

HIV/AIDS
Who Will Cry
For Me?

Who Will Cry For Me?

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DEDICATION

This manual is dedicated to persons who have lived and died with AIDS without the benefit of someone to cry for them. It is dedicated to families who have suffered alone, not able to share tears with others for fear of rejection and scorn. It is dedicated to pastors willing to step out, risking fear, pain, and emotional turmoil to offer hope and peace to those living and dying with AIDS.

CHAPTER 1

Lanni's Story

Lanni lay very still in his hospital bed. He could almost feel his body destroying itself. "I wonder when I will die," Lanni thought. "How much longer will it be? Where will I go? What will it feel like?" Then the recurring thought came again and again, "I wonder who will cry for me." A tear slid down his cheek, as he found no answers to the questions that haunted his long days and sleepless nights.

"I knew this might happen to me, but never knew quite how horrible it would be... I wish I could go back and do it differently."

—A person with AIDS



Key Points

- 1. Facts about HIV/AIDS
- 2. Reasons for Reluctance in Ministering to Persons with HIV/AIDS

1. Facts about HIV/AIDS

Lanni has AIDS. He will die. Who will answer his questions? Will he take his last breath thinking that his life on earth had no meaning and that there is no one who will notice his passing? Will he die without hope for life after death?

By 2007, over 35 million persons in the world were infected with HIV, the virus which causes AIDS. Over 25 million people worldwide have died from AIDS since the beginning of the epidemic. Today in certain countries of the southern region of Africa, it is estimated that as many as one-third of the young adults in the country are HIV-infected. Though Africa is leading the world in HIV infections and deaths from AIDS, other parts of the world are seeing more and more people becoming infected with the virus.

AIDS does not respect race or social class. It can infect newborn infants and elderly adults.

Without a medical miracle or a supernatural intervention, all persons infected with HIV will develop AIDS and die. There is no medical cure for AIDS. Many will die with questions, similar to Lanni's, haunting their final days.

Persons infected with HIV or who have AIDS are in desperate need of physical and spiritual caregivers who can compassionately assist them to live during the process of dying. The secular world speaks of the need for persons suffering from AIDS to be able to die with dignity. Literature which deals with caring for persons with AIDS encourages health care workers and caregivers to provide comfort and to instill compassionate hope to the dying (Fisher 1995; Garwood and Melnick 1995).

Encouraged methods of caregiving include those which show empathy (a personal understanding of the experience), give support, and listen intently to what the individual wishes to say. These are all good methods of caregiving, but they do not address the need for meaning in life. They do not bring the only hope that brings peace to dying: hope for eternal life.

AIDS is not a dignified disease. It ravages; it torments.

The infections associated with AIDS destroy and disfigure the body. Mental changes occur. From human understanding and human effort alone, it is difficult to offer death with dignity, hope of eternal relief, comfort in the midst of suffering, and peace in intolerable circumstances.

Christians, pastors, and lay spiritual leaders know that hope, true comfort, and peace can be offered only through a personal relationship with Jesus Christ.

"Therefore since we have been justified by faith, we have peace with God through our Lord Jesus Christ...

And we rejoice in the hope of the glory of God"

(Romans 5:1, 2 NIV).

Lanni's questions have answers. However, there seem to be few messengers willing to take the eternal message of the peace and love of Jesus to persons dying with AIDS.



Questions for Discussion

- Where is the church in this crisis?
- How should Christians respond?
- Are people reluctant to reach out to this group of people in desperate need of help? Why?

2. Reasons for Reluctance in Ministering to Persons with HIV/AIDS

HIV was identified as causing AIDS in 1984. Since it began sweeping across the world and causing millions of deaths, there has been a perceptible lack of response from the church and the Christian world to this crisis.

Filled with the love and compassion of Christ, it would seem that the church would lead the way in reaching out in ministry to persons living and dying with AIDS. Yet many of the care centers and hospice programs for persons with AIDS are operated by secular or humanitarian agencies. In many places churches are visibly absent in ministry programs related to AIDS.

Reasons for this reluctance may be summarized by a statement made by a church member when a Christian missionary physician spoke to a congregation about wishing to reach out with love and medical support to AIDS patients. The church member said, "Why are you interfering with the punishment that God has chosen to give these people? You have no right." One reason why the church is slow to respond is a negative attitude against those suffering with AIDS.

Negative Attitudes about AIDS and Persons with AIDS

When AIDS first began to come to light as a disease of major importance for the world, people in North America started to write about it. Early in the epidemic, persons suffering from AIDS in the United States were primarily homosexuals and IV drug users, with homosexuals being the greatest in number. Since homosexuality is an unacceptable lifestyle by evangelical Christian standards, there arose a theory from some of the Christian faith that this was a punishment from God and that homosexuals were getting what they deserved.

Acceptance of this theory allowed Christians to dismiss themselves from active participation in ministry to these hurting people, allowing God to take care of them in His way. Sadly, vast opportunities for ministry to persons in desperate need of hope and healing were, and continue to be, ignored.

If it is the case that HIV is a punishment from God, consider the following questions:

- How can it be that female homosexuals (lesbians) rarely contract AIDS?
- What explanation can be given when persons and often children, not by lifestyle but by accident, are infected from blood transfusions or contaminated equipment?
- What about those with blood diseases who received medication containing the HIV virus?
- Does God's punishment direct itself only to male homosexuals and IV drug users?

Though heterosexual promiscuity is also forbidden by Christian biblical standards, this type of transmission of the AIDS virus does not seem to receive the same stigma as that of homosexual transmission.

It is probable, then, that the most significant reason for a pastor, church, or individual to be reluctant to minister to persons living with HIV infection is a negative feeling against their lifestyle.

Secondly, there is a feeling that if God is judging someone, we have no need to interfere with what God is doing to bring punishment. Responses to these attitudes will be addressed in future chapters.

Fear of Infection

Another reason for reluctance to minister to persons with AIDS is the fear of becoming infected. Now that public education about AIDS is available, most persons know that casual contact will not put them at risk. Yet there is a pervasive feeling that there is something we don't know about the transmission of HIV and that giving pastoral care may put the pastor or spiritual caregiver at risk.

The modes of transmission of HIV will be discussed in the next chapter, but the reality is that since the disease was first described, the ways that HIV can be transmitted have remained the same.

AIDS is not as easily transmitted as the common cold or hepatitis; yet because of confirmed death once infection does occur, it brings about fear and causes people to avoid reaching out to persons with AIDS.

Fear of Dealing with Death and Dying

Despite one's trust in God and life with Christ after death, there remains a fear of death and the unknown. Dealing with a person who is destined to die and whose body is disfigured and wasted away may cause a person to be reluctant to get involved in one-on-one ministry. Though death is common and dealt with frequently in many parts of the world, death from a disease that carries no hope for recovery and which torments the body and mind can cause fear for those in close contact.

The purpose of this manual is to give help and support to pastors and Christians who wish to reach out in Christian compassion to persons with AIDS.

Its intent is to:

• Help Christian workers identify their own feelings and attitudes about the disease.

- Offer biblical mandates which demonstrate Christian responsibility for this type of ministry.
- Give guidance in offering spiritual care to persons with AIDS.

CHAPTER 2

The Reality of AIDS

"O God," prayed Pastor Johnson, "You know that I want to serve You. You know I want to reach out to those who need to know You, especially those who are sick and dying. My heart is burdened for that young man, Lanni, at the hospital. I know he's in that makeshift unit that they use to separate AIDS patients, and I know I should stop in and see him. But what do I say, Lord? How can I give him comfort? Why am I so afraid? Please give me courage and wisdom to know what to do."

The makeshift unit that Pastor Johnson referred to in his prayer is an older part of the hospital that had been closed. When the first AIDS patient needed to be admitted to the small rural hospital, the nurses got together and decided not to put the patient in the regular hospital ward. They cleaned out the closed unit, brought in a few beds and made a hasty isolation unit. They knew technically that they really didn't need to isolate these patients from the others and that with a few precautions, it would be safe to care for them in the main hospital. They were afraid. They felt that they wouldn't need to have as much contact if the AIDS patients were in another place.

"I can't stand to look in the mirror anymore. I've become someone else. I know my friends are repulsed when they see me, but they try to be brave."

—A person with AIDS



Key Points

- 1. What is HIV and AIDS?
- 2. Symptoms of AIDS
- 3. Cure for AIDS
- 4. How is AIDS Transmitted?
- 5. Ways in Which HIV Is Not Spread
- 6. Preventing Infection With HIV

Pastors, health care providers, family members, and friends often struggle with the issues expressed by Pastor Johnson. What to say, how to help, and fear of becoming infected are real issues to those caring for persons with AIDS. What are the facts about AIDS and the HIV virus?

1. What is HIV and AIDS?

The Human Immunodeficiency Virus (HIV) causes the disease called AIDS (Acquired Immune Deficiency Syndrome). In the weeks following the entry of the virus into the body, some people experience mild to moderate flu-like symptoms which last for a few weeks and then disappear. The virus then lives in the body for many years and the person doesn't suspect anything is wrong. Some people can live for ten or fifteen years before showing symptoms of AIDS—sometimes even longer.

People who are infected with HIV are able to transmit it to others starting shortly after they become infected. They seem to be healthy and don't suspect anything is wrong with them. The most common form of transmission is through sex, but it can occur through the blood or through an HIV-positive woman to her baby.

After entering the body, HIV targets and destroys a specific type of white blood cell in the body's immune system, called a CD4 defense cell. This defense cell defends the body against invading germs that cause infection and disease.

HIV multiplies inside the defense cell. When the cell is full of new viruses, they burst out, destroying the cell. They find new defense cells to enter and continue the cycle of destruction. The more of these defense cells that are destroyed, the less effective the body's immune system is in fighting off infection.

When all of the defense cells are destroyed, the body can no longer fight off certain types of infections. The person moves from HIV-infected status into what is known as AIDS. Scientists are not sure what makes a difference in the length of time it takes for symptoms to develop, but think it may have to do with a person's lifestyle, attitude, and body chemistry.

A person who is infected with HIV will not develop AIDS for many years. It is only after HIV has destroyed the defense cells that the person will begin to show symptoms of AIDS.

2. Symptoms of AIDS

AIDS is not a single disease, but a group of symptoms caused by multiple infections and different types of cancers.

Some of the symptoms and syndromes most commonly associated with persons with AIDS are:

- · Weight loss.
- Diarrhea.
- Lack of appetite.

- Fungal infections of the mouth and throat.
- Skin infections.
- Certain types of life-threatening pneumonia (Pneumocystis Carinii).
- Various cancers (Kaposi's Sarcoma is the most common).

Pneumonia and cancer are the most common causes of death. In many countries, tuberculosis (TB) is a complicating factor associated with AIDS. The TB bacteria are present in the lungs of many people. In healthy individuals with good immune systems, the bacteria may never develop into active TB disease. However, when a person is infected with HIV and the defense system begins to weaken, the TB bacteria become activated and develop into active tuberculosis. This is a serious health issue, especially in the developing world where TB is prevalent.

3. Cure for AIDS

To date there is no drug that will kill HIV. There is no vaccine against infection, and no medication that can cure AIDS. However, special medications called anti-retroviral drugs (ARVs) are used to slow the progress of the disease. Other more common drugs (antibiotics, medications for fever, diarrhea, etc.) can effectively treat some of the symptoms of AIDS.

A person with HIV can live for many years by taking good care of their bodies. Good health care includes eating the proper foods, drinking clean water, and getting enough exercise and rest. It includes receiving good medical care. Along with medical treatment, a healthy lifestyle can extend a person's life by many years.

In the end, however, no medication can cure the person of AIDS. Diarrhea often ends the life of a person with AIDS in Africa, while pneumonia and cancer claim lives more often in North America. Whatever the cause, most persons infected with HIV will develop AIDS, and short of a miracle, they will die.

4. How is AIDS Transmitted?

Some of the reluctance to minister to persons with AIDS may be diminished if spiritual caregivers understand the ways in which HIV is and is not transmitted. Though there are many rumors and myths about how it is spread, scientists who have been studying the virus since the early 1980s believe that there are only a few ways by which the virus can be transmitted.

HIV is found in highest concentrations in sexual secretions (semen and vaginal fluids), blood, and breast milk of infected persons. Though small amounts of HIV have been found in other body fluids such as saliva and tears, it is not in high enough concentrations to cause infection, and HIV has never been shown to be transmitted by these body fluids.

A person can be infected with HIV by sexual transmission, blood transmission, and mother-to-child transmission. This includes:

- Having sexual intercourse with a person infected with HIV.
- Cutting or piercing the skin with a sharp instrument that has cut or pierced someone with HIV and is still contaminated with their blood (medical and dental instruments, instruments used for piercing, tattooing, traditional practices, etc.).
- Using a needle and syringe that a person with HIV has also used.
- Receiving a blood transfusion or blood product that contains HIV.
- An HIV-infected mother passing the virus to her baby before or during birth or through breast-feeding.

Around the world, the most common way that HIV is spread is through sexual contact. In North America it is most commonly spread by sexual activity between homosexual men, though heterosexual transmission is also increasing. In Africa the main cause of HIV infection is by heterosexual intercourse. In other parts of the world, there is both heterosexual and homosexual transmission.

Having multiple sexual partners places a person at high risk to become infected with HIV or to pass it to another person. This practice is called having multiple concurrent partners. One of the big dangers in these relationships is that bonds of trust may develop and the partners stop using condoms. However, they might be having unprotected sex with others and risk bringing HIV into all their relationships.

Having multiple sexual partners places a person at high risk to become infected with HIV or to pass it to another person. This practice is called having multiple concurrent partners.

People who use needles to inject illegal drugs into their blood are easily infected by HIV. If an infected person shares a needle contaminated with HIV with a non-infected person, this person will be directly infected with HIV.

Contaminated needles and knives are a much less common means of transmission, though in rural areas of some countries, strict attention to sterilization of instruments and medical equipment is not practiced. In some areas of the world, blood is not screened for the presence of HIV before transfusions are given, resulting in many cases of HIV infection.

Mother-to-child transmission is growing, as more and more women are infected with HIV. If a pregnant woman is infected with HIV, there is a 20–40 percent risk she will pass it to her baby at the end of pregnancy or during childbirth. If the baby escapes infection, he or she may still become infected if the mother

gives the baby her breast milk. In this scenario, there is a twenty percent risk that the baby will become infected.

5. Ways in Which HIV is Not Spread

Since most ministry situations involve casual contact with persons with AIDS, there is no risk of acquiring AIDS when offering help, comfort, and spiritual care.

The following are ways in which HIV is not spread:

- Shaking hands, touching, or hugging,
- Kissing on the cheek, (Lip kissing is thought to be safe too.)
- Using the same eating utensils,
- Riding on crowded buses or in cars,
- Swimming or bathing together,
- Being together in the same room,
- Bites from mosquitoes or insects,

6. Preventing Infection with HIV

The ways in which HIV is transmitted from one person to another gives clear direction as to how this transmission can be prevented. It is a pastoral responsibility to see that this information is available to congregations and especially to young people. Experts in AIDS prevention may be brought in if the pastor does not feel adequate to address the subject. Since much of prevention deals with living life according to biblical standards, it does seem that the church is a logical place for this teaching to be given.

Living According to Biblical Standards

Most people become infected with HIV through sexual transmission. This mode of transmission of HIV could be greatly reduced if life is lived according to the principles given in God's Word.

Sexual Practices as Prescribed by the Bible:

- Avoid sexual activity before marriage (1 Thessalonians 4:3–7, 1 Corinthians 6:4–8).
- Be faithful in marriage. Do not commit adultery (Matthew 5:27).
- Do not engage in homosexual activity (Roman 1:26, 27).

Many people have already had sex before marriage. If a person who has already had sex desires to get married, he or she should have an HIV blood test to determine if the person has been infected with HIV.

Safe Sex

In terms of protection against HIV and other sexually transmitted infections (STIs) and pregnancy, there is no such thing as 100 percent "safe sex" with con-

doms. The correct, consistent use of latex condoms (not animal-membrane) offers some protection, but they are not always 100 percent effective. They may break or tear during intercourse, exposing the person to HIV and other STIs.

The only truly "safe sex" takes place in the sexual relationship between two uninfected spouses who are faithful to each other. And abstinence before marriage prevents a person from even being exposed to the virus through sex.

Drug Use

The Bible says that abuse of the body is wrong. The body is the temple of the Holy Spirit and should not be defiled (1 Corinthians 6:19, 20). Drug addiction is harmful to the body and causes irreparable damage to the body; according to Scripture, it is wrong.

Intravenous injection of drugs puts a person at high risk for HIV infection (and other infections) if needles are shared. The use of illegal or recreational drugs causes physical and emotional dependency. As the body becomes more and more dependent on the daily infusion of drugs, addicts become desperate to find ways to purchase the needed drugs. Often a person turns to stealing, prostitution, bribery, and deception to satisfy their habit. Drug addiction destroys the mind and body. It destroys a person's plan for the future. It even destroys families.

Intravenous injection of drugs puts a person at high risk for HIV infection (and other infections) if needles are shared.

Contaminated Equipment and Blood

Don't be tattooed, circumcised, cut, or have your ears pierced unless you are sure that the equipment has been sterilized. (Tattooing can cause the spread of other diseases as well and should be avoided.)

Before receiving a blood transfusion, ask if the blood has been screened for HIV.

Pregnancy

If there is any chance that a woman may be infected with HIV, she and her partner should take measures to avoid becoming pregnant. If the woman becomes pregnant, she should consult with a doctor, nurse, or midwife. Find out if anti-retroviral medications are available to help reduce the risk of passing HIV to the baby. If the family has the resources, the baby should be bottle-fed, using the correct type of baby formula and clean water. If the family cannot provide clean, appropriate alternative feeding, the baby should be fed ONLY breast milk for the first six months.

Lanni wondered how he had become infected with HIV. As he thought about it, he realized he had been with many sexual partners in his life. He had paid for sex with women a couple of times, but felt disgusted with himself afterwards and stopped. Besides, it was expensive, and he didn't have much money. He also had a few sexual encounters with men, but it had been several years ago. Questions about his sexual identity had plagued him for some time. He couldn't seem to form lasting relationships with men or women. "If only someone would come and see me," Lanni thought, "just to sit for awhile. I wish I had someone to talk to. I'm so tired of being alone. I guess my friends are afraid to come. I know my mother would come if she were alive."

CHAPTER 3

Reaching Out In Ministry

"Hello Lanni. I'm Pastor Johnson, the hospital chaplain. I've thought about coming to visit you several times, but to be honest, I was a little nervous. Now that I'm here I realize I didn't need to be afraid. If you don't mind, I would like to spend some time with you. How is it going for you?"

"Though I am dying, I feel at peace now that I've made my life right with God. To know that I am going to a better place and won't have to suffer anymore really helps get me through these days."

—A person dying with AIDS



Key Points

- 1. Christ's Concern
- 2. Preparing for Personal Ministry to Persons With AIDS
- 3. What Do Persons With AIDS Need?
- 4. Practical Ministry Helps for Persons with AIDS

Why should pastors and Christians feel compelled to reach out in ministry to persons with AIDS? The pastor in our story, Pastor Johnson, is the hospital chaplain, so it is part of his job responsibility to visit those in the hospital. But what about the average pastor, the average church member, or the congregation? Why should the church be concerned about ministry to persons with AIDS?

1. Christ's Concern

Time and again, Jesus reached out to touch and heal those who suffered. The Bible is full of passages that convey a personal responsibility to minister as Jesus did. Matthew 9:36 (NIV) describes the compassion that Jesus felt as He observed someone in pain. "Filled with compassion, Jesus reached out and touched the man" (a leper).

Jesus did not reserve His ministry to those who were like Him or believed as He did. He reached out to social outcasts, to the rich, and to sinners. He didn't say that only those who were acceptable and worthy in His sight would receive His healing touch. He ministered to the most unacceptable and unworthy.

James 5:13-15 (NIV) says, "Is any one of you in trouble? He should pray. Is any one happy? Let him sing songs of praise. Is any one of you sick? He should call

the elders of the church to pray over him and anoint him with oil in the name of the Lord. And the prayer offered in faith will make the sick person well; the Lord will raise him up. If he has sinned, he will be forgiven."

In James 2:14–16, a clear directive to meet physical needs is given. "What good is it, my brothers, if a man claims to have faith but has no deeds? Can such faith save him? Suppose a brother or sister is without clothes and daily food. If one of you says to him, 'Go, I wish you well; keep warm and well fed,' but does nothing about his physical needs, what good is it?"

In Matthew 25:35–36, Jesus was talking to His disciples and He said, "For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in. I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me." The disciples said to Jesus, "But really we didn't do these things for you." In verse 40, Jesus says, "I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me" (NIV).

Clearly, Christians are recipients of the grace and love of God. We are called upon, urged, and even commanded to reach out to those in need, those suffering, those who are sick, those who are helpless, and those who are alone. In Matthew and Mark, the disciples were commissioned to take the good news of Christ to all creatures and to heal the sick in the name of Jesus. Persons dying with AIDS are suffering. They are often left alone, isolated, searching for answers. They are in need of love, peace, hope, and possibly the forgiveness that only Christ can give. Those who have experienced these blessings themselves are well-placed to share their faith with those in need.

Clearly, Christians are recipients of the grace and love of God. We are being called upon, urged, and even commanded to reach out to those in need, those suffering, those who are sick, those who are helpless, and those who are alone.

2. Preparing for Personal Ministry to Persons with AIDS

Taking the first step to approach a person with AIDS is often the most difficult. Even if a person has overcome his or her fear of being infected with HIV, there is still a fear of dealing with someone who is dying or is disfigured by disease. There may be a fear of not knowing what to say or a fear of someone whose lifestyle may be vastly different from one's own. Howard Mueller says in AIDS: A Christian Response, "When reality is too threatening for our minds and emotions to handle, we instinctively turn off, avoid, deny, or claim that the truth is

exaggerated or wholly false." This may prevent people from becoming involved in ministry to persons living with HIV infection.

Before taking this first step towards someone living with HIV/AIDS, the person should do a self-assessment.

Admitting Fear

Persons with AIDS are very conscious of how others view them. They will recognize fear. Pastor Johnson was wise in admitting his apprehensions to Lanni. They were then out in the open and could be dealt with. Before beginning ministry to persons with AIDS, each person should evaluate his or her fears.

Ask the following questions:

- Do I fear the disease itself? Do I fear that this person will give me HIV?
- Am I afraid of feeling inadequate and ill-prepared to discuss issues of death and dying?
- Am I uncomfortable with or angry about the lifestyle of the person I may be dealing with?
- Am I denying that there is any real need for me or my congregation to move in this direction?

Begin ministry preparation with prayer, as Pastor Johnson did. Admission of fears to self and God is the next step.

2 Timothy 1:7 (NIV) says, "The Lord has not given us the spirit of fear, but of power, of love, and of self discipline." Psalms 27:1 (NIV) says, "The Lord is the stronghold of my life, of whom shall I be afraid?"

It may be helpful to memorize these verses, and then give the fears over to the Lord. Pray for courage and wisdom in dealing not only with persons with HIV but with any person with a terminal disease. Ask the Holy Spirit to give special sensitivity and courage.

Attitude Check

Chapter 1 addressed the negative attitude some Christians have towards persons with HIV infection, particularly homosexuals, IV drug users, or those with a sexually promiscuous lifestyle. Sometimes there is anger, hostility, and intolerance towards people who are living a homosexual lifestyle—even outright hatred. Some Christians are unable or unwilling to try to understand someone whose lifestyle is so different from their own.

Yet many pastors preach that God will forgive all sin if we ask Him to do so. Homosexuality and bodily abuse by use of drugs is sin, as is heterosexual promiscuity. Jesus will forgive these sins, just as He is ready and willing to forgive every other type of sin.

Pastors and Christian workers must confront their own attitudes about homosexuality, promiscuity, or anything else that causes barriers between them and the persons to whom they would minister. Christians must repent of these negative attitudes, feelings, and emotions and leave them behind when they move forward into ministry. Though Christians don't have to agree with the lifestyles represented by some of those who will be served, there must still be an acceptance of the individual receiving ministry. That person is God's precious creation, in need of an encounter with Jesus Christ.

If the idea that HIV is a punishment from God is embraced, examine again the thoughts expressed in Chapter 1. Think about the Ebola virus which has spontaneous outbreaks in Africa. This disease is twice as deadly as AIDS. It destroys every part of the body in about seven days. There is no cure and no way to even slow the assault of the virus. It is thought to be much more contagious than HIV. It is spread by sexual contact, as well as by other routes. Yet, it is not considered a punishment, but simply a deadly virus.

God hates sin, but He loves the sinner. How else would those who are now called Christians have been redeemed?

Do an attitude check:

- Do I think that AIDS is a punishment from God? Is that biblical?
- Do I feel the same about homosexuality as I do about heterosexual promiscuity?
- Am I uncomfortable interacting with a homosexual man or woman?
- What is it about homosexuality that makes me so uncomfortable?
- Do I hate or disdain this lifestyle?
- Do I hate or disdain the persons practicing this lifestyle?
- Do I believe that the sins of this person can be forgiven by God?
- Can I overcome my feelings about this subject enough to offer unbiased understanding and compassionate spiritual care?
- Do I need to ask for forgiveness for my lack of willingness to minister to persons so different from myself?

3. What Do Persons With AIDS Need?

Spiritual caregivers who have never worked with or even known persons with AIDS may find it difficult to know what their needs are. The best way to find out is to begin to develop a relationship with them.

"It was nice to have Pastor Johnson sit with me for a while today, even though I didn't feel like talking very much," Lanni thought. "I liked having him here."

Three visits later:

"Lanni," said Pastor Johnson, "I am enjoying getting to know you. I look forward to our visits together."

"Thanks, Pastor," Lanni said. "I do too. I had a question I wanted to ask you."

"Sure Lanni," Pastor said, "anything at all."

"Well, I know that I am going to die with this disease. But I don't know what will happen to me after I die," Lanni said, almost tearfully. "It really scares me."

"Lanni, I'm glad you asked that question because I wanted to tell you about Jesus. He loves you so much and wants to come into your heart and be your personal Savior." (Pastor Johnson proceeded to explain the plan of salvation and the concept of eternal life to Lanni and led him in a prayer of repentance.)

One week later:

Lanni sat by the window, deep in thought. "I hope Pastor Johnson comes today. I really look forward to his visits. He seemed nervous when he first started visiting me, but now he treats me like a friend. He's not afraid of me anymore.

"The nurses in this place avoid me. I notice that they don't touch me any more than they have to. I wish they would treat me like everyone else."

"Oh God," Lanni prayed, "Now that I know You, I feel more peaceful and I'm much less afraid of dying. But, well, I just wish You had a way of actually touching me. I can feel Your presence and that helps so much, but I just need someone with skin."

The needs given in this chapter come from people who have written about their experiences with AIDS. Every person is unique and it should not be assumed that these will be the experiences of all persons to whom ministry may be offered.

A person infected with HIV or who has AIDS needs to be thought of as an ordinary person who has contracted a terminal disease.

Despite the method of becoming infected with HIV, a person with a terminal illness wishes to be thought of as normal. Given people's sets of differing values and beliefs, a person with AIDS may feel that a pastor or chaplain will not be able to accept them due to their past (and possible present) lifestyles.

Response: Earlier in the chapter, we discussed the need to examine and deal with attitudes about homosexuality, drug use, promiscuous sexual activity, and lifestyles that differ from and are unacceptable to a person's own way of life. Ways in which a pastor might help a person with AIDS to feel accepted is by being

careful with the terminology used to speak about persons with AIDS. Persons with AIDS do not like to be referred to as victims, but rather just as persons with AIDS or persons living with AIDS. Using the term *victim* implies that they are powerless in the face of the disease and therefore hopeless. It is helpful to speak in terms of strength and hope, which obviously will be related to spiritual help when the time is right.

It is not helpful to ask individuals how they got infected with HIV. There may be an implication that they would be more acceptable if they got it in one way rather than another. It does not serve ministry unless the person chooses to relay that information. Asking about it may come across as judgmental, setting up barriers to communication.

It is not helpful to ask individuals how they got infected with HIV. There may be an implication that they would be more acceptable if they got it in one way rather than another.

Persons With AIDS Need to Be Touched

Persons with AIDS may suffer from a feeling of rejection due to their perception that people are afraid of them, their disease, or their lifestyle. They are particularly sensitive to the distance people put between them. With their own fears and despair and the physical pain and suffering, they experience an increased need for closeness. Yet the likelihood that someone will be willing to reach out and touch them is decreased.

Response: Don't be afraid to touch people with AIDS. Social isolation often occurs when people are dying with AIDS. Hospitalization is an isolating experience in any illness, but even more so with a contagious disease. For most people, social and physical isolation gives birth to a great need for human contact. Naturally, you need to form a relationship with the person first. When you have achieved a certain comfort level with the person, don't be afraid to hold his or her hand while talking. Hug the person if it is culturally appropriate. Whatever affectionate gestures are normally done between people in the culture, do those in abundance.

If the pastor is male, his wife can be a valuable link in ministry to persons with AIDS. Women may be more prone to offer affection freely and may feel less inhibited in developing a close relationship with the person being served.

The closer to death a person is, the more meaningful communication by touch may become. A kiss on the cheek would say a great deal about acceptance of that person. The HIV virus cannot be transmitted by these forms of casual contact.

If vomiting or bleeding occurs when you are close to the patient, wash your hands with soap and water immediately and call for someone to assist the patient. Caution must be exercised when handling body secretions, but normally that would not be a part of your contact with the person while giving spiritual care.

Persons With AIDS Have a Great Need for Relationships and Support

Persons with AIDS may be rejected by their families, shunned by their friends, and even held at a distance by the health professionals caring for them. The feeling that no one wants to be close further increases their feeling of isolation and aloneness.

Response: Taking time to be with a person with AIDS is very important. Developing a friendship that allows for easy sharing and allows the person to speak freely of his or her fears and concerns is essential. It is more important to listen rather than talk.

Use phrases that encourage people to share, such as:

- "What are you thinking about today?"
- "Are you feeling afraid?"

Sometimes just sitting with a person without saying anything may be what is needed. Be sensitive and follow the lead of the person. There is much to be learned and gained by knowing persons with AIDS. They have valuable insights and experiences to share. More may actually be received than will be given as a relationship develops and as pastors or providers of spiritual care have the privilege of knowing and caring for the person with AIDS.

Avoid the phrase "I understand what you are going through." It is unlikely that anyone can understand what it is like to have a terminal disease or to be facing certain death. It is impossible to know how it feels to have a disease which brings with it social stigma and rejection. Rather, a statement indicating that it is hard to understand what the person is going through may encourage the person to share concerns, fears, confusion, and dismay.

Most People With HIV Infection or AIDS Have a Desire for Spiritual Help

When death is inevitable, many people wish to reexamine their spiritual condition. They may want to have an assurance of life after death or a connection with a supernatural being. Many also have questions about why a loving God would allow such a thing to happen to them. Why would a small child have to suffer the horrors of AIDS? Be prepared for some difficult questions.

There may be anger and resentment against God, the church, and the person wishing to offer spiritual help. There may be an initial rejection of any attempt to speak about spiritual things. Try again, however. Don't accept an initial rejection

as final. There may be many sessions of questions and working through these issues before a person is ready to hear of a loving God.

This is a wonderful opportunity for pastors or the community of Christians to share the love of Christ with someone searching for and in need of His redeeming grace! Be sensitive as the subject of spiritual matters comes up. If approaching the person as a pastor, the pastoral role will bring an expectation of spiritual help.

This is a wonderful opportunity for pastors or the community of Christians to share the love of Christ with someone searching for and in need of His redeeming grace!

Usually, it would be best not to use the first visit to try to share Christ unless led by the Holy Spirit to do so, or if a direct request is made, or if death is imminent. Speak of the love of Jesus for this person, and of the mercy and grace available. Share familiar Scriptures. And definitely give the person the opportunity to pray to receive Jesus as Savior when you sense readiness. Talk about life after death and the assurance of eternal life. Pray for the peace and comfort of God to be present with the person. Don't be afraid to pray for physical healing. God is still a God of miracles and able to completely heal a person with AIDS. Speak in positive terms of strength, hope, and the bountiful and unchanging love of God.

4. Practical Ministry for Persons with AIDS

In addition to providing spiritual care to a person with AIDS, ministry includes reaching out in practical ways to demonstrate personal concern and the love of Christ. The actions and attitudes which the minister brings to the encounter are more important than the words spoken during the initial contact. Practical demonstrations of Christ's love may speak much more effectively than words. As AIDS becomes increasingly incapacitating, activities of daily living may become difficult or impossible to accomplish. Whether the person is hospitalized, in a center for terminal patients, or at home, he or she may be in need of outside help.

Though the minister may not personally be able to participate in all of these activities, pastors may be able to motivate church members to volunteer their services. The pastor will be the leader and the motivator to increasing the church's vision to reach out to those in need in the community and, in particular, to persons with AIDS. This will be discussed more in Chapters 5 and 6.

Business Matters

Persons with HIV infection may not have been able to get their business affairs together before becoming ill with AIDS. They may need to be put in contact with a lawyer or someone who can help them arrange their personal finances and see

to their desires for the distribution of their belongings after death. There may be an attorney in a congregation who would volunteer to serve persons with AIDS.

Meals

Depending on the location of the person with AIDS (home, center, etc.), he or she may not have meals available. Arranging with church members to deliver food on alternating days may be helpful. Before beginning this service, someone should discuss the dietary needs and likes of the person receiving meal help. Depending on the stage of the disease and the physical condition of the person, very specific dietary needs may exist. Even if meal service is provided where people with AIDS are being cared for, he or she may still appreciate a special meal or pastry brought in by someone in the church.

Caring for Property

If a person with AIDS is temporarily hospitalized or in a center, he or she may have a house, lawn, garden, etc., that requires attention. Volunteers from the church may be able to keep the property in order until further arrangements can be made. This is particularly important if the persons with AIDS have no family on which they can rely for help.

Child Care

In some cases, offering to care for children when the person with AIDS is hospitalized or too sick to care for them would be a tremendous relief and help. In a single-parent home, this would be even more critical. Worry over the welfare of children is a concern often expressed by those suffering with AIDS.

A critical concern of a person with AIDS without a spouse is what will happen to the children after he or she dies. In some cultures, the extended family will automatically assume responsibility. In other cases, the children may end up on the streets or as wards of the government. If there are no blood relatives who can step in, the church may be able to play a vital role in helping to arrange for the children to be incorporated into a family in the church. This would bring great peace of mind for a person dying with AIDS.

Running Errands

If a person is at home, he or she may be too sick or lack the energy necessary to go to the bank, buy groceries, go to the post office, pay bills, or take care of normal, routine activities. Offering to do these activities for the person or transporting them where they need to go is an act of kindness and demonstration of Christ's love. The physical capacity of a person with AIDS changes from day to day, and plans may need to be frequently altered accordingly to what he or she can do that day. Care providers should approach these voluntary tasks with an attitude of servanthood, caring, and flexibility.

Productivity

Until the final stages of the disease, people with AIDS wish to continue to feel there is meaning and usefulness to their lives. The dying process may be lengthy and drawn out, and it may be therapeutic to help them find activities that allow them to be productive. Perhaps the person could connect with someone who needs a task done that accommodates the person's physical limitations.

Until the final stages of the disease, people with AIDS wish to continue to feel there is meaning and usefulness to their lives.

Whatever the form of practical help, it is done unto the Lord. Read again the Scriptures given in the first part of this chapter. All of them urge the Christian toward practical care for those in need. Even the simplest of tasks done for another is ministry to Jesus himself. This type of ministry is living out Christianity as it was meant to be. The pastor's life and example will do far more than words in motivating congregations to lend hands of caring and compassion to those in need.

CHAPTER 4

Ministering to the Families of Persons with AIDS

"I wonder if my visit to Lanni's stepfather did any good," thought Pastor Johnson. "He seems so angry and wasn't very happy to have me come by. He didn't seem interested in the fact that Lanni was sick. He said he was unemployed, and since Lanni's mother had died, the stepfather hadn't had much contact with him. He knew he had AIDS, but said if he was gay, then he got what he deserved. I'm not sure that this fellow is going to be of any help to Lanni, but he sure seems to need some help himself."

"Lord," prayed Pastor Johnson, "How far do I take this? I don't know if I have time to work with this man. He seems so hard and bitter. He needs You so much. Help me, Lord, to sort out my priorities. Show me how to best use my time with Lanni and his family."

"We just couldn't risk the possibility of people not understanding. We felt it best to keep my brother's AIDS diagnosis a secret in our family. Somehow we thought we'd be rejected."

—A family member of a person with AIDS



Key Points

- 1. Dealing With the Facts of AIDS Transmission
- 2. Hope in Christ
- 3. Practical Helps for the Family

In many cases, the effect of an illness is rarely limited to just one person. Serious illness usually means a disruption of normal family life, regardless of whether the ill person is the child, parent, or spouse. The family experiences many special needs when the illness is terminal, as in the case of AIDS. Pastors who minister to persons with AIDS will usually minister to their families, as well. They, too, are in need of spiritual support, understanding, and the peace and comfort that Christ can bring.

In addition to the needs of any family members dealing with the inevitable death and loss of a loved one, the nature of the transmission of AIDS may bring increased family stresses that may require hours of counsel and help to resolve.

1. Dealing with the Facts of AIDS Transmission

There are two main ways in which HIV is transmitted between adults: sexual intercourse and the use of materials used to inject illegal drugs (needles, syringes, etc.). Thus, when the diagnosis of HIV infection or AIDS is made, parents may learn for the first time that their child is homosexual or has been sexually promiscuous or using drugs. In some cases, the family will have had no prior knowledge of this activity. A wife may learn that her husband has been unfaithful, has been visiting prostitutes, or that he has had sex with men. Children may learn that their father has done something very wrong. A husband may learn for the first time that his wife has been injecting drugs.

These are shocking revelations and can rock the very foundations of even the most solid families. The family, while discovering these behaviors and trying to deal with the shock and ramifications of the mode of transmission, must immediately and simultaneously grapple with the fact that a terminal disease is present and death will be the end result. Despite their feelings about the betrayal or deception or the way in which HIV was transmitted, they are now faced with the inevitable loss of this family member.

In other situations, a child of the family may be discovered to have AIDS as a result of a contaminated transfusion or a non-sterile procedure with contaminated equipment. A newborn may receive HIV from its mother. A blood transfusion years earlier may result in HIV infection.

Often rage and a feeling of total loss of control accompanies the knowledge of the diagnosis of AIDS.

A Christian family may discover that one of their immediate family members has AIDS and has been hiding his or her lifestyle. Questions arise as to whether to share this information with the pastor, the church, or other Christians. One such family member, when asked how the church ministered to her family when her brother was diagnosed with AIDS, said that the church didn't respond because the family chose not to share the information with the pastor or the congregation. They feared rejection and decided it was better to bear the pain and suffering alone than to face the possible scorn and humiliation they perceived might be there if their secret was known.

Allowing for Anger and Venting

Whatever the source of transmission, the result is the same. The family member will eventually die. In many cases, the initial response of the family is denial and confusion.

The following are common expressions of denial:

- "This can't be happening to our family."
- "It must be a mistake."
- "Maybe the test was wrong."

These emotions sometimes turn to helpless rage and hostility, and the person feels a need to lash out. The anger may be vented toward the guilty one, the person who did something unacceptable and now is causing the family to suffer. Or it may be vented toward a lover, the hospital, or a spouse who allowed it to happen. It may be vented toward God or to the pastor or the church that may be perceived to have failed the family or the person who acquired the infection.

Allowing the family to express and vent their anger is important in the pastoral role. It often takes weeks and months for the anger to dissipate, if ever it does.

In some cases, the anger against the person with AIDS is not resolved and the person is banished from the family to deal with his or her guilt in isolation. Occasionally, when the rage subsides, the anger may be directed toward a positive cause, such as involvement in HIV-prevention teaching or education against the use of drugs. This can be positive and therapeutic for the family and the person infected with HIV but often occurs later as the family recovers from the shock of learning of the HIV/AIDS diagnosis.

2. Hope in Christ

As the family learns to cope with the diagnosis of HIV infection, the role of the pastor will usually be one of listening and offering prayer. Attempts at reconciliation, if that is needed, may be futile during the stages of anger and denial. Eventually, a goal of reconciliation with the estranged family member should be set in motion. Transmitting messages between family members who are separated may be helpful. The goal is to help establish lines of communication between family members and encourage them to express their struggle.

The role of the pastor may be to help the family or person with AIDS channel their anger and frustration toward a positive cause. Find out what is being done in the community, if anything, and try to connect the family with local resources. There may be local support groups, and directing the family to them may be helpful.

However, the most urgent need for all concerned is to receive strength and help from God. When a trusting relationship has been established between the pastor and the family, begin to assess their spiritual needs. If they are not believers, there may be an opportunity to introduce the family to the love of Christ.

While presenting hope for eternal life for themselves and the family member suffering with AIDS, do not present false hopes for recovery. Prayer for healing is always appropriate, but the family must also face the reality of impending death and prepare themselves for that.

While presenting hope for eternal life for themselves and the family member suffering with AIDS, do not present false hopes for recovery.

Without hope for eternal life, that preparation would be difficult if not impossible. Once Christ is introduced into the family unit and if and when the person with AIDS receives Christ, then the family can be given hope of eternal life for themselves and the family member and a promise of a reunion in the future.

The previous paragraph strongly demonstrates why the pastor, the Christian, and the church should be on the front lines of support to persons with AIDS and their families. Humanitarian group and secular organization cannot offer the hope of eternal life with Christ. That is the greatest hope for someone who is dying—no matter the cause of death.

Therefore, spiritual care for the families dealing with AIDS will be personalized for the situation. It should, however, include:

- Intent listening.
- Allowance for venting of anger.
- Guidance in channeling anger into positive efforts to bring about change.
- Attempts at reconciliation if separation has occurred.
- Prayer for a personal relationship with Christ that will assure eternal life.

3. Practical Helps for the Family

"My wife's casserole does smell good," mused Pastor Johnson as he and his wife made their way through rush hour traffic to Lanni's stepfather's home. "I wonder if I will be more warmly received this time. Ah, well, it doesn't matter. I just pray that he will be able to see our love and concern for him and get a glimpse of Christ's love. Lord, please help him to interpret this gesture as love and not pity. Please touch his heart and soften him to your compelling love."

While showing spiritual care for the family dealing with AIDS is good, this care should also extend into the physical realm through practical demonstration of the love of Christ. As the pastor begins to deal with the family and the person with AIDS, their needs will soon become evident.

Finances

One of the greatest sources of stress during times of physical crisis is trying to finance the physical care that is necessary to sustain life as long as possible. In many cases, the person with AIDS will not have adequate finances for his or her care. If he or she is fortunate to have insurance, it may not cover all of the costs involved with the care. In many countries, health insurance is not available at all. Other countries practice social medicine where the hospitalization may be free but all medicines must be purchased. Sometimes the entire financial responsibility falls to the family of the person with AIDS.

The church can respond in various ways to this need:

- Special offerings may be taken, but in countries where many people in the congregation have family members with AIDS, the financial resources of the church may not be sufficient for the needs.
- Organizing individuals or groups within the church to help with food is a practical assistance for those affected by HIV/AIDS who don't have adequate food resources. The food may be for the persons with AIDS or for the families struggling to pay for medical costs.
- Some churches have set up a feeding kitchen. Every family in the church contributes a small amount of food ingredients or whatever is needed. Volunteers cook for the people with AIDS who are unable to do it themselves. This may also help to lift the continual responsibility from the family for feeding the person with AIDS.
- In farming communities, a member of the church donates a field or garden to be used as a project garden. With volunteer labor, the proceeds from sale of the harvest are used to set up a fund for those suffering from AIDS. The distribution of the funds could be decided upon by a project committee formed by the church. If the family is primarily responsible for the financial care of the person ill with AIDS, then they would be the recipients of the food.

Each church community in different countries and cultures can find a unique way to raise funds or lend a hand to families dealing with AIDS. In some way or another, the church should be reaching out to help during the crisis, even if the families are not members of the congregation. What better way to demonstrate practical Christianity and bring them to a relationship with the Lord?

Relief from Continuous Caretaking

Caring for a person with a terminal illness, especially one with as many complications as AIDS, can take a tremendous emotional and physical toll on family members and friends who are involved continuously with the care. Even if the person with AIDS is hospitalized, there is a stress related to continual visits and trying to bring comfort and cheer to someone desperately ill.

A form of ministry that may be greatly appreciated would be for volunteers to take over the care from time to time, allowing the family to retreat, go shopping, or get away for a weekend to become renewed and strengthened.

Burnout (fatigue from too much of the same thing) occurs frequently in caregivers for persons with chronic disease. Pastors, too, need to be aware of the potential for burnout if there is frequent involvement with chronically ill and terminal patients, and they may need to step away and let others take over for a time.

Inclusion in the Body

It is not only the person with AIDS who often feels rejected and ostracized by the community but also other family members and friends. Often family members are feared or shunned because someone in their family has AIDS. Sadly, sometimes persons with AIDS are not welcome in the body of Christ once their diagnosis is made public. Some families try to hide the fact that someone in their family has the disease, and they are left to carry the burden alone.

Christ's ministry was to reach out to those who were socially ostracized and considered outcasts by society. Recall the story of the Samaritan woman at the well. She was considered a sinner with a lifestyle unacceptable to the Jewish world. Jesus recognized how much she needed Him and reached out to her with love, compassion, and forgiveness. Jesus said that He didn't come to save and heal those who were whole, but those who were broken and in need of a Divine Physician.

The church cannot turn its back on persons with AIDS or their families. They have been broken by the tragedy that has come into their family by whatever means, and are in desperate need of healing and help and the relationship of a caring community!

It is ironic that persons with AIDS are often taken in by those with secular social concerns before they are welcomed into Christian churches.

It is essential to include persons living with HIV/AIDS and their families in all church activities. Personal invitations to each one should be the norm. Accepting them into the church is the key to bringing them to the knowledge of Christ, if they do not already know Him.

Recall the verse in James 2:14–16 that says, "If you see your brother in need and don't respond, how can the love of God be in you?"

A dynamic way to help youth groups become aware of their responsibilities as Christians in a troubled world is to have them reach out to people with AIDS. Spending time with persons with AIDS will dramatically change young people and help them in their spiritual development. While spending some time on educating young people about avoiding HIV infection, give equal time to equipping them to care for and minister to those who have been infected.

There is no risk of infection by having persons with AIDS in the congregation. The Christian community, the church, must reach out to these hurting people with a hand of fellowship and love.

Pastor Johnson looked up in surprise as he concluded his Sunday morning sermon. Lanni's stepfather was in the back row. He waited to speak with Pastor Johnson after the service and said that he would like to visit Lanni and asked if he would go with him. Pastor Johnson said that he would be glad to, but he asked if perhaps the stepfather would like to get things right with the Lord first. He led him in a simple prayer of repentance, and together they went to the hospital.

CHAPTER 5

Church and Community Awareness

"O Lord, it has been so wonderful getting to know Lanni. Thank you for touching his life with Your love," prayed Pastor Johnson. "Thank you for allowing me to be the one who brought him the good news of Your redeeming and forgiving grace. Thank You for bringing his stepfather to a knowledge of You and for the reconciliation with Lanni. You are so good. Lord, there are so many others suffering from AIDS. I can't reach out to all of them. Give me wisdom, Lord, to share my burden and vision with others. Help my congregation to see what I see when I look into their desperate eyes—just people needing You."

"I feel more acceptance from church people now, though some still seem to keep me at a distance.

I guess it takes time."

—Journal entry of a person with AIDS



Key Points

- 1. Board Meetings and Legal Counsel
- 2. General Congregational Meetings
- 3. Dialogue With the Youth Group
- 4. A Call to Prayer
- 5. Practical Helps

How can pastors share their burden for ministering to persons with AIDS and their families with others? There is so much to be done, and for those whose days before death are numbered, so little time to do it.

1. Board Meetings and Legal Counsel

Prior to a general congregational meeting, the official church board should be summoned to discuss the mission of the church as it relates to ministry to persons with AIDS in and outside of the church body. Some policy statements may need to be drawn up and legal counsel sought. At times, there may be a plea from church members to keep persons known to be HIV positive out of the church nursery, for example.

Though the possibility of transmission in this setting may be minimal or non-existent, the church could be held liable if a child is diagnosed with HIV and the parents feel it was contracted in the nursery. On the other hand, banning

an HIV person from a church activity such as nursery duty may also have legal implications. Seek legal counsel and be knowledgeable about these issues before going into a general meeting.

2. General Congregational Meetings

As a pastor commissioned to lead the congregation by biblical patterns, a special meeting of the congregation may be called to discuss the issue of ministry to persons with HIV infection or AIDS and their families. The meeting may begin by laying out the biblical foundation for ministry to the whole person. The life of Jesus portrays so often His compassion to reach out to people who were suffering physically, as well as spiritually. Share verses from the Bible which demonstrate this theme from the life of Christ (Matthew 8:16, 17, with references to Isaiah 53:4, 5: "He took up our infirmities and carried our diseases;" Mark 2:5–12, Matthew 14:14, "...and Jesus was moved with compassion," etc.).

Scripture clearly supports the premise that Christians must follow Christ's example in reaching out to both physical and spiritual needs. The Bible speaks of body, soul, and spirit as one, and ministry as reaching out to the whole person. Therefore, a Christian's approach to ministry would include reaching out to physical, emotional, and spiritual needs.

After presenting biblical mandates for the church's involvement in compassionate ministry to those in need, saved or unsaved, begin specific dialogue with the congregation to assess their interest, desires, and concerns.

Fear will often be the initial response. Anger may be expressed.

A typical response is that others will be driven away or kept from coming to the church if we have people with AIDS in the congregation. Some will be concerned about contracting the virus if they reach out to these individuals; others will bring up the punishment of God for sinful lifestyles.

Be prepared to give answers in a non-defensive way. The pastor may want to reread earlier chapters of this manual. Using Scripture, gently build a case for the church's responsibility in this type of ministry.

Offer to bring in a health professional or expert to talk about HIV infection, risks, and prevention. Be sure to interview the experts before bringing them to your congregation. There are health professionals and others who have gotten sidetracked into strange interpretations of how HIV is transmitted and where it came from. For example, some feel that the spread of the HIV is secretly engineered by the government. Others will emphasize the "punishment from God" theory. These nonscientific transmission theories would add more confusion than help to the congregation.

3. Dialogue with the Youth Group

Offer the same type of dialogue and opportunities for information to the youth. After adequate time for discussions and questions has been given (perhaps over several sessions) and an expert has been brought in to provide education and help, issue a call to prayer to the congregation with the youth included.

4. A Call to Prayer

Ask the congregation to pray for guidance in knowing if and how to reach out to persons in the community who are HIV infected or have AIDS. If it is not prevalent, there may be other concerns such as drug users, homeless persons, or prostituted women. Perhaps the church cannot be involved in all of the social issues that are present, but ask for prayer for guidance.

Depending on the church, the pastor may decide to form a special committee. In some churches, the congregation is small and everyone will be involved. Begin to strategize together as to how the church might reach out to persons with AIDS, to families, and to the community at large.

5. Practical Helps

Present some of the opportunities for practical helps given in Chapters 3 and 4 if there are no ideas from the congregation. Assign someone or a group to find out what the prevalence of AIDS is in the community near the church. Have the group find out what community activities may already be in place for help for persons and families with AIDS.

Bring the youth into these discussions and allow them to develop strategies within their group to reach out in Christ-like fashion.

The challenge of the church is to be a lighthouse in the community, the salt of the earth, a city on the hill that cannot be hidden (Matthew 5:13, 14). Christ is calling the church to be a beacon of His grace and truth to spread His love to the world.

The church that does not look beyond its own borders for ministry is a church that will surely wither and die. The church can no longer look the other way, excuse their noninvolvement with righteous indignation, and leave the social work to others. Christianity demands Christlikeness. Christ served those in most need as He demonstrated servanthood to the downtrodden, the greatest of sinners, the doubters, and the unlovable. The church, in following His example, must respond to the challenges of a new day. Christian compassion demands a response!

CHAPTER 6

Hospice Care

"I'm feeling a little better today," Lanni thought. "It has been good to talk with Pastor Johnson. He has become a good friend, and I know he really cares about me. I'm so glad to know that my sins are forgiven and I am going to be with Jesus soon. It has been good to see my stepfather again. He seems changed. But I can't go to his house; he is barely making it financially. Even so, I wish that I didn't have to stay here in the hospital. It's so scary here at night when I'm all alone. I wish I could even be in the main hospital building with the other patients. Mostly, I just wish I could go home—if only I had a home to go to. I'd just like to get out of here and die with some other people around—people who just might cry for me when I'm gone."

"Having people around me who know what I'm experiencing helps me. I can't stand being in the hospital again. I'd rather just die."

—Person dying with AIDS



Key Points

- 1. What Is Hospice?
- 2. Forming a Hospice

1. What is Hospice?

Hospice, meaning *host* or *guest*, is a word taken from medieval times when guest houses were established as places of shelter and food for travelers on their way to the Holy Land. The term was picked up again in Britain where there was the realization that hospitals were not able to provide a comfortable environment for the dying. It is now common in many countries to establish some type of facility or service to care for terminally ill persons who do not wish to remain in an institution such as a hospital for their final days.

Hospice really means providing a supportive environment for a person who is dying. It is not necessarily a place for care as much as a way of caring for a terminally ill person. Support may be in the form of providing health care staff to meet physical needs and pastoral staff to meet emotional and spiritual needs. Volunteer staff will often be available to do whatever needs to be done to make the person's final days as comfortable and meaningful as possible. Support and ministry is also offered to the family of the person who is dying.

Hospice sometimes takes place while the persons remain in their own home, or in the home of their family. The support people mentioned above visit the person in their home environment and offer whatever service is needed. The family is often involved in the care and is given assistance when needed.

Hospice may also take the form of a center where people can come for more supervised care. Some persons with AIDS, for example, who may have come out of the drug culture may have no home or family to whom they can go. Though family may exist, persons with AIDS, due to their lifestyle or other family situations, may not be welcome in their families.

Usually the environment of a hospice center is as homelike as possible. Sometimes this type of center is begun in someone's home—someone who has extra room and can take in several people. Medical equipment may be necessary but is usually kept to a minimum. A supportive atmosphere is maintained and hope, rather than despair, is instilled. While able, persons admitted to hospice try to assist with the function of the center and are given responsibilities which help to make them feel productive.

Spiritual care is offered consistently. If the hospice is a Christian organization, a pastor may be on call or even reside at the center or home so that spiritual help is available and offered at all times. If the disease process becomes critical, persons may need to go to a hospital, but it is usually their choice and they may wish to die at the center rather than face another hospitalization.

In some countries which deal with a large number of AIDS cases, hospitals will not admit anyone who has AIDS. Often there are not enough resources and not enough beds, and the few that exist are saved for people who may live and not used on those who will definitely die. Christian hospice centers may become an alternative in such situations.

In some countries which deal with a large number of AIDS cases, hospitals will not admit anyone who has AIDS.

The development of such a center should, it seems, be a tremendous opportunity for the church to reach out in Christian love to those who are suffering. Some churches have formed Christian care centers or hospice centers and have found many ways to demonstrate the love of Christ and to lead many to the Kingdom in their final days of life on earth. Despair turns to joy as Christ becomes all in all and His peace and love become sustaining as death draws near. Fellow Christians and persons of like experience stay together and draw strength from each other. Isolation is lessened, and a family feeling is more likely in a hospice environment. Friendships form, and for persons like Lanni, death is mourned and there is someone to cry when a person in hospice passes on.

Radiant Life Center

A beautiful example of hospice care is the Atunbi House developed by Radiant Life Center in Pittsburgh, California, USA. A nurse, filled with compassion for an acquaintance that had AIDS, opened her home to offer care for this person in his final days. It soon became evident to her that others were in need of the Christlike care that she and others could offer. She moved out of her home and Radiant Life Ministries converted her house into a Christian care center.

The philosophy of the program is: "Atunbi House is committed to preserving the sacredness of life as we promote wholeness in those suffering and dying from AIDS." Atunbi House provides for the physical and spiritual needs of the residents through:

- Twenty-four-hour attendant care.
- Nursing care services, as needed.
- On-site support group and counseling service.
- Nutritionally balanced meals.
- Transportation for medical, recreational, and social needs.
- Continual communication with physicians and support in treatment therapies.
- Support and guidance through the bereavement process—both for the family and the resident of the center.

The center is supported by donations from individuals, churches, and the community.

Project Hope

Another example of this church-based concept is in Santiago, Spain, where Assemblies of God missionaries Don and Bonnie Stuckless became burdened for the drug addicts of their area. As they began to work with these individuals, they found that many of them had AIDS and some had no place to go. They began opening their home for some to live with them until they could go to a drug rehabilitation center. They are finding that about 95 percent of the drug addicts with whom they work are HIV infected. Many of these also have tuberculosis and hepatitis. Nine of the people that they have worked with in recent years have died from AIDS. Many have received Jesus Christ as Savior as the Stucklesses have worked with them.

Plans are in process to establish a hospice or care center where persons in the final stages of AIDS can come to receive love, comfort, and care from a Christian perspective, and where they can live as fully and as comfortably as possible as they are prepared for the next step: eternal life.

2. Forming a Hospice

Regardless of whether a church is in a rural or city setting, some kind of a home or hospice could be developed for persons with AIDS. Since some hospitals and clinics in a number of countries will no longer accept infected persons into their facilities, persons who are dying with the disease need a place to go. Legal requirements may need to be met in some countries.

A church member may have a building that could be donated or sold to the congregation to be transformed into a hospice. If not, a simple structure could be built using inexpensive materials. The building does not have to be luxurious, only comfortable. Church members may wish to donate money, materials and/ or labor to the project.

Having good circulation of air through the home and plenty of light will make a pleasant and healthy atmosphere. Beds may be brought in by family members or built from local materials. Regular hospital beds are not necessary. Primarily, this facility will just make a person as comfortable as possible, but will not offer much in the way of medical care. However, a medical person, perhaps a nurse or doctor from the church, could help by donating several hours a week to stop by the hospice, just to check up on the persons and perhaps administer pain-relieving drugs if indicated. Food may be brought in by family members or by some of the methods mentioned in earlier chapters. Spiritual care and persons to sit with those who are close to death should be offered. The youth may be able to come and sing to the patients in the hospice.

Above all, an atmosphere of love, compassion, and godliness should be provided. Opportunity to accept Christ should be given to those who don't know Him.

The church, in providing this kind of care, is living out its faith. It is love in action and it will be a witness, not only to the persons with AIDS and their families, but also to the community at-large. This may be a witness that will draw many non-believers into the kingdom of God. At the same time, it is a needed and valuable service that can be offered to the dying.

Do not be afraid to start, even if it is a small room for one or two persons. God will bless and honor the effort and will multiply the resources.

Pastor Johnson and his wife hovered near Lanni's bed as he slipped closer and closer to death. Tears flowed freely down their cheeks as they watched his life ebb away. Knowing Lanni over these months had changed them. Somehow, they seemed to know themselves better. Watching Lanni's physical deterioration had been horrible, yet watching his spiritual development and his realization of a hope in Christ had been glorious. Ministry has new meaning for the Johnsons now. Their vision for their church has expanded and some members are beginning to sense it too. There are many Lannis yet to be touched—needing to be served.

EPILOGUE

I'm not quite sure how we became friends, but a young, effervescent girl made her way into my heart and into my life. Our friendship began during my early days as a medical missionary in Zaire, Africa. In my 14 years of service there, she became my closest Zairian friend.

Life in Zaire was hard, and Rebekka's life was filled with many heartaches. Her sons were sent away to another country by her husband, who then left her. Her daughter died at the age of 5. I journeyed through some of those difficult times with her. I noted that, despite the difficulties, her faith in God stood firm.

Several years ago, I received the sad news that she had been found to be HIV positive, not an unusual diagnosis in that part of Zaire. Other missionaries had taken her under their wings and become her friends, too.

Ironically, on the day of the original, final edits to this book, I received word that Rebekka had died. I and others are crying for Rebekka. Crying because we are sad to lose her—but crying for ourselves, not her. Though she had neither husband nor children with her, she was surrounded by a loving community of friends and believers in her final days.

Though I am grieving the loss of my friend, I can envision her transported from her little mud and thatch house and her bamboo bed into a heaven that is surely more than she could ever have imagined.

I won't cry long for Rebekka. She's home.

REFERENCES

- Barnett, Tony, and Piers Blaikie. 1992. *AIDS in Africa: Its present and future impact.* New York: Guilford Press.
- Crespo, Richard, ed. 1988. AIDS and the international organization: policy development guidelines for organizations with overseas staff. Brunswick, GA: MAP International.
- DeVita, Vincent, Samuel Hellman, and Steven Rosenberg. 1985. *AIDS: Etiology, diagnosis, treat- ment, and prevention*. New York: Lippincott-Raven.
- Donnelly, Katherine. 1995. Recovering from the loss of a loved one to AIDS: Help for surviving family, friends, and lovers who grieve. New York: Ballantine.
- Douglas, Paul, and Laura Pinsky. 1992. The essential AIDS fact book. New York: Pocket Books.
- Fisher, Mary. 1995. I'll not go quietly: Mary Fisher speaks out. New York: Scribner.
- Garwood, Anne, and Ben Melnick. 1995. *What everyone can do to fight AIDS*. San Francisco: Jossey-Bass.
- Johnson, Earvin "Magic." 1992. What you can do to avoid AIDS. New York: Times Books.
- Kiiti, Ndunge, Meredith Long, Esther Gatua, David Sorley, and Debbie Dortzbach, eds. 1993. Facts and feelings about AIDS: Learning about AIDS in Africa, a guide for community trainers. Nairobi: MAP International.
- Kiiti, Ndunge, Meredith Long, Esther Gatua, David Sorley, and Debbie Dortzbach, eds. 1993. *AIDS in your community*. Nairobi: MAP International.
- Landau-Stanton, Judith, Colleen Clements, and associates. 1993. *AIDS*, *health and mental health*, *A primary sourcebook*. New York: Brunner/Mazel Publishers.
- Mueller, Howard E. 1987. AIDS: A Christian Response. St. Louis: Concordia.
- Shelp, Earl, and Ronald Sunderland. 1992. *AIDS and the church: The second decade*. Louisville, KY: Westminster John Knox.
- Sunderland, Ronald, and Earl Shelp. 1987. *AIDS: A manual for pastoral care.* Philadelphia: Westminster John Knox.