek meaning and new directions for their lives. Being fully present psychologically, socially and emotionally involves not just the ears, but also the heart.

Attentive listening involves:

- **Understanding and interpreting both verbal and nonverbal messages:** Stories of people’s sufferings are usually a mixture of emotions and experiences. Listen carefully, try to understand people’s different experiences and feelings and pay special attention to nonverbal messages (body language) such as facial expressions, tone of voice, body movement, and reactions. Attention should be paid so as not to distort, over-interpret, or read meanings into what is being expressed.
- **Attending to the overall the context:** Pay attention to the whole person in relation to their social, cultural, political, and economic situation, and how these factors impact their condition.
- **Listening with empathy:** Be attentive to and as fully present with the person as possible. Empathic listening is a way of stepping into another person’s situation, trying to understand it as such and reflecting back what is being heard.

Other listening techniques include: facing the person squarely, adopting an open posture, leaning toward the person, maintaining eye contact, and being relaxed. Listening focuses on the subject of the conversation, summarizing what is being heard and checking to be sure that it is being understood.

Asking questions

Questions must be asked sensitively. The purpose of asking questions is to help the person, not to satisfy our curiosity. Asking how the person became infected is *not* a helpful or necessary question. Even where there may be issues related to lifestyle that should be addressed in counseling, one should not insist on finding out how a person contracted the virus.

Open-ended questions, such as the following, are more engaging:

- “Tell me about your fears and how you felt when you were going for the test”
- “Share with me your first reactions when you found out that you (your spouse, partner, child, etc.) were HIV-positive”

- “I heard you say that you are angry with your husband (wife, partner, son/daughter, pastor, God). Could you say more about that?”

When you feel nervous, stuck, or unsure about what to say next, it is fine just to bring the dialogue to a close. For example, you could say, “Thank you for sharing your life story. Maybe you can share with me how you feel right now, and how you want us to close our discussion for today.”

Confronting or challenging

Confronting or challenging may be needed in order to go deeper into what is being said. It is crucial that the person not be frightened. This involves giving them the opportunity (and perhaps encouragement) to explain what they are saying or to point out what seems inconsistent. The aim is to clarify any ambiguities. Examples of this would be when a person appears to be blaming others, is hesitant to take action, seems to avoid certain issues, makes excuses as to why certain things cannot be changed, or when what they are saying is unclear.

Setting goals

It is important for persons living with the virus to be able to cope and live a meaningful life. Encourage them to set some goals by taking the following into account: What do they want to do? How can they do this with the resources available to them? Who will accompany them? The goals should be clear, realistic and measurable. Explore the possible obstacles to reaching these goals.

Persons living with and affected by HIV and AIDS need to explore how they can live positively and with dignity. This can occur through open dialogue, by exploring such matters as what it means to go for testing, accessing treatment, dealing with issues of acceptance, informing their spouse or partner about their status, reconciliation with family or relatives, or practical needs such as material support.

Focus on life and hope

Living with any chronic illness means having to face one's own mortality. Fear of death is part of what it means to be human and needs to be addressed. However, the focus of care and counseling is not so much on the inevitability of death, as on how to live a meaningful life. Because of Jesus Christ, the church

is a community of hope. Jesus' resurrection brings hope in the face of death. As St Paul declares, "If we live, we live to the Lord, and if we die, we die to the Lord; so then, whether we live or whether we die, we are the Lord's. For to this end Christ died and lived again, so that he might be Lord of both the dead and the living" (Rom 14:8–9).

Acknowledge limits

Dealing with wills, medical complications, grief, and guilt, as well as practical needs such as accessing drugs, food and children's school fees can feel overwhelming. Acknowledging one's limits is a sign of strength rather than weakness. Instead of saying, "I know how you feel," a more positive responses would be, "I hear your pain," "I feel sad for you ...," or "I understand that this is a difficult time for you, but I am here for you."

If one is unsure as to what to say or do, it is better to acknowledge one's limits and to refer the person to someone in a position to provide further assistance. Persons living with and affected by HIV and AIDS may also be able to provide counsel on how to move forward in dealing with the complex emotions involved.

Bring closure

It is important from the beginning to identify issues that need to be addressed in order for the person to cope, and to know when to stop the counseling relationship. It is tempting for those who engage in this ministry to feel they are needed and thus to continue indefinitely. Although some situations may require counseling for a few sessions, there should be strategies so that those accompanied are encouraged to "stand up and walk," or find continuing care and support from family and others.

Spiritual care for those who provide care

Accompanying another person in their suffering is difficult; it takes energy and can be tiring and frustrating. Therefore, those who provide care also need to care for themselves, and receive care from others. Jethro warned his son-in-law Moses, "You and the people with you will wear yourselves out, for the thing is too heavy for you; you are not able to perform it alone ..." (Ex 18:18). Jethro's wisdom reminds us to care.

Caring for oneself means taking the time and space to deal with frustrations and emotions experienced in the process of providing care. This could include prayer, Bible study, or sharing with someone who cares (with sensitivity to confidential matters). Jesus modeled this by often withdrawing by himself or with his disciples to a quiet place to reflect, pray and find new strength (Mk 6:31; Jn 8:28).

Care providers need the presence and accompaniment of others. Being with people as they undergo testing, caring for those living with and affected by HIV and AIDS, accompanying those who are ill, their spouses, partners and children left alone, walking with grieving parents, conducting funerals, and consoling those who are grieving—these are heavy responsibilities. They can easily lead to exhaustion. It is therefore important that each person engaged in these responsibilities also has someone with whom to share their deep feelings, someone to pray for them, and a space to be human and to relax. (See also appendix 4.)

Resources for this chapter

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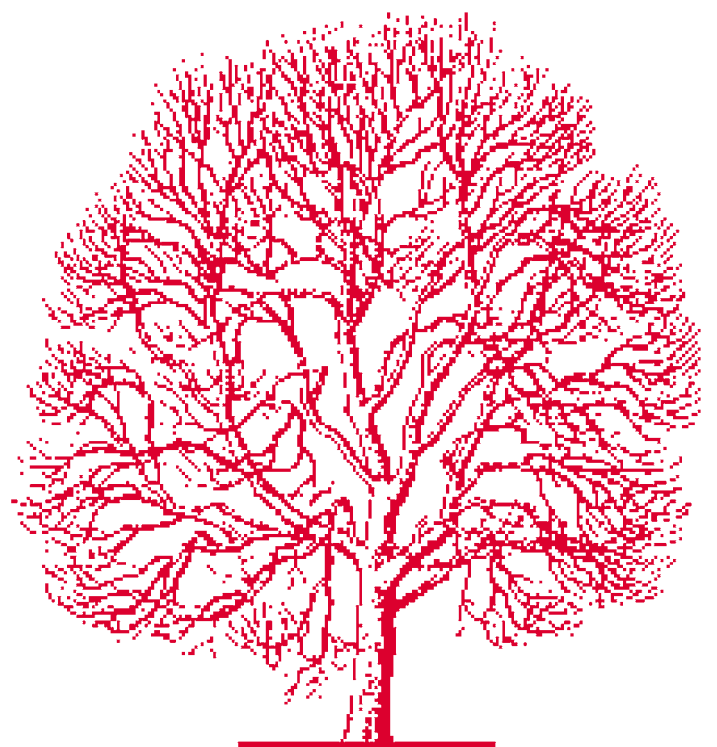
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UNAIDS, *Uniting the World Against AIDS*, at www.unaids.org/en/ISSUES/PREVENTION_TREATMENT/STIGMA.ASP

USA for Africa, *HIV/AIDS Stigma and Discrimination*, at www.usaforafrica.org (site currently under re-development)

Chapter 5: Home-Based Care



Home care is the provision of health care by formal and informal caregivers in the patient's home, rather than a hospital, and includes physical, psychosocial, palliative (easing of symptoms), and spiritual activities.

By providing high-quality and appropriate care, the aim is as far as possible to maintain the patient's independence, and to achieve the best possible quality of life. Home care is less expensive and can be easier on the patient, who does not have to travel long distances to seek care in a hospital, but can be cared for in familiar surroundings. Many illnesses and infections associated with HIV and AIDS can be managed at home if caregivers have some basic information, which is what we seek to provide in this chapter.

Ideally, the caregiver is trained to provide care and support services, either as a volunteer or a paid worker, and is linked to a health facility or health care professional for expert support, referral, monitoring, supervision, and supplies. Most of the work is done by the caregiver. Health care professionals provide additional support through supervision, training and managing more complex health situations. It is important for caregivers to be able to draw on other community resources in their area, such as hospitals, clinics, community-based care and support groups, traditional healers, and trained health workers.

Patients suffering from chronic illness such as AIDS have several needs including physical, psychological, social, and spiritual needs.

Physical needs

A caregiver should ensure that patients receive treatment for their ailments and appropriate nursing care. Nutrition is very important and the patient should be given a well-balanced daily diet. Hygiene is equally important to prevent infections. The patient and family members should be educated to practice basic hygiene, e.g., teeth, hair, skin, and home. Patients should get regular physical exercise. If the patient is too weak to do so, family members should assist the patient in doing passive exercises by gently moving their limbs.

Psychological needs

Patients suffering from chronic or terminal illnesses may have many worries and fears. Caregivers should encourage patients to express themselves, and identify alternative solutions for dealing with these.

Social needs

Because patients often suffer from loneliness and sometimes neglect, it is important for caregivers and family members to interact with them socially and through recreational activities. Patients need to be included in decision making discussions regarding anything that affects them.

Spiritual needs

Chronically ill patients may lose hope and the will to live. Caregivers should reassure them that every minute of their lives has a purpose, and focus on discovering what they can still do.

- Remind patients that they are persons of sacred worth and loved by God
- Reaffirm that death, whenever it may come, is not the final word for those who trust in God's promises (see chapter 4 and appendix 3).

The key role of caregivers

Home-based caregivers have significant responsibilities. They maintain the patient's quality of life and provide care and support services. They also provide HIV prevention information, education and communication services to individuals, families and communities. Besides having accurate, timely knowledge of the disease (see chapter 1), a caregiver should understand how to deal with the patient's hygiene, the cleanliness of their home and how to prevent infections and injuries. It is critical to know about the person's needed medicines, recommended nutritional guidelines and how and whom to call for information or in the event of an emergency.

It is important for the caregiver to make regular contact with patients and to help them avoid unnecessary hospital admissions. Caregivers also need to provide emotional support, help with activities of daily life (e.g., feeding, bathing, dressing, toileting, and household activities), provide basic medicines and supplies, store all medicines and supplies safely, and know when to refer patients who can no longer be cared for at home to another setting. Caregivers should furthermore document key activities in the patient's record, and assist with management of financial, legal, or other inheritance matters (e.g., preparation of a will) as requested by the patient.

Advantages of home nursing

Home nursing refers to any form of care given to sick people in their own homes, including physical, mental and spiritual support. The advantages of nursing patients at home are:

- Patients have less chance of contracting other infectious diseases
- Patients continue to live with their families
- Patients are cared for in a relaxed, familiar atmosphere
- Patients are kept in good company and feel more loved
- Family members often provide the best compassionate care
- The trauma of witnessing death in a hospital setting is avoided
- Confidentiality is observed and maintained.

Managing common conditions resulting from HIV and AIDS

Fever

Fever is a condition where a person's body temperature reaches more than 38°C. Low-grade HIV and AIDS fevers (37–38°C) often come and go, but fevers higher than 38°C can be dangerous if left untreated. In adults, it may cause confusion or delirium, and in children, fits or seizures. In both, it can result in dehydration (loss of body water). The fever may be caused by the HIV infection itself, or by related diseases such as malaria, tuberculosis, or pneumonia. In many instances, the cause of the fever is unknown.

In case of fever: keep the patient clean, give the patient a lukewarm bath or wipe the patient's body with a wet cloth, ensure privacy during bathing, and cover patient only with light bedding. Give plenty of fluids, i.e., water, tea, or juice. Give patient fever medication such as Paracetamol/Panadol or Aspirin every 4 hours with meals until fever disappears, but for no more than 3 days unless the doctor agrees. Follow directions on package or prescription label carefully. Do not exceed maximum dose of 8 (500 mg) tablets Paracetamol in 24 hours. Please note: children with a fever should not be given Aspirin, unless prescribed by a doctor.

In the following situations, the patient needs to be referred to the nearest health facility:

- The fever does not go away in 2 days with suggested treatment
- The following signs accompany the fever: stiff neck, severe body pains, persistent cough, unconsciousness, yellow eyes, sudden severe diarrhea, and fits
- The patient has recently delivered a baby or aborted.

Diarrhea

Diarrhea is the passing of loose or watery stools (feces, bowel movements) more than 3 times a day. In most people, it occurs at some stage of HIV infection. It can be very distressing to the person and lead to serious complications caused by dehydration. Some of the symptoms and signs of advanced dehydration include dry mouth, sunken eyes, poor urine output, confusion, and loss of consciousness.

An oral rehydration solution (ORS) can be very helpful. It comes in sachets and needs to be mixed with clean water. ORS can also be prepared at home by dissolving 1 level teaspoon of salt and 8 level teaspoons of sugar in 1 liter of clean drinking or boiled water and then cooling it.

In case of diarrhea: give plenty of fluids, e.g., clean water, soup, juices, porridges, and avoid caffeinated drinks such as tea and coffee, very sweet drinks and alcohol. Provide ORS and encourage patient to drink and eat as much as possible. Offer nutritious foods frequently. Check for severe dehydration, e.g., dry mouth, sunken eyes and loss of skin elasticity. Change and wash soiled linen and use gloves when handling contaminated items.

In the following situations, the patient needs to be referred to the nearest health facility:

- Severe dehydration (dry appearance inside the mouth, decreased urination, urine is dark, lightheadedness, restlessness, arms or legs feel cool to the touch, rapid heartbeat, inability to stand or walk, loss of consciousness)
- Persisting diarrhea
- Inadequate food intake—patient is too weak to eat
- Passage of blood in the stools
- Presence of high fever (over 38°C).

Nutritional recommendations for countering diarrhea:

- Encourage the drinking of 8–10 cups of liquids per day to prevent dehydration. Carrot soup helps to replace vitamins and minerals, contains pectin, soothes the bowels, and stimulates appetite
- Eat foods such as boiled white rice and potatoes that travel slowly through the gut and decrease the stimulation of bowel movements
- Eat bananas and tomatoes (bananas for their potassium)
- Eat 5–6 small meals rather than 3 large ones
- Add nutmeg to food
- Eat food at room temperature. Very hot or cold foods make the diarrhea worse
- Avoid foods high in fiber (e.g., take the skin off fruits and vegetables)
- Avoid fried foods
- Avoid sweet drinks and provide diluted juices instead
- Avoid milk products; intake may worsen diarrhea for some patients. Yogurt is better tolerated.

Pain

Some conditions related to HIV and AIDS result in a lot of pain and discomfort. The most common causes for pain are:

- Sensory peripheral neuropathy (nerves are inflamed)
- Headache due to chronic infection of brain coverings
- Herpes zoster (shingles)
- Malaria
- Thrush (a fungal infection of the mouth and/or genitals)
- Extensive Kaposi's sarcoma
- Infection of joints (arthralgia)
- Muscle pain (myalgia)
- Chest pain
- Anorectal pain
- Painful dermatological conditions.

In case of pain: help the patient to change into comfortable position, talk with them and provide activities to allay anxiety. Be patient, loving and understanding. Gently massage sore muscles, apply hot or cold compresses and give patient a warm bath. Give painkiller medication such as Paracetamol/Panadol or Aspirin every 4 hours with meals until fever disappears, but for no more than 3 days unless the doctor

agrees. Follow directions on package or prescription label carefully. Do not exceed maximum dose of 8 (500 mg) tablets Paracetamol in 24 hours. Please note: children with a fever should not be given Aspirin, unless prescribed by a doctor.

In the following situations, the patient needs to be referred to the nearest health facility:

- Pain becomes severe
- New symptoms arise, such as headaches, neck stiffness and fever.

Cough and breathing difficulties

Throat or chest irritation due to infections of the throat and lungs can result in persistent coughs. A person may also experience difficulty breathing. Possible causes of cough and difficulty breathing:

- Pulmonary tuberculosis (TB)
- Bronchitis (inflammation of the main air passages to the lungs)
- Pneumonia (an inflammation of the lungs caused by an infection)
- Allergies
- Asthma
- Heart problem
- Fluid in the chest
- Foreign body in the wind pipe or lungs
- A worm infestation in the lungs.

In case of cough and breathing difficulties: place patient in well-ventilated room in a propped up position—leaning forward and resting arms on a table may help. Use extra pillows or some back support. Sit with the person and do not leave them alone (breathing difficulties can be very frightening). Talk with and counsel the patient. Provide steam inhalation if possible—use local remedies such as menthol or eucalyptus leaves. Give adequate fluids (it loosens sputum) and throat soothing remedies, e.g., honey or hot lemon juice. Gently hitting or thumping the person on the chest and back with cupped hands helps loosen sputum and makes it easier to cough.

Patients need to be referred to the nearest health facility if they:

- Do not respond to treatment
- Develop a high fever

- Experience severe chest pains, discomfort and breathlessness
- Cough up blood
- Have foul smelling phlegm.

Tuberculosis (TB)

Tuberculosis, a common infection in persons with HIV and AIDS, is a chronic infectious disease caused by a mycobacterium (a type of germ). It usually affects the lungs and sometimes other organs. It needs to be diagnosed by a professional clinician. Signs and symptoms of TB include:

- Productive cough for more than 3 weeks with or without blood stains
- Weight loss
- Night fever and sweats
- Chest pains
- Loss of appetite
- Swelling of the lymph glands (glands in the neck, groin, etc.)
- Painful joints
- Prolonged backache.

In case of TB: encourage patient to take treatment exactly as prescribed. Provide adequate fluids and nutritious food, ensure adequate intake of fluids, ensure that patient is not drinking alcohol or smoking, and discourage the patient from doing excessive and tiring work. Make sure that the patient sleeps in a well-ventilated room. Provide support for the patient to sit up. Advise the patient always to cover the mouth when coughing and provide a covered container into which the patient can spit. Sputum should be discarded into a latrine/toilet, or buried. Encourage patient to comply with Directly Observed Treatment (DOT).

DOT is the process during which the TB patient takes every dose of the medication under the direct observation of health care professional. DOT is an internationally strongly recommended strategy as a most effective measure in the control of TB. By using DOT, TB patients can be provided the necessary support to complete the whole course of treatment.

In the following situations, the patient needs to be referred to the nearest health facility:

- There are no signs of improvement

- Patient vomits after taking drugs
- New fevers or breathing difficulty develop
- The patient stops taking treatment or refuses DOT.

Skin conditions

Skin conditions mostly affect the surfaces of the body. A person with HIV and AIDS often suffers from chronic rashes, itching, or painful skin sores. Possible causes include:

- Allergic reactions
- Heat rash
- Herpes zoster virus infection (shingles)
- Scabies (a skin infection caused by tiny insects)
- Poor hygiene
- Bed-wetting or diarrhea
- Bedsores (caused by lying in one position for a long time)
- Measles
- Kaposi's sarcoma.

In case of skin conditions: bathe patient regularly with warm water and soap (one tablespoon of vegetable oil in 5 liters of water can be used while washing the person), keep skin clean and dry, cool the skin or fan it, avoid heat and hot water on the skin. Cut finger nails short, keep them clean to avoid infection, and avoid scratching. In case of itchy skin, try rubbing with cucumber or wet tea bags (or tea leaves put in a clean piece of cloth and soaked in hot water). Apply gentian violet (topical antifungal and antibacterial agent) to open ulcerations. Apply appropriate prescribed skin lotion, e.g., Whitfield's (benzoic acid) or Calamine lotion. If allergy is identified, avoid the cause (e.g., a drug, soap, or food). Clean open wounds with mild, salty, water, apply a clean dressing daily and apply a prescribed skin lotion. Encourage patient to eat enough nutritious food. If patient experiences pain, give painkiller medication such as Paracetamol/Panadol or Aspirin every 4 hours with meals until fever disappears, but for no more than 3 days unless the doctor agrees. Follow directions on package or prescription label carefully. Do not exceed maximum dose of 8 (500 mg) tablets Paracetamol in 24 hours. Please note: children with a fever should not be given Aspirin, unless prescribed by a doctor.

In the following situations, the patient needs to be referred to the nearest health facility:

- A fever develops
- Wound becomes infected
- Pain worsens
- Bleeding starts
- Infected areas become swollen and hot
- The patient does not respond to treatment.

Conditions of the mouth and throat

Soreness in the mouth and throat causing painful swallowing is common among persons living with HIV and AIDS. Possible causes of mouth and throat conditions include:

- Thrush (ulcers/white patches in mouth and throat)
- Herpes simplex infection (cold sores)
- Cracks and sores in the mouth
- Malnutrition.

In case of mouth and throat conditions: encourage mouthwashes and gargles (dilute a pinch of salt in a glass of water, or ½ teaspoon of baking powder in ½ liter of water) if there are white patches in the mouth. Use a soft toothbrush or stick to remove debris. If available, mix 2 tablets of aspirin in water and rinse mouth up to 4 times a day. If thrush is present, apply 1% oral gentian violet solution every 8–12 hours. Encourage patient to take plenty of fluids and give nourishing diet. Help patient to maximize food intake during this period by avoiding citrus fruits, acidic and spicy foods, eating foods at room temperature or cold, eating soft and moist foods (e.g., porridge, potatoes, honey, cold milk, etc.), avoid caffeine and alcohol. If patient experiences pain, give painkiller medication such as Paracetamol/Panadol or Aspirin every 4 hours with meals until fever disappears, but for no more than 3 days unless the doctor agrees. Follow directions on package or prescription label carefully. Do not exceed maximum dose of 8 (500 mg) tablets Paracetamol in 24 hours. Please note: children with a fever should not be given Aspirin, unless prescribed by a doctor.

In the following situations, the patient needs to be referred to the nearest health facility:

- Patient is unable to swallow
- Patient is unable to breathe properly
- Patient is dehydrated
- A high fever develops
- Patient does not respond to treatment.

Depression

Depression can develop in the case of any physical illness, especially HIV and AIDS, due to the nature of the disease and the associated stigma and discrimination. Several factors work together leading to a person becoming depressed. In the case of patients with HIV and AIDS, these can be environmental and emotional factors, such as attitudes of family members and society, hostilities, isolation, grief due to loss of a family member, job, or income due to their HIV status, and having to face the inevitability of death. One must remember that depression is a result of biological changes in the chemistry of the brain, and one can also be depressed due to genetic or familial disposition.

Depression is a condition when a person feels very low and when symptoms such as the following last for over two weeks:

- A persistent sad, anxious, or empty mood
- Loss of interest or pleasure in life
- Feelings of guilt or low self-worth and self-esteem
- Disturbed sleep and/or appetite, decreased energy, or continual fatigue
- Low energy and poor concentration.

These problems can become chronic or recurrent and lead to substantial impairment in the individual's ability to take care of their everyday responsibilities.

In case of depression: provide a safe environment for the person and involve the person in daily activities whenever possible. Encourage friends to visit and the patient to talk frequently about your problems to someone they trust. Encourage the person to mix with others, especially peers and people living with and affected by HIV and AIDS. Chat regularly with them, and encourage them

to talk about their worries. Offer counseling services, including spiritual guidance. Ensure that the patient has all physical problems diagnosed and treated.

In the following situations, the patient needs to be referred to the nearest health facility:

- Patient is withdrawn
- Patient does not eat
- Patient shows suicidal tendencies
- Patient complains of lack of sleep.

Antidepressant medications and brief, structured forms of psychotherapy are effective for 60–80% of those affected and can be delivered in primary care. However, fewer than 25% of those affected (in some countries fewer than 10%) receive such treatments. Barriers to effective care include the lack of resources and lack of trained providers, as well as the social stigma associated with mental disorders such as depression.

Pressure sores

Pressure sores (e.g., bed sores) develop when a person's body has been in the same position for a long time. These ulcers develop due to an inadequate blood supply to an area of the skin, which causes the skin and underlying tissue to break down and die. They commonly develop on the elbows, hips, ankles, sacrum (small of the back), or the heels, and are very difficult to heal. Possible causes of pressure sores include:

- Prolonged pressure: when the patient is in the same position for a long time
- Friction: due to wrinkled bedding, food crumbs, or rough handling of the bedpan
- Moisture: due to inadequate cleaning of the body after urinating or a bowel movement.

Persons prone to developing pressure sores include those who have been sick for a long time and whose general condition is very poor, those with unhealthy tissue, those who are paralyzed and lie in the same position for a long time, and those who are helpless and unconscious.

In case of pressure sores: turn the patient regularly from side to side and massage the pressure areas every few hours. Encourage passive and active exercise and gently move the arms and legs several times a day. Make up their bed daily (if possible change bedding). Lift up the sick person in bed—do not drag as it breaks the skin. Put extra soft material such as a soft cotton towel under the sick person. Small sores can be cleaned with salty water and allowed to dry. If the sores are not deep, the wounds can be left exposed to the air. Deep sores need to be cleansed daily with salt water. Applying ripe papaw flesh is helpful and the wound can be covered with a light dressing. Oil the skin with cream, body oil, lanolin, or vegetable oil while bathing.

In the following situations, the patient needs to be referred to the nearest health facility:

- Patient's condition does not improve
- Patient's skin discolors.

Fatigue

Tiredness, weakness, or exhaustion are very common conditions in persons with HIV and AIDS. Possible cause of fatigue include:

- HIV infection and other related diseases
- Depression
- Anemia (a blood disorder)
- Poor nutrition
- TB
- Respiratory diseases
- Diarrhea and/or dehydration.

In case of fatigue: help the patient when going to the toilet, bathing, getting in and out of bed, and eating. Put the patient on a bedpan if they are too weak to go to the toilet. Gently move arms and legs several times a day, turn the patient regularly from side to side and massage the pressure areas every few hours. Bathe patient and keep the skin clean and dry. Provide and encourage the patient to eat and drink plenty of fluids and eat energy giving foods. Keep patients company and counsel them.

The patient needs to be referred to the nearest health facility if their condition does not improve.

Malnutrition

Persons become malnourished when their intake of food is insufficient or of poor quality. Signs of malnutrition include:

- Inadequate growth in children
- Edema (body swelling)
- Weight loss
- Peeling skin
- Change in hair color
- Diarrhea and/or anemia.

In case of malnutrition: ensure that the patient takes regular meals; small amounts of different types of food should be taken frequently. Provide a variety of foods and to add vegetable oil or groundnut paste to food. Ensure that money is not spent on non-nutritious and unnecessary foods. Give soft foods if patient is having difficulties with chewing and/or swallowing and encourage patient to drink plenty of fruit juices.

The patient needs to be referred to the nearest health facility if they refuse to eat and their condition does not improve.

Good nutrition

Nutrition and HIV are strongly interrelated. Good nutrition increases resistance to infection and disease, improves energy and thus can make a person stronger. Persons living with and affected by HIV and AIDS should eat a balanced diet that will help support their immune system. Access to healthy foods can help support the body's defense and slow the progression of the disease. Communities and extended family members should be encouraged to contribute in any way possible to healthy eating practices.

Food hygiene (cleanliness)

- Ensure that all areas where you prepare and eat foods are clean and free from insects
- Cover leftover food to avoid contamination
- Keep hot foods hot and cold foods cold

- Store cooked food for no more than 1 day and reheat before eating
- If you have a refrigerator, put all leftovers in the refrigerator.

Water

- Be sure water is clean. Bring water to a rolling boil for at least 1 minute. Timing starts when water starts bubbling
- Keep water stored in a covered container
- Always wash your hands with soap before and after handling foods.

Meat products

- Cook all animal products (meat, poultry, pork, fish, and eggs)
- Do not eat soft boiled eggs or rare meat (with red juices)
- Thoroughly wash utensils and surfaces where you placed uncooked foods, particularly meat and poultry, before you handle other foods
- Cover meat, poultry, or fish with a clean cover or cloth, and keep separate from other foods to avoid contamination.

Fruits and vegetables

- Use clean water to wash thoroughly all fruits and vegetables to be eaten raw
- Remove any visible molds.

Healthy eating

Good nutrition for all persons, but especially those with HIV and AIDS, requires eating adequate amounts of macronutrients (carbohydrates, fats and protein) and micronutrients (vitamins and minerals). A deficiency in macronutrients results in weight loss.

- Carbohydrates (starches) such as those found in starches and sugars provide the body with needed energy. Carbohydrates are usually cheap and easy to find. They can be especially helpful for countering fatigue. Foods rich in carbohydrates include bread, cassava, dry legumes (beans, peas, lentils), fruit, grain (maize, wheat, millet, sorghum, rice, oats), nuts, seeds, potatoes, sweet potatoes, yams, and sugars.

- Fats including oils, are a viable source of energy and an important part of living cells. They are important for absorbing vitamins (especially vitamins A, D and E), and useful for certain chemical processes in the body. Foods containing fats and oils include avocado, beef, chicken, coconut, olives, peanut butter, seeds, and nuts. Fatty fish, especially salmon, mackerel, herring, and sardines, are full of essential fatty acids. Seeds such as groundnuts and pumpkin seeds are highly nutritious.
- Proteins build, maintain and repair the body's tissues. A lack of proteins results in a breakdown of the body's ability to maintain itself, or a breakdown in the immune system. Meat is a good source of protein. Chicken and turkey are easier to digest than beef. Cultured dairy products such as sour milk, yogurt and cottage cheese are good sources of protein and easy to digest. Seafood is a source of easily digestible protein, but spoils very quickly and thus can result in food poisoning. Eat seafood only if you know that it is very fresh; never eat it raw.

Micronutrients, especially vitamins A, B6, B12 and iron and zinc are important for building a strong immune system and fighting infections.

Vitamins are essential to many of the body's functions. Most vitamins are found in fruits and vegetables that can be easily digested. Keep the skins of fresh fruits and vegetables free from bacteria. The best way of washing these foods prior to consumption is to wash them in lemon juice and salty water. Otherwise, add 1 teaspoon of household bleach or hydrogen dioxide, also called oxygenated water, to 1 liter of water. The following vitamins are important for the good nutrition of persons with HIV and AIDS:

- Vitamin A helps create white blood cells, promotes good vision and healthy skin, helps bones and teeth, and protects against infections. Too little vitamin A can lead to colds, dry skin, eye problems such as light sensitivity and night blindness, and weak teeth and nails. It is found in alfalfa, egg yolk, green vegetables, liver, milk, and orange and yellow fruits and vegetables. It has been shown that vitamin A supplements for children of HIV-infected mothers reduce illness, particularly diarrhea. Vitamin A is also recommended for mothers immediately after delivery and for infants 6 months and older. Vitamin A deficiency is associated with higher mother to child transmission rates, faster progression from HIV to AIDS, higher infant mortality, and slow growth rates in children.

- Vitamin B6 helps to produce antibodies, red blood cells and nerve transmitters. It also helps to break down fats. Anemia, depression, dizziness, irritability, muscle twitching, nausea, nerve problems, sore tongue, and tiredness are all side effects of vitamin B6 deficiency. B6 is present in alfalfa, bananas, cabbages, chicken, eggs, fish, leafy green vegetables, legumes, liver, meat, nuts, sunflower seeds, and whole grains. Vitamin B6 pills (10 mg per day) are recommended for TB patients being treated with Isoniazid (INH, Lanizid, Nydrazid), the most common drug used to treat TB.
- Vitamin B12 helps with the formation of red blood cells, enhances white blood cells and maintains nerve and gastrointestinal tissue. Anemia, confusion, dementia, memory problems, nerve problems, ringing in the ears, and tiredness are symptoms of vitamin B12 deficiency. It can be found in cheese, chicken, eggs, heart, kidneys, liver, red meat, sardines, tuna, whole grain, and yogurt.
- Vitamin C helps build healthy bones, teeth and gums. It helps fight infections, aids the absorption of iron and serves as an antioxidant (any substance that serves to counteract the damaging effects of oxygen in tissues). If someone is not receiving enough vitamin C, they may show signs such as bleeding gums, bruising easily, frequent colds, muscle and joint pains, and slow healing. Vitamin C is present in all fruits, especially oranges, guavas, alfalfa, leafy green vegetables, potatoes, sweet peppers, and tomatoes.
- Vitamin E supports the immune system, protects fats and vitamins from oxidation (combination of a substance with oxygen) and serves as an antioxidant. Dry hair, infertility, impotence, leg cramps, heart disorders, muscle weakness, nerve problems, and tiredness are related to insufficient amounts of vitamin E. Vitamin E is found in alfalfa, dark green vegetables, eggs, legumes, nuts, seeds, whole grains, and vegetable oil.

Minerals are critical for chemical processes in the body and overall body function. The following minerals are necessary in maintaining health for persons living with and affected by HIV and AIDS:

- Calcium is found in milk and fish and necessary for strong bones.
- Iron is necessary in assisting enzymes during the exchange of oxygen in the blood. Dizziness, fatigue, headaches, irritability, and pallor are signs of lack

of iron in the body. Iron is abundant in alfalfa, apricots, eggs, green leafy vegetables, kidneys, legumes, liver, meats, nuts, potatoes, seafood, and seeds.

- Magnesium is an antioxidant good for muscles, nerves and the process of breaking down fat. An absence of magnesium can lead to tremors, cramps, strained bowel movements, or constipation. Magnesium is present in avocado, dark green leafy vegetables, legumes, nuts, fruit and vegetable skins, seafood, seeds, and whole grains.
- Potassium is present in bananas and beans and is beneficial for muscle maintenance.
- Selenium is found in alfalfa, brown rice, egg yolk, garlic, liver, meat, milk, onions, and whole grain. It is not present in crops grown in soils that contain minimal amounts of this mineral. Selenium is also available as a tablet. Impaired growth, heart problems, pancreatic damage, and weakness are signs of selenium deficiency.
- Zinc is the most deficient in mineral in persons with HIV and AIDS. Zinc not only protects the immune system, it is also needed for digestion, muscle maintenance, healing wounds, and for metabolizing vitamin A. Zinc deficiency can cause appetite loss, diarrhea, poor healing of wounds, ringing in the ears, skin problems, slow growth, and loss of smell and taste.

Caring for infected children and adolescents

Children and adolescents who have HIV and AIDS are more likely to have frequent common childhood infections such as ear infections and pneumonia. Diseases such as chronic gastroenteritis (stomach infection) and TB are common. It is also common to find enlarged lymph nodes and an enlarged liver. In infected infants, the symptoms common to many treatable conditions include fever, diarrhea and generalized dermatitis (skin rash). Symptoms of children living with HIV and AIDS include:

- Weight loss or failure to grow
- Chronic diarrhea for more than 1 month
- Prolonged fever for more than 1 month

- Persistent lymph node enlargement
- Fungal infections of the mouth and/or throat (oral thrush)
- Chest infection (pneumonia or TB)
- Skin rashes.

It is often difficult to diagnose HIV infection in a child. Even when tested at birth or in early infancy, a positive test may merely be a reflection of the mother's HIV antibodies that have been transferred into the baby's blood. These maternal antibodies may remain for up to 18 months. All HIV tests for babies should be repeated at 18 months. A child born to an infected mother and who is very sick during the first 2 years is likely to be HIV-infected. On the other hand, a child who remains generally well and is developing normally is likely to be free from infection.

When caring for children and infants infected with HIV, arrange for regular medical and growth check-ups, maintain good nutrition to boost the immune system. Give the full course of the usual immunizations to the HIV-infected child, provided the child is well and does not have any signs and symptoms of advanced HIV infection. Ensure that all common childhood infections are recognized and treated as early as possible and emphasize early diagnosis and treatment of suspected TB for all family members.

Most HIV-related illnesses are caused by common infections, which can be prevented or treated at home or at a health center. It is important that infections are treated promptly.

Further recommendations for the care of HIV-infected children and adolescents:

- Children with HIV should be treated as normally as possible. Avoid stigma and discrimination. Encourage them to play with other children
- Do not try to hide the infection from the child
- Medicines may have side effects. If the child develops a reaction such as a rash or fever, stop the medication immediately and seek medical advice
- Ensure that the child has emotional support and counseling. It is important to listen to the child's questions or concerns
- The physical development of children with HIV may be slower, and they may be embarrassed by their small size and appearance. This requires emotional support
- Try to ensure that the infected child does not carry the burden of heavy household duties alone by mobilizing family and community members to help
- Encourage infected children to join in church-related and other activities where they can contribute their skills and develop spiritually

- Help to provide medication to protect against opportunistic infections as directed by a health care professional
- Advocate for the rights and dignity of children living with and affected by HIV and AIDS.

Precautions for caregivers

There is an extremely low risk of being infected with HIV and AIDS if the following precautions are taken:

- Wear gloves when in contact with body fluids—HIV is present in blood and body fluids
- Keep wounds covered (both those of the caregiver and the person with HIV and AIDS)
- Always wear gloves or plastic bags to protect hands when cleaning up spills of blood and other body fluids
- There is no risk from casual household contact (no gloves needed)—clean up blood, feces and urine with ordinary household bleach
- Clean cutlery, linen, bath, etc., with ordinary detergents
- Keep clothing and sheets stained with blood, diarrhea, or other body fluids separate from other household laundry. Use a piece of plastic or paper, gloves, or a big leaf to handle soiled items
- Do not share toothbrushes, razors, needles, or other sharp instruments that can pierce the skin
- Wash your hands with soap and water after changing soiled bed sheets and clothing, and after any contact with body fluids
- Use condoms in case of sexual activity
- Patient can be bathed without wearing gloves if neither caregiver or patient has wounds.

Care for the dying

Caring for the dying can be difficult and trying. The caregiver must be prepared to face the challenge and reality of the situation. When there is not much more that can be done in terms of treatment, the focus on medical treatment stops, and care for the dying begins. This change occurs when medical treatment is not available or no longer effective, when the person says they are ready to die, and/or when the

body organs (liver, kidneys, lungs, heart) begin to fail. Care for the dying can be provided in the hospital, but many people would rather die at home.

What can be done?

- Keep the person comfortable. Protect them from problems that can make them feel worse
- Help the person to remain as independent as possible
- Assist them through the grieving period, and in coping with the continuing losses they experience
- Help them and their family members prepare for death. This may include making a will, bringing closure to family or other relationships, and arranging for the transfer of responsibilities
- Keep the person within the community and family groups for as long as possible
- Pray with and for them
- Arrange for someone to be with them as death draws near, even when the person appears to be no longer conscious
- Give comfort
- If the person is in constant pain, give pain medication. Use relaxation techniques such as giving back rubs
- Continue basic physical care to keep the person clean and dry and to prevent skin problems and stiffness or locking of joints
- Encourage communication within the family and community
- Provide physical contact by touching, holding hands and hugging
- Provide or arrange for pastoral support and rituals (anointing of the sick, etc.)
- Respect the dignity of the dying person
- Accept the person's decisions, even if they refuse to eat, get up, or insist on getting up when rest would be preferable
- Respect personal requests (e.g., regarding visitors)
- Ask them what they are feeling. Listen and allow the person to talk about how they feel
- Accept the person's feeling of anger, fear, grief and other emotions
- Avoid covering over the truth of their impending death.

Preparing the person for death

- The person may fear death or may want to talk about death. They may make this fear known by being angry, depressed, or aggressive

- Provide spiritual support and a faithful presence
- Understand that one of the most common worries is the future of one's children
- Be aware of the patient's fear of being in pain as they near death
- Be aware that the patient may worry about what will happen after they die. Assure them of God's loving presence and of eternal life (see appendix 3)
- Provide continuous emotional, spiritual and physical support until death comes.

Care for the body after the person's death

- Deal with the body with the same respect as you did when the person was still living
- Respect the family's desires regarding the body of the deceased
- Protect your hands when cleaning and laying the body, particularly if there are body fluids such as diarrhea or blood. Use gloves and wash your hands with soap and water afterwards.

Bereavement

- Give people an opportunity to talk about events leading up to their death and death itself
- Reassure people that feelings of disbelief, denial, sadness, pain, and anger are normal
- Allow people to express their feeling and concerns especially if it is difficult for them to do this in the presence of other friends and family
- Enable people to accept their loss and to look to the future.

Helping the family after the person has died

- When the patient dies the family may still need help to grieve or to arrange practical matters. You can help by listening to them and assisting them with funeral arrangements in accordance with local customs and regulations
- If appropriate, help them arrange for the memorial service to celebrate the life of the person who has died
- Remind them that as Christians we believe that Jesus died to destroy death (Heb 2:9), and that our hope lies in God's promise of the resurrec-

tion of the dead to new life. Assure them that their loved one is now at rest with the Lord.

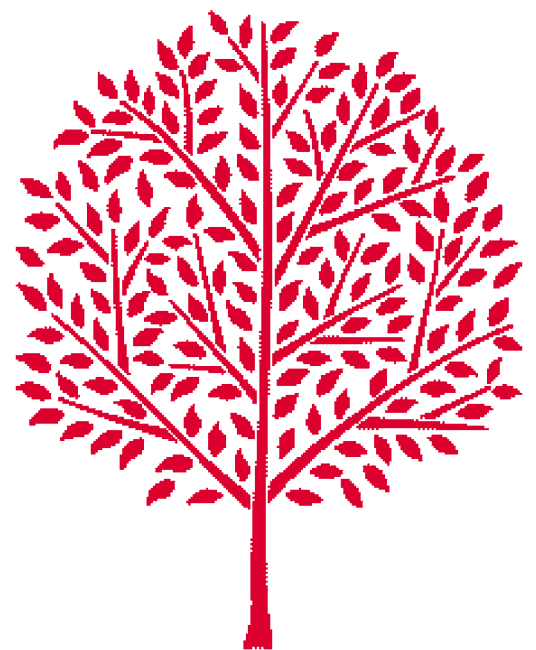
Resources for this chapter

Family Health International, *HIV/AIDS Care and Treatment: A Clinical Course for People Caring for Persons Living with HIV/AIDS*, December 2004, at WWW.FHI.ORG/EN/HIVAIDS/PUB/GUIDE/CAREANDTREATMENTCLINICALCOURSE2.HTM

WHO, *Caregiver Booklet. A Guide for Patients, Family Members and Community Caregivers*, at WWW.WHO.INT/HIV/PUB/IMAI/EN/IMAI_CAREGIVER.PDF

WHO, *Integrated Management of Adolescent and Adult Illness Modules (IMAI)*, at WWW.WHO.INT/3BY5/PUBLICATIONS/DOCUMENTS/IMAI/EN/1

Chapter 6: **Advocacy**



Advocacy is one of the ways through which we live out love for our neighbors in response to God's love given to us in Jesus Christ. As we work toward changes in society that will improve access to care and treatment required to live, and for more just conditions, we are caring for, standing with and serving people who are living with and affected by HIV and AIDS. These and other needed changes, as discussed in the previous chapters, are an ongoing aspect of advocacy.

“Advocacy” means to plead another’s cause with and on behalf of them. In light of increasing opposition against him, Jesus points to the coming of the Holy Spirit as the “advocate” or helper who will testify on his behalf (Jn 15:26).

Christians often refer to Christ as their advocate before God the Father. When the biblical prophets addressed kings and priests on behalf of those suffering injustice, they were advocating for them.

“I will also speak of thy testimonies before kings, and shall not be put to shame” (Ps 119:46).

Advocacy seeks to influence those in power to use their power differently and to change policies and practices whose effects on people and the rest of creation are unfair. This kind of advocacy is often the most challenging for local communities to pursue, because these “powers” often seem so remote from (or unresponsive to) the actual faces and situations we encounter locally. We may also encounter opposition or even personal risk when we speak out and confront others.

Advocacy occurs at many levels, including:

- Interpersonal, family, or community relationships
- Local governmental and other authorities
- State, provincial, or regional agencies and governmental bodies
- National governments and agencies
- Intergovernmental (e.g., UN) and Non-Governmental Organizations (NGOs).

Decisions made at one level often affect people at quite another. Because of this interconnection, advocacy is needed at all levels if change is to be effective and long lasting. It is also important that information is accurate and to know what decisions are made where. Since the church is present at all levels, it is in a strategic position to advocate for changes, especially by connecting local communities with those in positions to make changes.

Pray, walk with and change attitudes

In naming and lifting others up in prayer, we participate in the most basic form of advocacy. We are advocating to God on behalf of this person or situation. When this is done in public gatherings of worship, the silently suffering and needy are given voice and made present before God and the whole assembly. Prayers become the basis for action. We cannot pray for people and *not* do something about their situation.

Through prayer we communicate or “connect” with God, the source of our spiritual power. The Spirit of God sustains us for the long and difficult advocacy work that follows and encourages and empowers us to challenge those powers and practices resulting in injustice and death.

The many ways in which we walk with and care for persons and families living with and affected by HIV and AIDS are a type of advocacy. The ministry of care and counseling includes advocating for and being in solidarity with those who suffer from the effects of the virus.

Some of us may be uncomfortable sitting at the side of a person or family living with and affected by HIV and AIDS. This is so because it means facing so many related issues that make us uneasy, and around which many defensive theological and moralistic understandings have been built. Such barriers distance us, the church, from those who are most in need of care and acceptance, and hinder the church from speaking out prophetically on behalf of those who are suffering or whose dignity is being violated. Responding with compassion to persons living with and affected by HIV and AIDS means challenging and moving beyond boundaries that have kept us from loving one another, and seeking justice for all who are made in the image of God.

As we work closely with people in local settings, we are likely to encounter assumptions, comments and myths that stigmatize and lead to patterns of discrimination (see chapter 4) which must be challenged when they arise. Advocates need to be alert to the actual effect that other people’s attitudes and practices have on those who are living with and affected by HIV and AIDS, especially when they are stereotyped, overlooked, or silenced. Because of their painful effect on the humanity of others, advocates will confront and work toward changing such attitudes and practices. They should also be vocal in encouraging the use of effective methods of prevention. Conversation, awareness raising and education

Advocate for the rights of persons who are HIV-positive, including:

- Full participation in church life, including being elected and employed in church positions
- Access to health care, medication and preventive measures
- Right to adequate nutrition, shelter, education, and employment
- Legal rights
- Putting an end to discriminatory policies or practices.

are essential aspects of advocacy. Churches must look again at their own attitudes to gender, sex and HIV and AIDS and recognize the part they often play in fueling stigma and discrimination.

Change policies and practices

Identify and analyze

There are many structural obstacles, practices and policies that compound or worsen the situations of those living with and affected by HIV and AIDS. These are especially manifested in

the multifaceted realities of poverty. This often results in a lack of access to treatment, adequate nutrition, health care, education, means of livelihood, as well as a denial of basic rights (especially for women, see chapter 2), and other injustices.

Furthermore, culturally reinforced practices contributing to the increase in people's vulnerability to the virus and its spreading must be changed (e.g., body tattooing, body piercing, polygamy, human trafficking, female genital mutilation, tribal marking, forced marriage, sex with young girls, etc.).

It is important to identify the most urgent and important obstacles or practices, to analyze what needs to be changed and how this can occur, and to strategize as to who or what needs to be influenced to make these changes.

Recruit and network with others

After identifying, analyzing and beginning to strategize about what needs to be changed, recruit others to participate in this effort and network with coalitions or other organizations who have similar concerns. Include those of other faiths as well as secular organizations. Whenever possible, include persons who are living with and affected by HIV and AIDS. Networking and organizing is important to communicate, support, or reinforce each other's efforts, strategies and work for effective changes that will make a positive difference in the actual situations of those living with and affected by HIV and AIDS.

Organize and plan

In coming together, it is important to focus on specific goals and objectives and propose how to accomplish them. What kinds of actions are needed? Who will do what when? What human and financial resources are needed? How can people be mobilized to support these efforts? How will this be communicated to others, including through the media? What are the possible risks and obstacles, and how will they be dealt with? When might confrontation be necessary and appropriate?

Monitor and evaluate

It is necessary to check whether the advocacy work is on track, whether objectives are being reached and whether changes in strategy need to be made. We can learn from what has been done well or fallen short, and be accountable to those who have a stake in the outcome of this work.

In monitoring we ask, Are we doing what we said we would do? If not, why not? What needs to change? In evaluating we ask, Have we achieved what we set out to achieve? If not, then why not? What needs to change?

Advocate through the media

Contact the local media to communicate your concerns related to those living with and affected by HIV and AIDS. Besides church related media, consider how to get your message communicated through secular, especially community based media including radio, TV, Web sites, printed media, videos, audio/visuals, CD ROMs or DVDs, drama, public forums, community based theatre, story telling, poetry, mock sessions, photography, art, mobile cinemas, stickers, pastoral letters, postcard campaigns, essay or art competitions, concerts, etc. The use of local celebrities or respected political leaders can be particularly important in communicating messages about stigma and discrimination.

Focus on a specific target group or groups you wish to reach with your message. Different approaches are likely to be needed to reach church leaders, leaders of other faiths, teachers and other educators, children and youth, women, men, marginalized people such as street people, squatters, slum dwellers, people living with and affected by HIV and AIDS, community health workers, differently abled people, prisoners and others in places of confinement, and refugees and internally displaced persons.

Language used in all media messages must be appropriate, inclusive and sensitive to gender and cultural contexts. Avoid stereotyping or distinguishing between “us” and “them.” Ensure that your message is clear and think about the possible “gatekeepers” and how to make sure the message gets through. Use national and international occasions such as World AIDS Day (December 1), special Sundays and other church gatherings, or events when these concerns can be highlighted. Mobilize your local secular media, and ask those responsible for church bulletins or newsletters to publicize information or events related to HIV and AIDS.

Recognize the key role of government

Churches sometimes view government and the political dynamics involved as arenas they want to avoid. However, from a theological perspective, good government is considered as an important means through which God works to maintain and promote just and humane conditions for the common life of all, especially the most vulnerable. Faith communities have a responsibility to be the voice of the voiceless, and to hold governments accountable to their own people, constitutions and laws, as well as to the human rights and other international conventions or agreements they have signed. International agencies and governments increasingly acknowledge the work of churches and faith-based organizations, and want to engage them further in HIV and AIDS prevention work.

On the basis of its faith, the church is authorized and empowered to hold governments accountable. It acts out of hope and courage when others succumb to cynicism and despair.

Churches can hold governments accountable through/by:

- Critical solidarity with the marginalized or excluded
- Naming the issues and root causes of injustice and poverty
- Encouraging truth telling and transparency in public life
- Supporting local efforts to increase civic literacy and involvement
- Raising up new models for the development of communities that are participatory, sustainable and people centered.

Meet with those who can make a difference

These are likely to be elected or appointed persons in government or decision makers in business or NGOs. They may be at the local level (some may even be members of your congregation), at a state/provincial/regional level, or at the national level. Although initial contacts with them might be through letters, e-mail or telephone calls, face-to-face meetings are likely to be most effective.

In planning for such a meeting, the following are some helpful reminders:

- Learn beforehand about the responsibilities and perspectives of the person you are requesting to make the necessary changes
- Define the objective(s) of your visit
- Provide some background material about your work prior to your meeting
- Anticipate some questions and your possible responses
- Be positive rather than argumentative
- Clearly identify your advocacy position and state your case
- Request specific responses or actions
- Explore how you might continue to work together for these changes
- Report back to your group and determine how to hold these persons accountable for following through and making the necessary changes.

Participate in international networks and alliances working for change

Even after advocacy has been pursued in the ways discussed above, some matters still require changes at the international level, through the United Nations, or other international organizations. Therefore it is important to remain in contact with the advocacy work being pursued at this level, through the Ecumenical Advocacy Alliance, the Lutheran World Federation, the World Council of Churches, various development agencies, and others. Advocating together with others in civil society is crucial. Experiences and findings from your work at the local level should be shared with those pursuing this work internationally, and, in turn, local participation encouraged in international advocacy campaigns.

Finally, being an effective advocate means understanding that faithfulness is part of our witness. We will not win all our battles; sometimes we may lose even

those that seem simple. It is important to remember that we need to be present in order to be an effective witness. The advocacy witness is a way of sharing God's love for all people, as we insist and persist in bringing the needs of those living with and affected by HIV and AIDS before those who can make a difference.

Conclusion: Where then is our hope?

Then I saw a new heaven and a new earth ... And I heard a loud voice from the throne saying, "See, the home of God is among mortals. ... he will wipe every tear from their eyes. Death will be no more; mourning and crying and pain will be no more ..." (Rev 21:1-4).

As Christians, we not only believe in life after death, but even more so in life before death. And so, we live in the here and now, in the light of God's promised reign as it breaks into the chaos we are experiencing. When we despair and become compassion weary, we are reminded that God promises another world than the one in which many continue to suffer and die physically, spiritually and socially. As Christians, our expectant hope is lived out in the here and now, as we actively seek to counter the sinful stigmas that cut off God's abundant life for all (Jn 10:10), and as we act to make that life possible for all. We refuse to let the diagnosis of HIV or AIDS become a death sentence, and seek to make the needed care and medication available for all. We do so, because we believe in life in the midst of death, and in the resurrection of life. Thus, we continue working for a more just and inclusive church and society, here and now.

Resources for this chapter

WWW.E-ALLIANCE.CH

WWW.ELCA.ORG/ADVOCACY

WWW.LUTHERANWORLD.ORG/WHAT _ WE _ Do/OIAHR/OIAHR-WELCOME.HTML

"Reclaiming the Vocation of Government: A Statement from an LWF Consultation," in Karen L. Bloomquist (ed.), *Communion, Responsibility, Accountability. LWF Documentation 50/2004* (Geneva: The Lutheran World Federation, 2004).

Appendices

Appendix 1:

WHO clinical staging of HIV disease in adults and adolescents

(2006 revision)

In resource poor communities, medical facilities are sometimes poorly equipped, and it is not possible to use CD4 and viral load test results to determine the right time to begin treatment. The World Health Organization has therefore developed a staging system for HIV disease based on clinical symptoms.

Clinical stage I:

- Asymptomatic
- Persistent generalized lymphadenopathy

Clinical stage II:

- Moderate unexplained* weight loss (under 10% of presumed or measured body weight)**
- Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis)
- Herpes zoster
- Angular cheilitis
- Recurrent oral ulceration
- Papular pruritic eruptions
- Seborrhoeic dermatitis
- Fungal nail infections

Clinical stage III:

- Unexplained* severe weight loss (over 10% of presumed or measured body weight)**
- Unexplained* chronic diarrhea for longer than 1 month
- Unexplained* persistent fever (intermittent or constant for longer than 1 month)

- Persistent oral candidiasis
- Oral hairy leukoplakia
- Pulmonary tuberculosis
- Severe bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)
- Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
- Unexplained* anemia (below 8 g/dl), neutropenia (below 0.5 billion/l) and/or chronic thrombocytopenia (below 50 billion/l)

Clinical stage IV:***

- HIV wasting syndrome
- Pneumocystis pneumonia
- Recurrent severe bacterial pneumonia
- Chronic herpes simplex infection (orolabial, genital or anorectal of more than 1 month's duration or visceral at any site)
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Extrapulmonary tuberculosis
- Kaposi sarcoma
- Cytomegalovirus infection (retinitis or infection of other organs)
- Central nervous system toxoplasmosis
- HIV encephalopathy
- Extrapulmonary cryptococcosis including meningitis
- Disseminated non-tuberculous mycobacteria infection
- Progressive multifocal leukoencephalopathy
- Chronic cryptosporidiosis
- Chronic isosporiasis
- Disseminated mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
- Recurrent septicaemia (including non-typhoidal Salmonella)
- Lymphoma (cerebral or B cell non-Hodgkin)
- Invasive cervical carcinoma
- Atypical disseminated leishmaniasis
- Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy.

Note:

- * Unexplained refers to where the condition is not explained by other conditions.

- ** Assessment of body weight among pregnant woman needs to consider the expected weight gain of pregnancy.
- *** Some additional specific conditions can also be included in regional classifications, such as the reactivation of American trypanosomiasis (meningoencephalitis and/or myocarditis) in the WHO Region of the Americas and penicilliosis in Asia.

AVERT.org has more information about HIV/AIDS treatment and care and more about HIV testing.

Resources

Avert, at WWW.AVERT.ORG/HIVSTAGES.HTM

Appendix 2:

Antiretroviral drugs

Drug class	Method of action
Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	Inhibits the enzyme reverse transcriptase which is responsible for converting viral RNA to DNA
Non-nucleoside Reverse Transcriptase Inhibitors (NNRTIS)	Same method of action
Nucleotide Analogue Reverse Transcriptase inhibitors (NtRTIs)	Same method of action
Protease Inhibitors (PIs)	Inhibits the enzyme protease responsible for building up the protein units to form new daughter viruses
Fusion Inhibitors (FIs)	Prevents the fusion of virus to the CD4 cell preventing entry into the cell

Names of ARV Drugs

Generic name	Trade name
NRTIs (Nucleoside Reverse Transcriptase Inhibitors)	
3Tc-Lamivudine	Epivir, Lamivir
AZT-Zidovudine	Zidovir, Retrovir
d4T-Stavudine	Zerit, Stavir
DdC.-Zalcitabine	Hivid
DdI.Didanosine	Videx
Abacavir	Ziagen
FTC-Emtricitabine	Emtriva
AZT/3TC	Combivir, Duovir
Abacavir/3TC	Kivexa,
Abacavir/3TC/AZT	Trizivir
NNRTIs (Non Nucleoside Transcriptase Inhibitors)	
Nevirapine	Viramune
Efavirenz	Sustiva
Delaviridine	Rescriptor

Generic name	Trade name
NtRTIs (Nucleotide Reverse Transcriptase Inhibitors)	
Tenofovir	Viread
PIs (Protease Inhibitors)	
Indinavir	Crixivan
Amprenavir/Fosamprenavir	Agenerase, Lexiva, Telzir
Nelfinavir	Viracept
Ritonavir	Norvir
Saquinavir(Hard gel)	Invirase
Saquinavir(Soft Gel)	Fortovase
Ritonavir/lopinavir	Kaletra, Aluvia
Tipranavir	Aptivus
Darunavir	Prezista
Atazanavir	Reyataz
FIs (Fusion Inhibitors)	
T20 Enfuvirtide	Fuzeon

For more information about HIV/AIDS drug classes, names and brand names consult WWW.AIDSMAP.COM and WWW.THEBODY.ORG

Resources

Bartlett, John G., *The Pocket Guide to Adult HIV/AIDS Treatment: January 2006*, at WWW.HOPKINS-AIDS.EDU/PUBLICATIONS/POCKETGUIDE/POCKETGD0106.PDF

Appendix 3:

Some biblical resources for ministries of care

People living with and affected by HIV and AIDS need assurance of God's grace, especially when their health begins to deteriorate. It is important to hold up the gospel's promise of forgiveness, hope and eternal life. The following are some key biblical resources for spiritual care:

- **God loves us all:** God's love is extended to all people unconditionally; nothing can separate us from the love of God in Jesus, whether we are HIV positive or negative. Even when we feel unworthy of God's love, it does not change God's own love. Even when we fail or are abandoned by others, God continues to love us. Being HIV-positive may make us feel separated from others, but the promise is that nothing can separate us from God's love (*cf.* Rom 8:39), not even AIDS. To paraphrase Paul's words, "For I am convinced that neither being HIV-positive, nor stigma, nor discrimination, nor sickness and suffering, nor AIDS and being confronted by mortality and death, nor grief and mourning, nor things present, nor things to come, nor isolation, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord" (*cf.* Rom 8:35–39; see also Jn 3:16–18; Jn 10:27–29; 1 Jn 4:7, 8).
- **God promises to draw near to us:** When others may flee from us, God draws near and stands with us in our fears and hope, our joys and griefs, and calls others to do likewise. Even in our deepest pain we can be sure of God's promise, "I will never leave you or forsake you" (Heb 13:5; see also Ps 145:18)
- **God promises to forgive us:** We all feel guilty at times about what we have said or done, "since all have sinned and fall short of the glory of God" (Rom 3:23). Nevertheless, God invites all of us, persons living with and affected by HIV and AIDS and those who have tested negative, to unload our burden of guilt: "come now, let us reason together, says the Lord: though your sins are like scarlet, they shall be white like new cotton in the cotton fields" (paraphrase of Isa 1:18; see also 1 Jn 1:9; 2:2). We are

all invited to lay down our burdens and be freed by God's forgiveness to continue our life's journey.

- **God's loving presence is always with us:** The world, including our closest friends and families, may turn its back on us, but God's loving presence will always be with us. God assured Joshua, "I will not fail you or forsake you" all the days of your life (Josh 1:5). Psalm 23 proclaims that God prepares a table "in the presence of my enemies," including the hated HIV virus. Our earthly bodies are as "clay jars" in which is hidden the presence of God. We may be afflicted (including with HIV and AIDS), but not crushed; perplexed, but not driven to despair; abandoned by other human beings, but not forsaken; struck by the HIV and AIDS pandemic, but not destroyed (2 Cor 4:7–10, paraphrased; see also Mt 28:18–20).
- **God promises to bring good into our lives:** We suffer because of the existence of evil in the world. We suffer because of natural disasters and processes. We suffer because of our mistakes, bad decisions, or choices that bring negative consequences. We also suffer because of the mistakes of others and injustices in society. But in the midst of these situations, God desires for us life in its fullness. God promises to bring good into our lives (see Rom 8:28; Jas 1:2–4, 12, 17; 1 Peter 1:3–9).
- **God gives us purpose for our lives:** People living with and affected by HIV and AIDS may feel hopeless and that they no longer have a purpose in life. But God affirms that we always have a purpose. Each one of us is endowed with talents and gifts with which we can reach out to others (see Jn 14:1–15; 2 Peter 1:1–8).
- **God promises to give us strength:** When hit hard by the challenges of life, we may start feeling that we cannot overcome the next difficulty we may face. Yet, in Christ there is strength and renewal: "My grace is sufficient for you, for power is made perfect in weakness" (2 Cor 12:9); "I can do all things through him [God] who strengthens me" (Phil 4:13).
- **God promises us the gifts of peace, hope and joy:** The need for peace, hope and joy intensifies when our lives are affected by HIV and AIDS. Finding the peace and courage to live is critical. God gives us peace differently from the world's peace (Jn 14:27). The human body may be in pain, but Jesus assures us that God goes through this with us. God's hid-

deness is revealed to us through fellow human beings standing with us, supporting us, praying for us. Therefore we receive peace and can live. “Let us therefore approach the throne of grace with boldness, so that we may receive mercy and find grace to help in time of need” (Heb 4:16).

- **God sides with the poor, sick and oppressed:** God is concerned about all persons, but especially those who are poor, sick and oppressed. Central throughout the Bible is caring for the poor, the stranger and the afflicted. Injustices are condemned, as are those who abuse their positions of power, or close their eyes to the needs of others. Persons living with and affected by HIV and AIDS are often excluded, and become poorer as they suffer. But God stands with and sides with them, as must we also (see Am 5:10–15, 21–24; Mt 5:1–12; Jas 1:27; 2:2–9).
- **God never gives up on us:** People sometimes break their promises, which in turn breaks our trust in them. We may become so disappointed at the negative attitudes in church and society that we begin to give up on them. When the people who hurt us are members of the faith community, we are tempted to give up on the church. We may even be tempted to give up on God. But God does not fail us. “Because the poor are despoiled, because the needy groan, I will now rise up,’ says the Lord; ‘I will place them in the safety for which they long’” (Ps 12: 5–6). Even if we have given up on people, we must not give up on God.

Appendix 4:

Stress and burnout in caregivers

Caregivers should be aware of the various causes of stress so that they can respond in healthy ways. Burnout occurs when stress overwhelms us and we cease to be effective. It is a common occurrence in providing care for those living with and affected by HIV and AIDS. By recognizing stress, we can try to make changes that will reduce its causes.

Signs of too much stress

- Concentration becomes difficult
- Thinking of one's problems all the time
- Bad dreams or difficulty sleeping
- Isolation (the caregiver avoids being with other people)
- No longer doing the things one used to enjoy
- Feeling nervous, fearful, irritable, sad, or tired
- Lack of appetite.

Individual causes of stress

- Poor time management
- Trying to do everything without asking others for help
- Having unrealistically high expectations of oneself
- Unclear job descriptions
- Poor communication with others
- Feelings of powerlessness in decision making
- Emotional involvement with patient
- Feeling hopeless due to recurrent deaths in spite of caregiver's efforts.

Stress related to other people

- Being asked to do what one has not been sufficiently trained to do
- Frequent clashes with superiors, patients and family members
- Denial of entitlements (e.g., transport money, meals)
- Shortage of supplies (e.g., gloves and medication)

- Poor conditions of service (e.g., inadequate or no pay)
- Too many people demanding attention at the same time.
- Home, family situation, or wider environment.

What can you do to reduce stress?

- Listen to your body to detect warning signs (e.g., feeling of tiredness, headaches, bad dreams, difficulty sleeping, feeling of overwork)
- Take time to talk to people you trust who can understand and help you solve problems
- Engage in regular, gentle exercises
- Reduce the amount of coffee, tea, or Coca-Cola you drink
- Develop a regular pattern of going to bed early and getting enough sleep
- Engage in doing something you enjoy
- Take time to pray and be in fellowship with your church community.

What can help burnout?

- Keep a sense of humor; it helps in stressful situations
- Do a variety of tasks rather than one stressful task all of the time.
- Work a reasonable number of hours. Most people who work too much do not work well after a while
- Encourage volunteers and reward them with parties or small gifts to let them know their work is appreciated. Make yourself available to answer questions, and acknowledge their efforts in front of others
- Recognize work that is well done. People need to know they are doing a good job. Each person needs something different, so give personal compliments
- Keep your eyes on the big picture—all good things in life—so that you do not get lost in the day-to-day struggles
- Recruit dedicated people from within the community with which they will be working. They are often more committed and comfortable with the job
- Give people days off from their job so that they can rest and recover from the strong emotions they may experience at work
- Everyone can burn out, even a director, or group leader. Be aware of signs of burnout in yourself and others, and work together to avoid it.

Appendix 5:

Some suggested further reading

AIDSCAP Project, Policy and Advocacy in HIV-AIDS Prevention. Strategies for Enhancing Prevention Interventions, at www.fhl.org/en/HIVAIDS/PUB/GUIDE/BCC+HANDBOOKS/POLICY+AND+ADVOCACY+IN+HIV-AIDS+PREVENTION.HTM

Clifford, Paula, *Theology and the HIV/AIDS Epidemic*. Christian Aid Publication, 2004.

Cimperman, Maria, *When God's People have HIV/AIDS. An Approach to Ethics*. Maryknoll, New York: Orbis Books, 2005.

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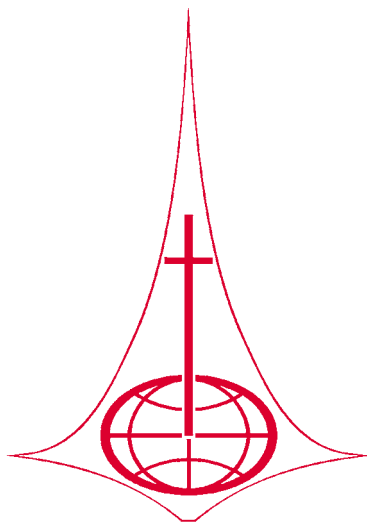
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