3

GLOBAL AIDS PARTNERSHIP

HIV/AIDS
A Manual for Home-Based Care

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Contributing Editors:
JoAnn Butrin, Ph.D.
Christine Morgan, M.A.
Beth Davis, M.A.
Jenny Pandolfo, R.N.
Nancy Valnes, R.N.
Brenda Strysko, C.N.M., M.S.N.

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A Global AIDS Partnership Publication
1445 North Boonville Avenue
Springfield, Missouri 65802 USA
Phone: 417-862-2781, Ext. 2079
Email: info@globalaidspartnership.org
Website: www.globalaidspartnership.org

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It is the hope of the consultation group and the editors that in the midst of the most horrific crisis of modern day, this manual will provide a useful guide to offering compassionate, thoughtful care to those in desperate need.

TABLE OF CONTENTS

INTRODUCTION

It is devastating to receive a diagnosis of HIV infection. Even if the person suspects he or she might be infected, to hear the words, "I'm sorry, but you have HIV," is overwhelming. The diagnosis has far-reaching effects on the life of both the individual and his or her family and loved ones.

However, receiving a diagnosis of HIV infection cannot tell someone how long he or she is going to live! It doesn't provide any information on the person's state of health or determine if an HIV-related disease is present. The positive side of receiving the diagnosis is that it allows infected individuals and their loved ones to make good decisions regarding medical care and healthy living. And it allows them to think to the future, and plan what they can do when the person becomes ill.

This manual looks at the progression of HIV infection from the moment the diagnosis is received, until the time the person starts to become sick with AIDS. As the infection progresses and the person becomes sicker, he or she may need someone to help care for certain physical needs. This manual presents ideas on ways that family, friends, community, and church can come to the assistance of a person when they become too ill to care for themselves.

Hospice Care: Home-Based Care and Facility Care

The word *hospice* was first used in England to describe a *resting place* for weary travelers. Today, *hospice* usually means offering physical, emotional, and spiritual care to individuals and their families who are facing a life-threatening illness. It assists family and friends in adjusting to the reality of illness and its consequences.

Every year throughout the world, the number of people who are sick with AIDS is increasing. This puts a heavy burden on the traditional systems of caring for those who are critically ill. Medical costs are high, and some families don't have the resources to pay for such care. In some areas of the world, so many people are sick with AIDS that the number of healthy people available to care for the sick is limited. Some are dying alone, a situation greatly dreaded by people across the globe.

People needing physical care are often dependent on relatives for assistance. Many prefer to be cared for at home. Others have no one at home to help them and need people in the community to come to their aid. People living with HIV infection may not have resources to pay for formal medical care. However, churches and other community groups are developing hospice care facilities where people sick with AIDS can receive the care they need as they face the end of their lives.

Purpose of the Manual

The purpose of this manual is to:

- Discuss the physical, emotional, and spiritual needs of a person living with HIV/AIDS.
- Teach basic caregiving skills which will prepare family, friends, and members of the community and church to offer care to a person facing the end of life.
- Address the needs of the caregiver.
- Discuss various options for care, including the implementation of hospice care in a home or a hospice care facility.

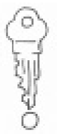
This manual can serve as a guide or training manual for family members, friends, volunteers, or employees who will or are caring for someone who is facing the end of life. It only provides ideas and information: there is no one way that is the right way to offer care. Each person's needs and responses are different, and care will need to be tailored to accommodate those differences.

Culture, ethnic background, and the manner in which care is offered also play a role in the way in which a person responds to end of life issues. Though this manual cannot address the myriad of cultural diversities represented by potential caregivers, it is felt that there will be enough similarities that adaptations of the information presented will be possible.

Section 1:
Offering Emotional Care

CHAPTER 1

Receiving the Diagnosis of HIV Infection



Key Points

1. **Individual Responses**
2. **Fears of a Life-Threatening Illness**
3. **Common Reactions to a Diagnosis of HIV Infection**

Role-Play

Person (who is ill): *"What's going to happen to me? I can't believe I'm really going to die. What will happen to my children? I wonder how long I will live. Maybe the doctor is wrong—I really don't feel very sick and certainly don't feel like I'm going to die."*

Friend: *"Listen; there is no need to ask all those questions now. Just try to put it out of your mind. Maybe the doctor is wrong, like you said. You should try not to think about it and just go on as you were. Everything will be okay."*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

Questions for Discussion

Disbelief is often the first reaction that occurs when a person receives a diagnosis of HIV infection: "This can't be happening to me!" The person receiving the diagnosis needs to verbalize his or her emotions. But the person who hears those words may have no idea what to say. Consider the following questions:

- What do words like "Try not to think about it" communicate?
- What do you think a person really needs at this time?
- How might you help see that those needs are met?
- What are some common reactions that people have when they first hear that they have a life-threatening illness?
- What types of reactions follow?

As the role-play illustrates, persons who have learned that they have a terminal illness, no matter what it is, are usually shocked. Maybe they thought something serious was happening and now their suspicions are confirmed. But for others, it will come as a total surprise.

It is helpful for both those who have found out they have the virus and their loved ones to be aware of the many emotions that come along with the diagnosis. This section discusses some of these reactions.

1. Individual Reactions

After receiving the news of HIV infection, no two individuals will react in the exact same way. Many factors impact how a person responds. These include the individual's personality, cultural or ethnic background, faith, available resources, available family, etc. However, people in end-of-life situations commonly have certain experiences. These experiences may serve as a preliminary guide to help the patient, their loved ones, and caregivers know what to anticipate.

2. Fears of a Life-Threatening Illness

Individuals with a diagnosis of HIV and their loved ones, experience a wide range of feelings when they realize they are faced with a life-limiting illness. These feelings are sometimes difficult to talk about and are often mixed with positive and negative emotions. They are often confusing and difficult to understand.

- **Physical pain**. Physical pain often is the main concern to people who are facing the end of their lives. This raises fear and worry for both the patient and their family members.

- **Increasing dependence on others**. Increasing dependence on others can be a major source of suffering and presents a series of gradual losses for the individual. Many people have more distress from being unable to function than they do from physical pain. They think, "When I become sick, I will not have control of my life and will have to rely on others to do things for me." It is important to help the patient to retain control for as long as possible.

- **Isolation**. There is also a fear of isolation from family and friends. A person may have few visitors and may have fewer as time passes. They may also be forced to deal with the sadness of failed plans regarding friends, family members, job, etc. They may also feel isolated from society, work, friends, meaningful communication, and involvement in life activities.

- **Future for loved ones**. A patient can become very distressed while speaking of loved ones. Such sadness may center on:

    o The effects that the illness has on the loved ones.
    o The impending separation.
    o The fear of the future.

- **The search for meaning.** The person who is dying may tend to review and evaluate life and search for meaning in their past as well as in the present illness and suffering. There is a strong desire in each of us to believe that our life has been meaningful and useful.

- **The process of death and dying**. Some people with HIV experience a fear of dying alone. There is also fear that pain and symptoms will not be controlled. Some people will want to talk about heaven and eternity.

Changing Our Expectations

A patient must progress through the grieving process in order to be able to change expectations. More about grief will be explored in further chapters.

Expectations must be changed or they will lead to discouragement, disillusionment, and despair.

- Proverbs 13:12—Hope deferred makes the heart sick.
- Proverbs 18:14—The human spirit.
- 2 Corinthians 4:7–9—We are hard pressed, but God does not abandon us.
- Hebrews 13:5–6—God will never fail you.
- Revelation 21:1-7—God will wipe away every tear.

3. Common Reactions to a Diagnosis of HIV Infection

Many authors have written about the responses or stages that people go through when faced with loss. Every person and every culture find their own ways of coping, but there are common thoughts and emotions associated with the news that a person has HIV/AIDS or any illness that will ultimately take his or her life. The following are taken from, *Living with Dying, Dying at Home*, AIDS Committee of Canada 1998.

- **Shock or numbness**. When people first learn of their diagnosis, there is often a period of disbelief or disorientation, a feeling of shutting down because the emotion is too much to bear. People often say they feel numb or don't feel anything at all, as if they're suspended in a cloud where nothing makes sense. Persons may feel physical symptoms such as nausea or vomiting, but often there is simply no feeling at all. This usually passes in a few days as the reality of the situation sets in. The next emotion is often fear.

- **Fear**. Fear is an emotional response to something recognized as a threat or danger. It can also be due to something unknown or something that is not understood. The diagnosis of HIV infection brings people face to face with the fear of death, disfigurement, or abandonment and dying alone. Usually fear brings anxiety, which can leave a person feeling out of control.

- **Anxiety**. Anxiety is an uncomfortable feeling of tension or dread that occurs when we face a threat to our physical or psychological state. Feelings of anxiety may be mild, moderate, or severe. If not brought under control, severe anxiety can lead to panic.

- **Guilt**. Guilt is a common response among people with HIV/AIDS. It is common for people to blame themselves for getting infected or to feel guilty about infecting others. Some people may feel guilt for their lifestyle or feel that they are being punished by God. Women may feel guilty about being bad mothers or that they will be leaving their husbands and children. Guilt can be a very consuming and destructive emotion during the process of death. It is a time when spiritual help, which brings God's forgiveness and strength, will be of great importance. This will be discussed further in Lesson 5.
- **Denial**. In denial, people refuse to acknowledge any thoughts, feelings, or concerns about what they are facing. It allows them to maintain control by shutting out those negative feelings. Some people refuse to admit that they're dying. Sometimes Christians who believe in divine healing deny that they will die; they insist that they will be healed. Though the Bible instructs us to believe that healing is possible, sometimes healing actually comes through death.
- **Anger**. This is one of the most common emotional responses to AIDS. People may be angry with the person they believe gave them the disease. They may feel angry with God, feeling that He has deserted them or allowed this to happen. They often feel powerless and helpless knowing that there is no cure or that they are living in a country where the drugs that prolong life are not available. Anger may be expressed by the use of bad language or lashing out at those around them. There may be intense negative feelings expressed toward certain individuals and toward God. At first, people may refuse food, treatment, or any type of help. Once the anger subsides, this may change.
- **Depression**. When people turn anger or guilt inward, they often become depressed. Depression is when a person is overcome by sadness, pessimism, listlessness, hopelessness, and emptiness. The diagnosis of HIV infection can often bring on depression because of the inability to find hope of being cured. Sometimes the depression can become so severe that a person refuses to eat, sleeps all the time, and cannot or will not talk with anyone. This is called *clinical depression* and is very difficult to deal with for the caregiver.

These feelings provide the means, the energy, and the ability to move the person to a healthy adjustment to his or her loss, rather than getting stuck in the process. The goal is to encourage the sharing of such feelings, which makes it possible for the person to move through the feelings and complete the process.

- **Resolution or peace**. Resolution is the process of acceptance of the illness that is threatening one's life and the ability to find peace and comfort and eternal hope in the ending days of life. Not every person reaches this stage, but it is a goal of hospice to provide the emotional and spiritual support to help a person to come to this point and spend one's final days with the least amount of struggle possible.

We will discuss more about grieving and counseling in further chapters.

Questions for Discussion

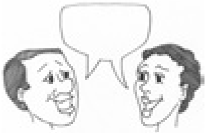
- After reviewing the above reactions to loss and a terminal diagnosis, how do you think they relate to your culture?
- Which of these reactions have you most commonly observed? Why?
- Do you feel that people tend to die peacefully? Why or why not?

CHAPTER 2

Preparation to Become a Caregiver

Key Points

1. **Personal Issues of Caregivers**
2. **Qualities of a Caregiver**
3. **Special Concerns for the Caregiver**
4. **Coping Strategies for the Caregiver**
5. **The Importance of Self-Awareness in Caregivers**



Story of Louisa

"My sister seemed so sad today. I feel like I don't know what to say to her anymore. I know she is concerned about her children and the money is running out. I have to try to find another job so I can help more with the finances, but then who will watch out after her? I can't seem to sleep anymore. When I do fall asleep, I have awful nightmares. It seems everything is about death. My body feels so heavy, like I could just fall over. I know I need to eat more. I'm losing weight, but I'm not hungry and my poor sister can't eat at all, so why should I? I don't think I'll bother praying anymore because it doesn't seem to be doing any good. Things are just getting worse."

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

Questions for Discussion

- What do caregivers need when caring for someone who is dying?
- What are some of the signs that a caregiver may be having difficulty?
- How can difficulties like this be avoided or taken care of?

1. Personal Issues of Caregivers

Before being able to help someone else, it is important for caregivers to examine their attitudes, fears, and personal issues. For example, if a caregiver has recently undergone a personal loss, he or she may not yet have completed the grieving process. Being with someone else who is dealing with a loss may cause a range of emotions that could interfere with one's ability to be of assistance to another.

A caregiver should also examine his or her personal feelings about HIV/AIDS and any judgmental attitudes that may be present concerning the way in which the virus was contracted. Often the first step to providing meaningful care is to come to the care-giving role with the heart of Christ: without an agenda and simply to give love and care.

The person who is going to become the caregiver needs to be prepared to experience a variety of emotions that will be felt and often expressed by the persons for whom they are caring.

Questions for Discussion

- If you were facing death, how do you think people might help you the most?
- What are some qualities that a caregiver might have that would be helpful to someone who is facing an end-of-life/terminal illness?

2. Qualities of a Caregiver

Not everyone chooses to be a caregiver. The person closest to a sick person will often be expected to take on that role. Whether voluntary or by nature of the relationship, caregiving has some requirements. It is essential to continually pray and ask for God's strength for both the caregiver and the person being cared for. Strength that comes from dependence on God is critical.

Whether voluntary or by nature of the relationship, caregiving has some requirements.

The following qualities will help the caregiver provide better physical care and also maintain his or her own emotional stability when dealing with a person facing a terminal illness.

- **Patience**. At times the person who is ill can be very demanding, or the symptoms they experience can demand much attention from the caregiver. Often the caregiver, especially if a family member, is on call all the time. Though it is difficult, both the caregiver and sick person will have more peace if both can remain patient in the face of these demands.
- **Commitment**. Volunteers may sign on to be a caregiver and then decide that it is too much work or too draining. The person with HIV/AIDS already fears rejection, and having someone show up and then forsake the task may reinforce their fears and feelings of inadequacy. People who volunteer should know that the commitment they make may last over a number of weeks, months, or even years.
- **Consistency**. It is important to provide consistency for the person who is ill: the same caregivers, same demeanor, same warmth and caring. This takes effort and persistence.

- **Love**. With fatigue and demands, it is not always easy to maintain a loving attitude. It takes daily communion with God and a daily attitude check to offer consistent love and acceptance.

- **Kindness**. All people deserve to be treated with kindness and dignity. There may be times, especially when the ill person has AIDS dementia (defined in a later chapter) or is in great pain, that he or she will lash out at the caregiver and say unkind things. Though difficult, the caregiver tries to understand this as part of the illness and continues to be consistently kind.

- **Respect**. Throughout each phase of the end of life, a person's dignity, privacy, and confidentiality should be given the utmost respect.

Caring for a friend or family member who is suffering is an emotionally and physically exhausting task.

3. Special Concerns For the Caregiver

Caring for a friend or family member who is suffering is an emotionally and physically exhausting task. A person who does this for a period of time may become very tired and depleted emotionally, spiritually, and physically. Though there are personal rewards that come from knowing that love and support are being offered, this may not be enough to overcome the stress and burnout that may affect the caregiver.

- **Over-identification**. Caregivers may find themselves becoming so emotionally involved with what is happening with the person they are caring for that they can no longer objectively carry out the help that is needed. This may be due to their emotional attachment to the person, which is a normal response. It is often, however, due to some grief or loss that has happened in the life of the caregiver prior to this care-giving event. The emotions that accompanied the former event may resurface and cause the caregiver to relive the experience.

- **Under-identification**. For the same reasons as over-identification, caregivers may distance themselves from the person they are caring for to protect themselves from feeling the pain of the present situation or a past loss. Though they carry out the tasks, they do so with an emotional detachment. Their care may lack warmth and they may transmit non-acceptance or distance to the recipient of their care.

4. Coping Strategies for the Caregiver

Awareness is the key to effective caregiving. The caregiver must be aware of his or her response to what is happening to the person being cared for. He or she must also be aware of what is happening inside himself or herself as caregiver, in order to protect from becoming overly stressed. A person who is overstressed will not be able to provide good care.

Signs of Being Overly Stressed:

- Feeling like crying constantly.
- Inability to sleep.
- Wanting to sleep too much.
- A constant feeling of being overwhelmed.
- Inability to stop thinking about the person being cared for.
- Loss of appetite.
- Overeating or exhibiting nervous habits, like biting finger nails.
- Inability to focus or concentrate; forgetfulness.
- Developing physical symptoms that do not seem to be related to a particular illness.
- Becoming irritable and short-tempered.
- Feeling depressed and "blue" most of the time.

Steps to Avoid "Overstress"

Though some of the above signs of stress would be normal reactions, some can be avoided by the following strategies:

- Find someone to allow the caregiver timeoff, even for short periods.
- Find someone to talk to about the experience and feelings associated with it.
- Join a support group of people who also give care.
- Pray and read God's Word. Allow God's grace to give strength and renewal each day.
- Attend church services and find fellowship with other believers who can pray for the situation.
- Realize that it is okay to feel tired and need a break. Try not to feel guilty.
- Recognize personal limits and respect them. One person can't do everything.
- Accept assistance from others when offered. Don't try to be a hero.
- Do something relaxing or enjoyable every day, even for a few minutes. This gives the caregiver something positive to look forward to.
- Try to get enough sleep.
- Try to eat adequate food.

Caring For Oneself

Caregivers might not feel like they have time to take care of their own needs, because the needs of the people around them are so much greater. However, if care is not taken, he or she may not be able to continue to care for those in need. It is critically important for caregivers to take care of themselves. If they do not, they may not be able to continue offering care or will give care that is not as effective as it could be.

Caregivers will experience all the emotions of grief at one time or another during their times of caregiving. Active grieving over the loss of the patient is necessary. Caregivers need to do for themselves what they do for others: help themselves work through feelings of grief.

Caregivers will experience all the emotions of grief at one time or another during their times of care giving.

Being in a caregiving role can be as overwhelming emotionally as it is physically. It's okay for caregivers to take short rest periods during the day to refocus and regenerate strength.

(A paraphrase from 1 Corinthians 13): *Love is patient; love is kind; love is not envious, boastful, arrogant or rude. It does not insist on its own way; love always protects, always trusts, always hopes, always perseveres…love never fails.*

5. The Importance of Self-Awareness in Caregivers

Most people choose to become involved in caregiving for a reason. It is important to be aware of those reasons, because they will affect the relationships between the caregiver and the person receiving care. Being aware of and accepting those motivations will enable the person to provide better care and grow as an individual. There will be things that the caregiver will discover about himself or herself, and those things will need to be dealt with. It is essential to accept feedback and constructive comments from others.

Caregiving requires self-confidence and courage. The caregiver must recognize and accept his or her own feelings and express them at the correct time. He or she must be able to cope with strong feelings from patients/families without feeling overwhelmed and incompetent. Each patient is an individual. The caregiver must show respect and empathy without prejudice, judgment, or expectations based on his or her life experience.

A dying person (perhaps someone with HIV/AIDS) may cause pain in the caregiver by stirring up feelings from past losses. Or the situation may be similar to one the caregiver fears will happen to him or her. Dealing with dying people makes a person more aware of his or her own death and weaknesses. For these reasons, it is very important to come to terms with feelings and fears of death.

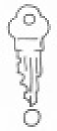
A dying or grieving person may make a caregiver feel helpless, inadequate, angry, and frustrated. It is important for the caregiver to look at his or her personal experiences with personal loss in order to better understand the mourning process. This helps the caregiver understand how to cope with painful situations and will affect communication with the person receiving care. Examining feelings of loss and being self-aware will help the caregiver determine his or her limitations in terms of who he or she provides care for. It also allows the person to determine the best ways to offer help.

A dying or grieving person may make a caregiver feel helpless, inadequate, angry, and frustrated.

The caregiver must assess how much time he or she can give, what he or she can tolerate, and his or her level of skill. The caregiver should be aware of how much of the patient's pain he or she is taking on and when he or she needs to offload and ask for support. Not only does the caregiver need to give help, he or she needs to be able to ask for and accept it from others. It is vital for the caregiver to know when to talk about his or her own feelings. He or she should have other interests and find ways to replenish energy when needed—physically, spiritually, and emotionally.

CHAPTER 3

Counseling Skills for Caregivers



Key Points

1. **Interpersonal Helping Skills For Caregivers**
2. **Encouragement Through Scripture**

Role-Play

A brother and sister talking.

Robert: *"Katrina, I thought that you would be dropping by to see our brother Mukesh today. We waited all day but you never came. I think he was disappointed not to see you."*

Katrina: *"Oh, yeah, I thought I would make it over, but you know I just have a lot to do. The children take a lot of my time, and well, you know I just can't seem to fit it in."*

Robert: *"Katrina, you said the same thing yesterday. You know Mukesh may not have too much time left. I really think you should stop by tomorrow."*

Katrina: *"Yeah, I know I should, but well, I don't know. I'm really pretty busy."*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

Questions for Discussion

- What do you feel when you are with someone who is dying?
- What are the reasons you might feel this way?
- How might issues you are dealing with yourself affect the way you might help someone who is dying? Can you give an example?

1. Interpersonal Helping Skills for Caregivers

People who have been diagnosed with HIV/AIDS may have even more concerns than those who are facing cancer or other illnesses. They may face the social stigma, rejection from their families and society, rejection by the medical community and, sadly, even rejection by their church family.

The family and loved ones of someone with AIDS also grieve. They may also need to talk to the caregiver about the things they're experiencing in their own lives.

The following helping skills are good tools to use when working with people who are grieving or facing loss of any kind.

Listening Skills

Listening is hard work and requires focus and determination. When working with those who are struggling with end-of-life issues, the caregiver may not have all the answers.

- In some cultures, listening involves making eye contact to show attention. In others, this would not be appropriate, especially between two people of the opposite sex.
- Sit close enough to reach out and touch the person who is taking, if this is culturally appropriate. Even if touch isn't appropriate, sit close enough so the person doesn't have to strain to talk.
- Don't interrupt unless clarification is needed, or you don't understand. A useful phrase is "I thought I heard you say" or "Let me see if I understand what you are saying."
- Remain neutral while listening. Don't jump in with your point of view.
- Don't finish sentences for people. It may take a while to express what they need to say.
- Try to listen with the body: lean towards the person, nod, etc., which lets the person know that what he or she is saying is important.
- Don't feel that you have answers to all the questions. Saying you don't know is okay.
- Try to really understand what the person is saying. Reflect on what is being said and share some of your reflections when appropriate so that the person feels listened to.

Listening is hard work and requires focus and determination.

Empathy

This is the capacity to put oneself in the other person's experience. It doesn't mean that the two have experienced the same things but that the person listening can imagine how he or she might feel in the same situation.

- It isn't helpful to say "I understand exactly what you are going through," even if you feel that you do. Every person's experience is uniquely his or her own and no one else can know exactly how another feels.
- Give non-judgmental feedback, such as "I can see why you might feel that way."

Genuineness

Freely be yourself and try not to play a role. Let the person hear and feel that you genuinely care.

- Don't be afraid to show pain and say that you are hurting over the thought of losing him or her.
- It's okay to cry together.

Respect

Communicate to the person receiving care that he or she is worthy of respect. Emphasize that you believe that he or she has the capacity to continue living as long as possible. Let the person know that you will help him or her to be as independent as possible for as long as possible. It is also important that the individual has a part in all decisions that concerns his or her destiny.

Warmth

Though touching may not be appropriate in certain cultures and situations, if it is, use it generously. Touch conveys caring and love, and can make someone feel valued. This is especially important for persons who have HIV/AIDS, as they may feel that no one wants to touch them due to the fear of being infected. Casual touch is not a means of infection, and if used appropriately and sensitively by a caregiver, it can be a powerful communication tool. Remember to continue to touch, even if a person appears to be unconscious or in a coma.

Touch conveys caring and love, and can make someone feel valued.

Presence

Sometimes all someone needs is not to be alone. A supportive, non-anxious presence of another is often very comforting.

Maintaining a Sense of Humor

Often there is not much to smile or laugh about in the midst of devastating illness. However, finding ways to bring some joy and laughter to someone who is dying is a wonderful gift. This needs to be done with sensitivity and at appropriate times, but can do wonders to turn a bad day around.

2. Encouragement Through Scripture

The following are common expressions of those facing illness and death. Included are Bible verses that support the validity of these feelings.

- I need you to be honest with me. (Romans 12:9)

- Laugh with me; cry with me. Allow me to express intense emotions. (Ecclesiastes 3:4)
- Don’t feel sorry for me—your understanding helps preserve my dignity. (Proverbs 31:25)
- Let me be silent if I want to—your presence alone can be comforting. (Ecclesiastes 3:7)
- Touch me. I want to be accepted despite the way I look. (Leviticus 19:18)
- Let me talk about my illness if I want. Talking helps me work through my feelings. (1 Corinthians 13:4)
- Space out your visits and calls. (Romans 12:10)
- Help care for my children. Please help them. (Mark 10:13–16)
- Support my family. (James 1:27)
- Help with simple chores. (Matthew 26:36)
- Continue to be my friend. Don’t let my illness overshadow all the good times we’ve shared together. I know this is hard for you too. (Proverbs 17:17)

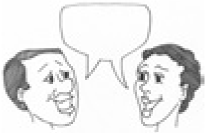
Section 2:
Spiritual Care

CHAPTER 4

Spiritual Needs of People Facing Terminal Illness

Key Points

1. **Offering Spiritual Care**
2. **Guidelines for the Spiritual Companion**
3. **Spiritual Rituals and Traditions**
4. **Readiness to Discuss Spiritual Things**
5. **Keys to Effective Ministry**
6. **God's Love Extended Through the Caregiver**



Role-Play

Caregiver (newly assigned to a patient): *"I'm so glad I could come and spend time with you today. I know you are probably wondering what will happen to you, and I'm here to help you get saved and have the certainty that you will go to heaven."*

Patient: *"I don't know what you mean by 'saved,' but if you are talking about God, I don't want any part of it. What kind of God would allow a thing like AIDS to come into the world? And what kind of a God would let me get it? Forget about trying to tell me about a loving God."*

Caregiver: *"Oh, I know you are upset right now, but you need to know the truth. God does love you, and the only way you can get to heaven is by accepting him as your personal savior. You don't have a lot of time, so you need to get this taken care of as soon as possible."*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

1. Offering Spiritual Care

A person with a terminal illness, regardless of his or her religious persuasion or beliefs, will face thoughts of what will happen after they die. Though he or she may not be ready to discuss those issues, there will certainly be inward thoughts about one's final destiny.

Though a religious figure such as a pastor or priest may be a part of the care team, it may be the person offering daily comfort or physical care who will have the most opportunity for these profound and intense discussions. There is no formula for who should offer spiritual care or how it should be offered, but there are some points to consider.

Before one can minister to the spiritual needs of another, it is important to look at what a person believes and why. Sometimes people may have prejudices against a certain belief system or against a lifestyle represented by the person being cared for. If this is true, those need to be set aside to give the quality of unconditional care that the person who is ill deserves.

2. Guidelines for the Spiritual Companion

- **Presence**. The most valuable gift you have to offer may be the ministry of presence. This is coming alongside a person who is dying. In so doing, we represent the Holy Spirit, who functions as our daily guide.

> ***"Those who have the strength and the love to sit with a dying patient in the silence that goes beyond words will know that this moment is neither frightening nor painful—but a peaceful cessation of the functioning of the body."***
>
> ***—Elizabeth Kubler-Ross, M.D.***

- **Laughter**. Recognize the important role of laughter and play in spiritual care for the terminally ill. This can be a useful tool until the very end of life.

  "A cheerful heart is good medicine, but a crushed spirit dries up the bones" (Proverbs 17:22).

- **Facilitate spiritual growth**. The goal of spiritual care is to encourage growth until the end of life. The fruit of the Spirit—joy, peace, patience, kindness, goodness, faithfulness, gentleness, and self-control (Galatians 5:22–23)—are evident even in weakness of body.
- **Encourage reminiscing**. The patient's story reflects the essence of his or her spirituality. Often, it is through telling one's story that unfinished business emerges and thus creates a safe atmosphere for emotional and spiritual healing. (See Appendix A, Life Review.)
- **Create a sacred place**. This should be easily accessible to the patient either in the room or somewhere nearby. A sacred space may be as simple as a place to keep a Bible and journal, or it could be a separate room with music, a candle, sacred art, a small water fountain, favorite books, or other sacred objects.

Questions for Discussion

- What about oneself as a caregiver might enter into the role of offering spiritual care?
- If you were dying, what thoughts might come to you concerning spiritual things?
- With whom would you most likely want to discuss these thoughts? Why?
- What might be some barriers to these types of discussions?

3. Spiritual Rituals and Traditions

It is important when assessing the spiritual needs of the person who is ill to ask what spiritual or religious rituals have been or would be meaningful to them. Despite the caregiver's beliefs about these rituals, attempts should be made to allow for them.

It is important when assessing the spiritual needs of the person who is ill to ask what spiritual or religious rituals have been or would be meaningful to them.

Common Rituals and Traditions:

- Communion
- Water baptism
- Scripture reading (See Appendix B for Scripture list.)
- Worship music (recorded or singing)
- Christian meditation
- Prayers (spontaneous, silent, reflective, or written)
- Community celebration (a circle of friends or family at bedside)
- Anointing with oil

4. Readiness to Discuss Spiritual Things

Sometimes the fervor to see someone come into a relationship with Christ causes caregivers to force a discussion about spiritual matters before a person is ready. It is also possible that the person receiving care would feel more comfortable discussing these issues with a different person.

Ultimately, those who have faith in Jesus Christ desire to share their faith. However, they must be sensitive and think of the other person. Both the timing and the readiness of the person to discuss these issues must be kept in focus. (See Appendix B, "Spiritual Assessment.")

5. Keys to Effective Ministry

- Each person needs to come to terms with his or her own theology of suffering and healing. Examine the suffering of Job (Job 1–42), Jesus (Matthew 26:38–46), and Paul (2 Corinthians 11–12).
- Recognize that a miracle of healing can be present or eternal. The body of Christ is invited to anoint with oil and pray for the sick (James 5:4–16). At the same time, Paul gives encouragement to seek eternal healing, which is eternal life (2 Corinthians 5:2 and Philippians 1:20–21).
- If the patient is not a Christian, practice loving the sinner regardless of his or her lifestyle. Jesus modeled this to us when He ministered to the thief on the cross (Luke 23:40–43); the woman who worked as a prostitute (Luke 7:36–48); and the adulterous woman (John 4:1–26).
- Seek appropriate timing for conversations that deal with salvation and spirituality. Jesus waits at the door, allowing the individual on the other side to choose the time that is right for salvation (Revelation 3:20).
- Provide assurance that God is present even when there is pain and suffering. (See Appendix C, "Suggested Scripture Readings.")
- Share difficult situations with others. Caregivers are not able to minister effectively to every patient. Personalities, backgrounds, and genders sometimes interfere with ministry. People need to know their limitations and call on others to help when necessary.

Certain questions will encourage a person to think about spiritual issues. These same questions may even open the door to conversations about these matters. For example:

- Are you comfortable talking about spiritual issues?
- Where do you find your source of strength?
- What provides meaning for you?
- What do you think is going to happen to you?
- What are you afraid of?
- What role does God play in your life?

Some persons feel relief when offered a chance to speak about these matters. Others find facing end-of-life issues very frightening. They may feel more comfortable discussing them with a pastor or spiritual leader. The caregiver can then arrange for that to occur.

6. God's Love Extended Through the Caregiver

Some people have had very difficult and hard lives and have experienced very little love or care. The caregiver may be the first person to show kindness, gentleness, and love. This may be the first glimpse of God's love that someone has experienced. If the caregiver can realize what a special gift it is to be God's hand of grace, mercy, compassion, and love for this person, it will make the burden of care lighter.

Jesus said. "Come to me, all you who are weary and burdened, and I will give you rest" (Matthew 11:28).

The goal in caregiving is to be committed to the person, staying beside them, loving them, and representing Christ. The caregiver can offer hope for an eternity with Christ! Some people will appreciate this message and others will not. A caring, loving relationship may speak more than any words could ever communicate.

The goal in caregiving is to be committed to the person, staying beside them, loving them, and representing Christ.

It is appropriate to be patient and pray constantly that God will allow the privilege of introducing the person to Christ. But do not be discouraged if the message is rejected. The reason for being with the person remains: to share the love of Christ while ministering to their needs.

CHAPTER 5

Dealing with Grief and Loss

Key Points

1. **Effects of HIV/AIDS on Families**
2. **Encouragement for Families**
3. **Defining Grief, Anticipatory Grief, and Mourning**
4. **Suggestions for Helping a Grieving Person**

From a family who lost a son with AIDS: *"We just couldn't risk the possibility of people not understanding. We felt it best to keep my brother's AIDS diagnosis a secret. We didn't share it with our church or pastor or even our close friends. Somehow we thought we would be rejected."*

Questions for Discussion

- In your community, how do people respond to families who are dealing with AIDS? Why?
- What is the attitude of Christians in your community toward AIDS?

1. Effects of HIV/AIDS on Families

Serious illness, especially life-threatening illness, causes a disruption in normal family life. Each member of the family must adjust to new routines, new responsibilities, and the idea of losing a loved one.

A diagnosis of HIV/AIDS brings with it issues that may not be present with other illnesses. In some cases, family members are confronted with the possibility that a lifestyle choice made by a loved one may have been the cause of HIV infection. Spouses may realize that there has been unfaithfulness. If a child is dying, there may be guilt and blame, especially if HIV was passed from the mother to the child.

Social stigma and possible rejection also impacts the family. As discussed above, secrecy and trying to hide the cause of illness may cause the family to withdraw and not make their needs known. Families may end up suffering alone in silence.

Another cause of concern is the uncertainly the family faces about how they will survive after the loss of a parent. This causes additional fear and anxiety for the family who is also dealing with the grief that accompanies a diagnosis of HIV infection.

Questions for Discussion

- What can be done to give support to a family who chooses not to share what is happening in their family?
- How can these families be helped without becoming intrusive?

2. Encouragement for Families

After losing a loved one, families need emotional and spiritual support. Whether they choose to share the actual facts or not, they need to know that there are friends who will stand beside them no matter what the circumstance. Often a pastor or close friend may be able to say, "No matter what is going on here, you are cared for and we want to help," or, "It's okay to be angry and to say that you are angry and hurt and outraged."

Offering prayer, support, and practical helps at this time helps the family to know they are not alone and can depend on the strength of others.

Comments like this may allow for families to express what they feel and know they are supported even if they still are reluctant to share the diagnosis. It is unhelpful to try to push them to do so or to say, "I know it is AIDS that you are dealing with." Sometimes the secrecy is a coping mechanism and is needed at least in the early stages of coping.

Offering prayer, support, and practical helps at this time helps the family to know they are not alone and can depend on the strength of others.

3. Defining Grief, Anticipatory Grief, and Mourning

- **Unresolved grief**. Unresolved grief is when someone doesn't allow himself or herself to feel the pain of the loss process. They refuse to feel or to express emotions. They tell themselves and everyone else that they are okay. Later this may lead to serious physical or emotional problems.

- **Anticipatory grief**. Anticipatory grief is grieving before the actual loss has occurred. Family members, friends, spouses, and caregivers usually anticipate the loss that they know will occur due to death. This may go on for months before the actual loss occurs and is sometimes done together with the person who is dying. Though this can be a healthy process, persons who are close often wish to deny the reality that death will occur and refuse to allow feelings of grief to begin. There is a balance between being hopeful for healing and accepting the reality of eventual death and loss.

- **Mourning**. Mourning is the process gone through to undo, reshape, or attach new meaning to the connection with what has been lost. It is the method of expressing the grief and letting go of the person or thing that is lost. Unlike grief, mourning may go on indefinitely, even though its intensity grows less with time. On anniversaries of death, even years later, a person will mourn the loss. If mourning continues to bring intense pain after time has passed, it may be that the grief was not properly resolved and issues remain.

Questions for Discussion

- What are the mourning rituals in your culture or family?
- What is good about these rituals?
- What may not be good?

4. Suggestions for Helping a Grieving Person

- **Be present**. One of the best things a friend can do for a griever is just to be there. Simply sit with the person. Don't be afraid of long periods of silence. Your presence is often as important as anything that might be discussed.

  Take the advice of author Henri Nouwen. *"The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not-knowing, not-curing, not-healing, and face with us the reality of our powerlessness, that is the friend who cares."*

- **Listen**. When the person wants to talk, you can provide a tremendous service by actively listening. Pay close attention to what the griever says, even if he or she repeats many of the stories. Repeating the story of how a loved one died is very common and can provide a great deal of relief for the griever. Listen with patience and without judgment.

- **Accept the griever's feelings**. Probably nothing helps a grieving person more than expressing feelings and releasing pent-up emotions. You can help by accepting whatever feelings—anger, guilt, sadness, fear—the griever is experiencing at the moment. Affirm those feelings by saying something like "It's okay to feel that way" or "It must be a difficult time for you."

- **Talk about the person who died**. Friends sometimes think that bringing it up will remind the griever of the loss and cause more pain. Most grievers say their loss is always foremost in their thoughts. They'll tell you that they can't be in any more pain. They love to recall stories of their loved one, even if the memories stir up strong feelings. They will be grateful you cared enough to ask.

- **Be patient**. Grieving the death of a loved one may take a long time. Be patient with the griever, realizing that there will be many ups and downs, many mood swings, and many behavioral changes. Your listening presence, a weekly phone call, and a periodic note over the course of many months could make a huge difference.

- **Understand the need for a balanced response**. Be present without being overbearing. Keep in touch without being intrusive. Provide specific help without being pushy and overprotective.

What to Say

"I'm sorry" is often the simplest and best thing to say. This allows the person to express his or thoughts, and feel that the person listening is also sharing in their sadness and grief.

What Not to Say

Avoid clichés and platitudes, such as:

- "It was God's will."
- "I know just how you feel."
- "You'll get over it in time."
- "She's better off this way."
- "Life is for the living."

Questions for Discussion

- What is grief?
- How is it expressed in your culture?
- How are grief and mourning different?

Section 3:
Physical Care

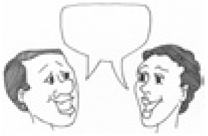
CHAPTER 6

Basic Information about HIV/AIDS

Key Points

1. **What is HIV? What is AIDS?**
2. **What Happens in Your Body?**
3. **How Is HIV Transmitted?**
4. **How Is HIV NOT Transmitted?**
5. **Myths That Some People Believe about AIDS**
6. **Signs and Symptoms of AIDS**
7. **Diagnostic Testing for HIV**
8. **Treatment/Cure for AIDS**
9. **How to Prevent HIV Infection**
10. **Pregnancy & HIV**

Tea Room Discussion



Three men are sitting in a tearoom having a cup of tea after work. This day they are talking about AIDS.

Steven: *"One of the men I work with has AIDS. I wish he would go away. We often share meals and work together and I don't want to catch it from him."*

John: *"How did he get AIDS?"*

Steven: *"He says he got it from being in the hospital, but I think he probably got it from his girlfriend."*

Bono: *"You can't get AIDS in a hospital. All the blood is tested now. He should have protected himself with that woman. It's too late now. He doesn't need to bother with condoms anymore."*

John: *"Well, I'm careful. I only go with women who look healthy. Besides, if I start feeling sick, I'm going right down to the clinic to get a vaccination against HIV."*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

Questions for Discussion

- What does HIV stand for?

- What does AIDS mean?
- How is AIDS transmitted from one person to another?
- What are some thoughts about HIV/AIDS in your culture?

1. What is HIV? What is AIDS?

The Human Immunodeficiency Virus (HIV) is a tiny germ that causes the disease called the Acquired Immunodeficiency Syndrome (AIDS). HIV is passed from person to person by contact with body fluids which contain the virus.

HIV lives and multiplies in the body for many years before AIDS develops. During this time, the person will appear to be in good health. However, he or she can still pass HIV to another person.

The Human Immunodeficiency Virus (HIV) is a tiny germ that causes the disease called the Acquired Immunodeficiency Syndrome (AIDS).

2. What Happens in Your Body?

HIV destroys the body's defense system (the immune system) that fights off diseases. After several years, the defense system will be too weak to defend the body and the person will develop AIDS.

A person with AIDS will get very sick from different illnesses such as tuberculosis, diarrhea, pneumonia, and serious types of skin diseases and cancer. These illnesses will lead to the death of the person with AIDS.

The progression of the disease from infection to death is different for everyone. Medical experts usually say the range is from 3 to 15 years without medical treatment. However, with medical treatment, many people are living for twenty years or longer.

It takes many years for HIV to destroy the defense system. However, a person with HIV can pass it to another preson immediately after becoming infected. Even if there are no symptoms, he or she can still pass HIV!

3. How Is HIV Transmitted?

HIV is found in certain body fluids of people infected with the virus. HIV is passed when these fluids coming from an infected person enter the body of a non-infected person. This passing of HIV from one person to another is called transmitting the virus.

HIV is transmitted through three body fluids:

1. **Sexual secretions**

2. **Blood**
3. **Breast milk**

There are therefore only three ways of transmitting HIV:

1. **Sexual transmission through contact with sexual secretions** (semen or vaginal secretions).
    - Having sexual intercourse or anal intercourse with a person infected with HIV.
2. **Blood transmission through contact with blood**.
    - Using any sharp instrument (medical or dental instrument, knife, razor, etc.) that has cut the skin of a person with HIV if the object has not been cleaned before being used again.
    - Using the same needle or syringe that has been used by or on someone infected with HIV.
    - Receiving blood transfusions or blood products that contain HIV.
3. **Mother-to-child transmission at the end of pregnancy, during delivery, or through breast milk**.
    - An HIV-infected mother may pass HIV to her baby during pregnancy or while the baby is being born.
    - A baby drinking breast milk may receive the virus from an HIV-infected mother.

4. How Is HIV NOT Transmitted?

HIV is not transmitted through saliva, tears, urine, etc. Therefore, HIV is not passed by the following activities:

- Shaking hands, touching, or hugging
- Kissing on the cheek or lips
- Using the same eating utensils
- Riding in crowded buses or in cars
- Swimming or bathing together
- Bites from mosquitoes or insects
- Being together in the same room
- Using the same toilet seats

Because HIV does not spread through ordinary, daily contact, people with HIV infection do not pose any risks to the people living around them.

Because HIV does not spread through ordinary, daily contact, people with HIV infection do not pose any risks to the people living around them. When caring for a person with HIV—as with any infection—some precautions may be necessary to prevent further complications for both the infected person and the caregiver. These will be discussed in further chapters.

Mosquitoes cannot spread HIV! When a mosquito bites someone, it injects some saliva into the person. Then it sucks out some blood, which enters into the mosquito's stomach. In a short time, HIV is destroyed by the enzymes in the mosquito's digestive system. When it bites another person, it again injects saliva—but there is no HIV in it!

After a mosquito bites someone, there is no blood left in the tiny "needle" it uses to inject its saliva and pull out the victim's blood. If mosquitoes and insects could pass HIV, everyone that lived around someone with the virus would become infected!

5. Myths That Some People Believe About AIDS

NOT TRUE: A person with HIV will always look sick.

NOT TRUE: You can cure AIDS if you have sex with a virgin, a baby, or a young child.

NOT TRUE: Certain herbs will cure AIDS.

NOT TRUE: Condoms are 100 percent effective.

NOT TRUE: Mosquitoes and other insects can transmit HIV.

All of the above statements are FALSE! When a person understands the correct facts about HIV/AIDS, they will be able to recognize the errors in the above statements!

6. Signs and Symptoms of AIDS

Many people living with HIV infection have no idea that they are infected. In the first few weeks following initial infection, they may develop a flu-like condition which will disappear in a few days or weeks. A person with HIV will live a normal, healthy life for many years before experiencing the symptoms of AIDS.

Early Symptoms

After a number of years, HIV will cause a person's immune system (the body's system of defense against germs that cause disease) to weaken. The person will start to experience symptoms that indicate the weakening of the defense system. A person with HIV will begin to experience symptoms that indicate his or her immune system is starting to weaken, such as:

- Weight loss
- Diarrhea
- Lack of appetite
- Mouth problems, such as thrush (white spots), sores, change in taste, dryness, trouble swallowing, or loose teeth
- Skin rashes and infections
- Fever
- Feeling tired all the time

Later Symptoms

When HIV has almost completely destroyed the defense system, the symptoms will become more serious. The person will become very sick. At this point, it is said that the person has developed AIDS.

- Severe weight loss
- TB usually gets worse, resulting in coughing up sputum and blood
- Cancer may develop
- Pneumonia is common
- Mental confusion and delirium can also occur

All these symptoms can be associated with other illnesses. The only way to know whether or not it is AIDS is by being tested.

7. Diagnostic Testing for HIV

There is only one way to know for sure that a person is infected with HIV. He or she must have a diagnostic test at an HIV testing center, laboratory, clinic, or hospital.

What is an HIV Test?

There is only one way to know for sure that a person is infected with HIV. He or she must have a diagnostic test at an HIV testing center, laboratory, clinic, or hospital.

Shortly after infection with HIV, the body's defense system starts to produce a substance called an antibody to destroy HIV. Unfortunately, these antibodies will never succeed in destroying the virus. However, even though they can't destroy HIV, these antibodies will always be present in the blood. If a person is not infected with HIV, they will not have the antibodies to the virus.

Most HIV tests do not detect actual HIV particles in the blood; they detect the antibodies. These antibodies will become detectable by the HIV test about two weeks to six months after initial infection with the virus.

After explaining the test and getting consent, the technician will take a drop of blood from the finger. In some cases they will take a bit of blood from the vein in the arm, and some places may use saliva. If a "rapid test" is used, the results are usually ready in about 30 minutes.

What Do The Results Mean?

In a person over the age of eighteen months:

- If the test detects HIV in the body, the person is "HIV-positive." The person can transmit HIV to others.
- If the test is negative, the person is "HIV-negative." This could mean:
  - o The person is not infected with HIV, or
  - o The person might be infected with HIV, but the body has not yet produced enough antibodies to be detected by the HIV test. This is sometimes called the "window period." The test should be repeated in three to six months.

HIV Testing and Babies

All babies born to mothers with HIV infection will be born with the mother's antibodies to the virus. However, this does not mean that the baby is actually infected with HIV! Only about 1 out of 4 of these babies will actually be infected with the virus. The test may simply be detecting the antibodies passed from the mother to the baby.

All babies born to mothers with HIV infection will be born with the mother's antibodies to the virus. However, this does not mean that the baby is actually infected with HIV!

In a child under the age of eighteen months, a positive test result could mean:

- The child is actually infected with HIV, or
- The child is not infected with HIV, but the test is detecting antibodies passed to the baby from the mother during pregnancy.

Because of these two possibilities, it is impossible to tell if a baby is actually infected with HIV until the child is at least 18 months old. By this age, the antibodies from the mother are usually gone. If the baby has not actually been infected with HIV, the HIV test will become negative.

The HIV test:

- Does not provide any information about a person's present state of health.
- Does not determine if a person has HIV-related disease.

- Cannot tell when or how a person became infected with HIV.
- Does not provide any information about whether a person with HIV infection has transmitted the virus to anyone else.

There are many benefits to having the test. When people know that they are infected, they can make responsible decisions regarding sexual behavior and future pregnancies. They can plan for the future of their families and children. They can also learn how to take care of their health: proper medical care and good nutrition will allow an infected person to live a longer, healthier life.

8. Treatment/Cure for AIDS

There is no drug or vaccine that can prevent a person from becoming infected with HIV. No medication or treatment can completely destroy the virus. *There is no cure for AIDS.*

The most effective weapon against the spread of HIV/AIDS is prevention! When people understand how HIV is spread, they can take measures to avoid infection.

There are special anti-HIV drugs which help a person with the virus live longer. They can even reduce the risk of a pregnant woman passing HIV to her baby. People with HIV should find out if these medications are available in their area. They are expensive, but some countries make them available at lower prices.

There is no drug or vaccine that can prevent a person from becoming infected with HIV. No medication or treatment can completely destroy the virus. There is no cure for AIDS.

Certain common drugs, such as antibiotics, help people fight certain infections that occur when the defense system becomes weak. Good nutrition is also essential in helping someone with HIV to live a longer, healthier life.

9. How to Prevent HIV infection

1. Sexual Transmission

   - Abstain from sexual activity before marriage.
     - o Have an HIV blood test of both partners before marriage to be sure neither has HIV.
   - Be faithful in marriage: do not have sex with anyone but your spouse.
   - Condoms can reduce the risk of HIV transmission. Medical experts agree that the correct use of condoms decreases the risk of becoming infected, and of transmitting the virus to another person. They provide some protection, but are not always 100 percent effective.

2. Blood Transmission

    - Do not allow your skin to be pierced or cut unless the instruments have been properly sterilized before use.
    - Do not use needles or syringes that have not been properly sterilized.
    - Do not accept a transfusion of blood unless it has first been tested for HIV.

3. Mother-to-Child Transmission

    - To prevent the risk of passing HIV to her baby, a woman with HIV should take measures not to become pregnant.

10. Pregnancy & HIV

Pregnant mothers who have HIV/AIDS can pass the virus to their baby during the pregnancy, during delivery, or while breast-feeding.

- If a woman has had a blood test and knows she has HIV, she should take precautions not to become pregnant.
- If a mother knows she is pregnant and has HIV, she should find out how and where to get the antiretroviral drugs to reduce the risk of passing the virus to the baby.
- If it is within reason, the family should consider giving the baby alternative feeding if the mother is infected with HIV.

> **Pregnant mothers who have HIV/AIDS can pass the virus to their baby during the pregnancy, during delivery, or while breast-feeding.**

If the family cannot guarantee that the water for the alternative feeding is clean and the replacement formula has the correct nutrients, the baby should receive only breast milk for the first six months of life. Dirty water and poor quality alternative feeding cause infection and malnutrition in a newborn. These pose a greater, more immediate threat to the baby's life than potential infection with HIV.

CHAPTER 7

Protection Against Infection and Injury

Key Points

1. **Infection Control**
2. **Protecting the Patient and Caregiver From Injury**

1. Infection Control

Diseases are called infectious when they can be passed from one person to another or from an insect to a person. HIV is considered infectious because it is passed from person to person. This chapter discusses basic principles of preventing the spread of infectious disease.

When caring for a person with an infectious disease, one goal is to prevent it from spreading or infecting the caregiver or others. Another goal is to prevent the sick person from being infected with additional germs.

The immune system of people living with HIV/AIDS can't completely protect the body from germs that cause infectious disease. As a result, these people are more susceptible to becoming infected with these germs. Care must be taken to prevent them from being exposed to these germs.

> ***The immune system of people living with HIV/AIDS can't completely protect the body from germs that cause infectious disease.***

Caregivers with a cough, cold, flu, or other illnesses should wear a protective mask when caring for a person sick with AIDS. (If possible, it would be better to have someone else do the care giving until the illness has passed.) A sick child should not get too close to someone with AIDS, since the child might pass the infectious germ to the person.

Universal Precautions

Every person is a potential carrier of any number of infectious germs. When someone is sick, the type of germs causing the sickness may be known, but they may also be infected with unknown germs. Caregivers may have germs in their bodies, even though they are not sick. Universal precautions mean that every person is treated as if he or she is actually carrying infectious germs. Therefore all blood or body fluids (such as semen, vaginal secretions, urine, feces, vomit, and drainage from wounds or open sores) should not be touched without a barrier.

All blood or body fluids (such as semen, vaginal secretions, urine, feces, vomit, and drainage from wounds or open sores) should not be touched without a barrier.

Barriers Against Infectious Germs

- **Gloves**. Gloves are the most commonly used barrier protection. Everyone should use rubber or plastic gloves if there is a possibility of touching someone's blood or the other body fluids mentioned above. Use disposable gloves only one time, and throw them away in a secure location. If using non-disposable gloves, wash them thoroughly and make sure they're dry before putting them away. If gloves are not available, cover the hands with clean plastic bags to prevent touching blood or body fluids.

- **Face protection**. Face masks and goggles are good to use if the mouth, nose, or eyes could be exposed to droplets of blood or body fluids. Masks would be most useful when a person is vomiting forcefully or coughing up sputum. Masks can also reduce the risk of breathing in the TB bacteria if there is not much air circulating in the sick person's room.

- **Protective clothing**. A plastic apron or some other type of protective clothing is good to wear when cleaning up a large spill of blood or body fluids. Tying a piece of plastic around the waist will help to keep the blood from soaking into the caregiver's clothing.

Hand Washing

This is the most important and effective way to prevent the spread of infectious disease. Proper procedure is to wash (using warm water and soap), rinse, and dry the hands before and after caring for someone. Use hand lotion to prevent drying and cracking of the skin. Cracks and open areas on the skin can be ports of entry for infectious germs. The skin is the first line of defense against bacteria and viruses, so it is important to keep it healthy and free of cuts, scratches, and dryness.

Ventilation

When a person has an infection in his or her lungs, coughing and sneezing can send those germs into the air. If another person breathes the air containing germs into their lungs, they, too, can become infected. This is especially true in tuberculosis (TB).

When the air in a room is circulating, either with a fan or an open window, this helps remove germs from the room. If a sick person is confined to a single room, make sure the room has a window. It is good if the sick room is across from another window, allowing the air to flow between windows.

Sharp Items

If giving an injection using a disposable needle, do not replace the cap on the needle. The caregiver might slip and accidently poke himself or herself with that needle, which could potentially cause infection in the caregiver. Use a puncture-resistant container (like a heavy plastic bottle) marked "SHARPS" to dispose of your needles. Use extreme care with these needles so that they cannot be reused, and keep them out of the reach of children. When full, these containers should be disposed of, where they will not come into accidental contact with people or animals.

Laundry and Garbage

Laundry and garbage dirtied with blood or body fluid requires special care.

- Keep soiled clothes or linen in containers separate from regular laundry. Use plenty of hot water and laundry soap when washing. If it is available, use a small amount of bleach to clean laundry stained by blood or body fluids. Remember to protect the hands by wearing gloves or use a plastic bag as a barrier when washing this type of laundry.
- Garbage with blood or body fluids should also be kept separate from regular garbage. Dispose of the garbage in a safe manner. Bury or burn the contaminated garbage in a secure place where no one will come into contact with it.

Daily Habits That Help Prevent Illness

There are some basic habits that can be practiced to decrease the chance of getting sick:

- Regular bathing removes microorganisms (germs that cause infections) from the skin. Lotion keeps the skin from becoming dry and cracked.
- Oral hygiene helps to keep germs from growing in the mouth.
- Drinking plenty of fluid keeps urine flowing through the bladder and urinary tract, which helps prevent bladder infections. Make sure the drinking water is clean by boiling or using a filtration system.
- Coughing and deep breathing are important exercises for those who are unable to get out of bed. These exercises help the person cough up mucus that accumulates in the lungs.

- A well-balanced diet provides the body with strength to help fight off infection. Be sure that meats and eggs are thoroughly cooked. Raw foods can carry infectious microorganisms.

2. Protecting the Patient and Caregiver From Injury

Seriously ill people may have an increased risk to falling because their perception of their surroundings could be altered. Provide a safe setting for them by picking up rugs, clearing a straight path, and providing good lighting.

Seriously ill people may have an increased risk to falling because their perception of their surroundings could be altered.

CHAPTER 8

Managing the Symptoms of AIDS

(Much of this information is taken from *AIDS Home Care Handbook, World Health Organization Global Program on AIDS, 1999.)*

Key Points

1. **Pain**
2. **Fever**
3. **Diarrhea**
4. **Skin Problems**
5. **Mouth and Throat Problems**
6. **Managing Symptoms of Tuberculosis**
7. **Changes in Mental Functioning**
8. **Comfort Measures**

Only the most common health problems and symptoms associated with AIDS will be listed here. This manual serves only as a guide for caregiving and is not comprehensive.

A person with AIDS and his or her caregiver should learn these simple skills to help manage some of the physical symptoms of AIDS. These skills are not meant to replace medical care but serve as a bridge between medical treatment and measures that can be done at home.

Some of the symptoms do require the administration of medication. Most of the medications will be non-prescription medicines that can be administered without formal training. It is important to record systematically in a notebook when medicines are given, how much is given, and any reactions or side effects that are noted.

1. Pain

Pain is a difficult symptom to deal with, but with careful attention it can managed. Two good points to remember:

- Pain is personal, private, and unique to the person who is feeling it.
- Pain is whatever the person says it is, and it exists whenever a person says it does.

People will commonly experience at least two different types of pain:

- **Acute pain**: Acute pain is intense, sharp, and usually is in one specific area. For example, the pain that comes from an injury is acute. When the source of pain is known, it can be treated.
- **Chronic pain**: This is usually the result of a prolonged illness. It is often described as dull or aching and often can't be pinpointed to any particular area. It can stay constant or come and go. Sometimes it is more intense than other times. Chronic pain can become the focus of one's life and can result in frustration, depression, anxiety, irritability, decreased appetite, and suicidal thoughts.

Assessing Pain

When someone says they are having pain, ask the following questions: What is the location of the pain? When did it start? How frequent is it? How long does it last? What makes it better or worse? Make notes about the responses in the patient notebook.

Drugs for Pain Management

It is important to administer pain medicine as soon as the person becomes aware of pain. This may keep the pain from getting out of control and becoming intolerable.

Usually a non-medical caregiver will only give basic medications such as aspirin, Tylenol (acetaminophen or paracetamol), or ibuprofen. If a physician is treating the person, he or she may leave prescriptions for stronger medications. As always, keep the medications in a safe place where children and others cannot get to them. Remember too that they may cause drowsiness, so assistance in walking may be required.

> ***It is important to take pain medicine as soon as the person becomes aware of pain. This may keep the pain from getting out of control and becoming intolerable.***

Other Measures for Pain Management

Repositioning, rubbing and massage, and applying heat or cold may also help relieve the pain. Using these measures along with the medicines is often most helpful.

2. Fever

Fever is not a disease but a signal that something is wrong. Fever often accompanies some type of infection. When someone has AIDS, fevers may come and go with great frequency. This makes it difficult to know if the fever is due to a treatable infection, to the HIV infection itself, or to something like malaria or TB.

Checking for Fever

It is best to use a thermometer to check a person's temperature. If a thermometer is not available, put the back of your hand on the person's forehead and your other hand on your own—you should be able to tell if the person feels hotter than you. After a while you will know just by touching the person when his or her temperature is elevated.

Treatment for Fever

- Remove unnecessary clothing and blankets. Open a window or door and allow fresh air in to the room. A breeze will help lower the fever, and contrary to popular thought, it will not harm the person.
- Cool the skin by pouring water on it or rubbing water on the body. A child can be immersed in a tub of cool water. Dip cloths in cool water and fan the cloths. The air and breeze pulls heat from the body.
- Drink plenty of fluids. A fever causes liquid to leave the body, and may make the person become dehydrated.
- Take Tylenol (acetaminophen or paracetamol) or aspirin every four hours until the fever is gone.

How to take aspirin and paracetamol for pain or fever:

- People over 12 years: 2 tablets (300 mg) every four hours.
- Children 6 to 12 years: 1 tablet (300 mg) every four hours.
- For children under 6, consult a health care worker.

If the fever stays high and will not come down for a long time, consult with a medical person. If living in an area where malaria is common, consider treating for malaria.

3. Diarrhea

Diarrhea is very common in people with AIDS. It is usually clear and watery and is sometimes accompanied by abdominal cramps and vomiting.

Having a bowel movement of normal consistency several times a day is not diarrhea. Someone has diarrhea if they pass three or more loose, watery stools a day. Diarrhea is dangerous because it causes dehydration, which is the loss of salt and water from the body. If a person becomes too dehydrated, it can lead to death.

Common causes of diarrhea:

- Intestinal infections from food or water
- Infections related to AIDS

- Side effects of medications

Some types of diarrhea can be cured with antibiotics. See a healthcare worker who can tell you the correct antibiotic to take for the diarrhea.

Treatment for Diarrhea

The act of drinking water or fluids does not cause diarrhea. When a person has diarrhea, they should drink enough water to replace the liquid in their body lost through diarrhea. A very sick person may not be able to swallow large amounts of water in a single sitting. They may need to take frequent sips of water or other fluids from a cup or frequent sips from a spoon.

Packets of oral rehydration solution (ORS) may be purchased from a pharmacy, drug store, or clinic. If ORS is not available, a rehydration drink can be made by mixing a liter of clean water with four heaping tablespoons of sugar, a level teaspoon of salt, and some lemon juice, if it is available. If this drink cannot be made, weak tea, unsweetened juice, soup (not greasy), or rice water can be used. For children and adults, give ½ cup (infants ¼ cup) after each loose stool and/or vomiting.

Diarrhea is very common in people with AIDS.
It is usually clear and watery and is sometimes
accompanied by abdominal cramps and vomiting.

Even if the person doesn't want to eat, continue to offer food. If they stop eating, they will lose strength and become weak. Certain foods can make diarrhea worse, so avoid foods that are bulky or high fiber, such as fruit and vegetable peels and whole-grain cereals. Food or drinks with a lot of sugar can also make diarrhea worse.

A person with diarrhea may become very weak. They may require assistance to walk to the toilet or latrine, and to stand up again.

Usually it is best not to give medication to stop diarrhea unless a doctor has prescribed it. Most medications bought over-the-counter stop the diarrhea temporarily but do not treat the problem.

Signs of Dehydration

- severe thirst
- little or no urine (the urine is dark yellow)
- dry mouth
- sunken eyes
- the skin loses its stretchiness

Medical help should be sought if the person is extremely thirsty and dehydrated or becomes drowsy and confused. If the person stops urinating, contact a medical person immediately.

Disposing of Body Waste

Use caution when disposing of the diarrhea waste. Protect hands with gloves or plastic bags. HIV cannot be transmitted this way, but other diseases can. Be sure to dispose of the waste in the toilet or latrine. If neither of these is available, a hole should be dug in the ground and the stool buried and covered over.

4. Skin Problems

Skin problems in persons with AIDS are common. These conditions can be treated but can be difficult to cure. The following are common skin problems in persons with AIDS:

- Rashes
- Itching skin
- Painful sores on the skin
- Increased dryness of the skin
- Slow healing

There are many causes of conditions. These may include yeast infections, fungal infections, bacterial infections, shingles, poor hygiene, sores on the skin, and allergic reactions to medicines or certain types of skin cancers.

Managing Skin Problems

To avoid complications from skin problems, keep the skin as dry as possible. Clean the skin every day with soap and water. Keep fingernails cut short so that scratching does not break the skin.

Control itching by:

- Cooling the skin with water or fanning it.
- Applying lotions such as calamine that sooth the skin and prevent the skin from becoming too dry.
- Some traditional remedies may be useful to help calm itching.

Vaseline, glycerin, and vegetable or plant oils can be as effective as expensive oils and creams sold in shops.

Treatment of Open Sores or Wounds

It is important to take care of open sores or wounds before they become infected.

- Wash the affected areas with clean water that has been boiled and cooled. Add a small amount of salt (one teaspoon to one liter of water) or gentian violet solution can help the wound heal.

- Protect the area by covering it with clean gauze bandages or cloth, wrapped loosely. Change the covering every day.
- Make a warm compress by soaking a clean cloth or towel with warm, salted water. Place this warm compress on the area four times a day.
- If the wound is on the leg or foot, raise the affected area as high as possible several times a day. Sleep with the affected area propped up on a pillow.

Treatment of Closed Sores or Wounds

Closed wounds (including abscesses and boils) may become infected. Boils and some abscesses are red, raised, painful lumps on the skin. They are most common on the groin, buttocks, armpits, back and upper legs. Clean, warm compresses should be applied over the area for 20 minutes four times per day. This helps the boil to mature or form and harden and eventually drain its contents. If it does not burst on its own, a medical person should be called to open it with sterile instruments. Antibiotics and further wound care may be required.

Closed wounds (including abscesses and boils) may become infected.

When bandages are applied, make sure they are clean and not applied too tightly. If bandages are to be reused, wash them in soapy water and dry them in the sun. Dressings should be changed at least once a day.

Protective covering of the hands is important when dealing with any open wounds. Gloves, plastic bags, or even a large leaf should be used. Bandages and drainage should be disposed of carefully by burning or burying. If the bandages will be reused, they should be washed immediately and not left where flies or someone may come in contact with them.

Always wash hands carefully after wound care and after disposing of bandages and drainage.

5. Mouth and Throat Problems

Soreness in the mouth, usually accompanied by white patches on the tongue and sides of the mouth, is a common problem in people with AIDS. It is called *thrush*. It can go down into the throat and esophagus, causing pain while swallowing and difficulty in eating and drinking.

In addition to thrush, many persons with AIDS have oral herpes simplex that causes blisters and sores on the lips. Kaposi sarcoma, a cancer, can attack the mouth and throat.

Preventing Problems in the Mouth and Throat

Though not all of these problems can be prevented, it is helpful to rinse the mouth with warm salt water (half a teaspoon of salt to a cup of water) or with a mouthwash solution after eating and between meals. The wash should be swished around the mouth, and then spit out. Eating soft, bland foods without spice may also help. Using straws for liquids and soups may make them easier to swallow. Frozen food or ice can also help numb the pain.

Treating Thrush

Thrush looks like milk curds stuck to raw meat. If the white plaques scrape off with a brush or a fingernail, it is probably thrush. If it does not, it may be another condition called hairy leukoplakia, which isn't serious and will not go down the throat.

These are some ideas for treating thrush:

- Gently scrub the tongue and gums with a soft toothbrush at least three or four times per day, then rinse the mouth with diluted mouthwash or a saltwater rinse.
- Suck a lemon or tomato if it is not too painful. The acid of lemon or tomato juice slows down the growth of the fungus.
- Apply gentian violet solution three or four times a day. The solution is made by dissolving one teaspoon of gentian violet crystals in half a liter of clean water. Be aware that this will cause the mouth and skin to turn purple.
- If these measures do not work, a doctor can prescribe antifungal medications.
- Seek medical help if a person with thrush or other mouth problems becomes dehydrated or malnourished from the inability to eat.

6. Managing Symptoms of Tuberculosis

Tuberculosis (TB) is a chronic contagious disease that is caused by bacteria. Tuberculosis usually affects the lungs and causes coughing and spitting. It is severe if blood is being coughed up. In children and those with AIDS, tuberculosis can also affect the bone, brain, lymph nodes, and other parts of the body.

> ***Tuberculosis (TB) is a chronic contagious disease that is caused by bacteria.***

Many people are living with the TB bacteria in the body. Thanks to their healthy immune system, the TB bacteria live in their body without causing sickness. But HIV weakens the immune system. As the body weakens, the defense system is no longer strong enough to keep the TB bacteria from making the person sick.

The most common symptoms of TB are:

- Chronic cough (lasting more than 3 weeks), which is often worse just after waking up. The person may also cough up blood.
- Loss of weight and increasing weakness.
- Mild fever.
- Sweating at night.
- Pain in the upper back and chest.
- Loss of appetite.

Because TB occurs commonly with AIDS, people with HIV/AIDS should be suspected of having TB. Persons with TB should be suspected of having HIV/AIDS. If either occurs, testing for the other should be carried out.

Because TB occurs commonly with AIDS, people with HIV/AIDS should be suspected of having TB.

Treatment

TB can be treated. Treatment usually consists of three or four different medications, and the medications are usually taken for about nine months. Many governments offer the TB medicines without charge, as well as X-rays and testing to see when the sputum no longer has the bacteria.

Preventing the Spread of TB to Family Members and Caregiver

- Everyone should seek early assessment and care for a cough that lasts more than three weeks.
- Everyone should cover their mouth when coughing. (TB is spread by droplets of sputum that come from the mouth and go into the air.)
- Everyone should avoid being in an unventilated room with a person who has been coughing for more than three weeks.
- Places such as homes, hospitals, etc., need to be well-ventilated with fresh air.
- Care should be taken with handling and disposing of sputum that is coughed up by a person with TB.
- Newborn babies and small children should be vaccinated with BCG, which provides good protection against the more serious forms of TB. (If the baby is known to be HIV-positive, it should not be vaccinated.)

7. Changes in Mental Functioning

When someone has received the diagnosis of HIV and/or AIDS, it is normal to feel anxious and depressed. However, when these feelings are very intense and last a long time so that daily activities are totally interrupted, they are considered abnormal.

Anxiety

This feeling of nervousness can have both physical and mental symptoms, including:

- Lack of appetite.
- Feeling short of breath.
- Shaking.
- A sensation that the heart is pounding.
- Sweating, tingling sensations.
- Feeling faint.
- Difficulty sleeping.
- A feeling of being out of control.
- Feeling very worried.
- Feeling jumpy.

When someone has received the diagnosis of HIV and/or AIDS, it is normal to feel anxious and depressed.

Depression

When someone has HIV/AIDS, they experience many losses in a very short period of time. Examples are loss of health, loss of physical beauty, loss of job, loss of ability to function, loss of mobility, and loss of eyesight. For all of these losses, a person must grieve and will at times feel very devastated. A person may experience depression in the following ways:

- A feeling of hopelessness.
- Feeling tired and generally without energy.
- Inability to find pleasure and a sense that everything is a chore.
- Irritability.
- Inability to concentrate and poor memory.
- Waking up early in the morning or having trouble sleeping.
- Eating too much or being unable to eat.

Periods of depression may come and go, alternating with periods when the ill person doesn't feel depressed at all.

Depression is more than a passing mood and is something to be concerned about if it lasts a long time or occurs very frequently. At times, people can become so depressed they wish to harm themselves or end their lives.

Treatment of anxiety and depression varies from culture to culture. In some places support for such problems is provided by trusted elders in the family. Sometimes pastors and spiritual leaders can be of help. Some of the counseling skills in this book may be helpful too.

If depression becomes severe, medications that combat anxiety and depression can be prescribed by the doctor.

AIDS Dementia

Some degree of mental confusion (or dementia) is common among people with AIDS, especially in later stages of the disease. The symptoms may be caused by HIV infecting the brain. The mental changes resulting from this may be barely noticeable or become a serious disability.

Some degree of mental confusion (or dementia) is common among people with AIDS, especially in later stages of the disease.

People suffering from this describe feeling dulled or slow in their thinking. Usually the family and friends are the first to notice these changes.

The mental changes may include difficulty in any or all of the following areas:

- Inability to think clearly, lack of concentration, or losing track of conversations.
- Irritability, disinterest, or unpredictable behavior.
- Loss of strength or coordination, dropping things, falling, or a slowness in movement.

Dealing with AIDS Dementia

Mental confusion is very upsetting and frightening for everyone involved. People suffering from this may have moments when they realize they are losing mental ability, and it is very distressing. Support from pastors, counselors, family, and friends is very important at this time.

There is not any specific treatment for this condition. The caretaker should try to protect the person from harming him or herself, keep walkways clear, and try to provide support when the person is walking or moving about. It may be well to remove sharp objects from within reach, since in moments of confusion the ill person may harm himself, herself, or others.

- Avoid arguing and trying to correct wrong statements.
- Be calm and gentle and try to not be easily excited by bizarre behavior.
- Speak slowly and clearly.
- Gently present reality.
- Provide distraction.
- Touch, if appropriate.
- Put on calming music.

Seek help if the person becomes harmful to himself or herself or others or is totally unable to be controlled.

There are many other conditions that can arise while caring for someone in the late stages of AIDS. Seek help and advice from local health professionals if there are situations that arise and the caregiver does not know what to do. Remember, there are many people who want to help. Don't be afraid to ask.

There are many other conditions that can arise while caring for someone in the late stages of AIDS.

8. Comfort Measures

People living with AIDS should take care of themselves as long as possible. However, at some point most people with AIDS will want and need assistance with what are termed *comfort measures*. The following are ways in which comfort might be offered:

- Respect a person's independence and privacy.
- Give people as much control as possible. Ask permission to help with something, sit beside them, etc.
- Ask what can be done to make them comfortable.
- Help with things like using the toilet, bathing, shaving, eating, and dressing.
- Try to keep the room or home clean and looking bright and cheerful.
- Leave things within easy reach so they don't have to go too far to get what they need.
- If the person can't get out of bed, help them turn in bed every two hours. Help them to roll onto one side, and gently tuck pillows or cushions behind their back to keep them from rolling back.
- Rub bony areas, including the back and buttocks, with lotion, cream or oil.
- Keep the sheets or mattress dry and as unwrinkled as possible.
- Exercise the arms and legs by lifting, pushing, and bending to keep the blood moving and the muscles as strong as possible.
- If someone is having trouble breathing, raise the head of the bed or prop the person up with pillows.

Care of someone with a terminal illness also has a goal of relieving the pain and suffering of physical symptoms such as nausea, diarrhea, or discomfort. These symptoms can be due to the person's illness or side effects of medications and treatments that he or she is receiving.

It is important to keep a record of the treatments that are provided. Be sure to note which treatments relieve the discomfort or symptoms and those that do not. Determine if this is a new or ongoing problem by asking a few simple questions like:

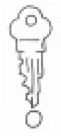
- When did the problem start?
- How long has it been going on?
- Does anything make it worse or better?

If the problem is new and there is a medical person available, it would be appropriate to inform him/her of the answers to the above questions.

It is important to keep a record of the treatments that are provided.

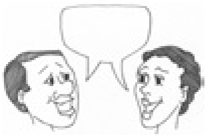
CHAPTER 9

Practical Helps for the Patient and Family



Key Points

1. **Assessing the Needs of the Patient and Family**
2. **Practical Ways of Providing Assistance**



Role-Play

Person with AIDS: *"I don't want to discuss this. Don't ask me again. I'm not going to die yet, and I don't want to think about what I want to do with things. We'll have plenty of time for that."*

Wife of person with AIDS: *"But if we don't have something in writing, I'll lose everything when you die. Your brothers will take the property and the house, and who knows what will happen with the children. All you have to do is write your wishes on a piece of paper and then it will be okay."*

Person with AIDS: *"I don't want to talk about this anymore. I'll do it when I'm ready and not before."*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

1. Assessing the Practical Needs of the Patient and Family

Often family members, community and church volunteers, and friends want to give assistance to the person nearing the end of life and the family, but are unsure of what is needed. If the caregiver is an outsider and unsure of what is needed, a list might be made of practical assistance that others can give.

Questions for Discussion

- What might be the most common needs of the family dealing with a terminal illness?
- What are some ways those needs might be met?

2. Practical Ways of Providing Assistance

Legal Advice and Setting Business Affairs in Order

As seen in the role play, it is extremely important that business be set in order while a person who is sick still has the ability to make decisions. Legal advice is often expensive, but organizing a group of attorneys who will offer their assistance would be a great help to families who cannot afford legal counsel. (See Appendix D for an example of a last will and testament.)

> ***It is extremely important that business be set in order while a person who is sick still has the ability to make decisions.***

Even if legal help is not available, a written document that directs the distribution of personal and family belongings and property may protect the surviving family from losing everything. Witnesses can sign the document if there is no legal counsel available.

Financial Resources

When someone is facing a terminal illness, they usually spend a significant amount of money for medical treatment. Unfortunately, the financial needs of the household and family members continue, and often there isn't enough money to cover everything. Sometimes the caregiver is also the person who is responsible for earning money for the family.

Churches and communities can help with financial needs by taking special collections for families with serious financial needs. Starting gardens or small businesses to raise money for families who are in desperate financial need is another way to help.

Meals

Even if cash cannot be provided, friends, neighbors, and churches can help with food and meal preparation. This is a great help to both the sick person and the caregiver, who may not have the time or energy to shop and prepare meals.

Nutritional needs vary depending on the stages of HIV infection. If the person is sick with AIDS, it is important to determine what types of foods can be tolerated and how they should be prepared.

Household Chores and Gardening

Volunteers can be organized to help with house chores and clean the yard. If the family has a garden, volunteers can help with planting, weeding, and harvest.

Care of Children

The HIV/AIDS epidemic has left millions of children orphaned. This has been a huge problem in Africa, but other regions of the world are also experiencing the effects of young parents dying from AIDS, leaving their children without family to care for them.

One of the great concerns when a parent is infected with HIV is how the children are being cared for during the illness and how they will be cared for after the death of the parent. This is extremely painful for single parents who worry over the destiny of their children.

Volunteers from the church and community can offer to help with child care. There are many options, including watching children in the home or taking the children out for a period of time to distract and entertain them.

Children may have great emotional needs as they sense and observe the changes in their parent or loved one. They are sometimes overlooked when adults get very involved in care giving. Children will need a great deal of love and support from others during—and after—this difficult time.

Children will need a great deal of love and support from others during—and after—this difficult time.

Running Errands

If a person is sick at home or in a hospice facility, he or she may feel too bad to go to the bank, buy groceries, pay bills, and take care of normal activities that require movement. Offering to do these types of things, or driving the person to do them, is a very practical help.

Respite Care

This term means allowing the caregiver to have a break from the caregiving role even for short periods of time. A volunteer can come in and allow the caregiver to step out for a while. Sometimes even an hour away will make a big difference to a caregiver working in an intense situation.

Change of Energy Level

The energy and physical abilities of a person sick with AIDS changes from day to day. During an acute period of illness, activity may be greatly diminished. If the infection is able to be treated, energy levels may rise. Schedules need to be flexible, according to the daily capacity of the individuals to do for themselves.

Consider the following points:

- Are there objects in the middle of the floor that could cause someone to trip and fall?
- Is there enough light to see potential obstacles that could cause a fall?
- Is the floor slippery or wet?

Role-Play

One person is trying to help another to rise from a chair. The person tries to pull the other person up from a chair using only their arms. The person in the chair is heavy and doesn't come up easily. The first person struggles quite a bit and finally manages to get the person up, but he or she comes up with so much force that they both tumble to a heap on the floor.

Protecting the Caregiver from Injury

Sometimes persons who are very sick require assistance in moving around in bed or getting from bed to chair or going to the bathroom. Whenever assistance in moving is given, it is important to do it in a way that will prevent injury to the patient or caregiver. Using the body properly is called *body mechanics*. Follow these principles of body mechanics::

1. Keep the back straight.
2. Place the feet about a foot apart to widen the base of support.
3. Place one foot slightly in front of the other.
4. Hold the person close to the caregiver's body.
5. Lift with leg muscles rather than the back muscles (leg muscles are much stronger than back muscles).
6. Bend the knees.
7. Before starting the move, plan how you will do it: Don't get caught in the middle with no place to set the patient!
8. Communicate the plan with everyone involved. Make sure enough help is present if the person is heavy or unstable on his or her feet.

Be cautious when grasping a person's arm or leg. Try to cradle the arm with the flat of the hand rather than using fingers. Muscles are often tender and the skin very fragile. Trying to move a person by pulling at them with your fingers can injure skin and cause pain.

Offering physical care and comfort is often very appreciated by those who are ill. When done with gentleness and respect, it is a wonderful way of showing love and concern. Protection for the caregiver and the patient will keep both healthier longer.

Section 4:
Setting Up Hospice Care

CHAPTER 10

What is Hospice Care?

Key Points

1. **When Is the Time for Hospice Care?**
2. **Where Is Hospice Done?**
3. **Who Does Hospice Care?**
4. **What Materials Are Needed?**

1. When Is the Time for Hospice Care?

Hospice care emphasizes that each person has a right to the best quality of life as long as possible. It also implies that the patient has a right to be a part of the decision making concerning life issues as long as he or she is able. The person who is ill should also be able to decide if he or she wishes to die at home, in a hospital, or in some type of care facility. Due to limited financial resources, some people won't have access to medical care.

Hospice is not an alternative to institutional medical care. The goal of hospice is to try to help the person who is sick and dying to be as free of pain and as comfortable as possible. Support for physical, spiritual, and emotional needs is the goal, even if they are not receiving formal medical treatment.

Hospice is not an alternative to institutional medical care.

Usually hospice or end-of-life care begins when medical treatment can no longer change the course of the illness and the person is facing death in the near future. Therefore, though some medical treatment may continue to be given at another location, hospice care primarily provides comfort measures.

Though it may be appropriate for the person and their loved ones to retain hope for healing or cure, they will most likely need assistance to come the realization and acceptance that the person is truly facing the end of life.

2. Where Is Hospice Done?

Hospice care is often given in the home of the person who is ill. Many people would rather die at home with friends and family near than in a hospital. In some places, especially when there is no family to care for the person who is ill, a facility may be dedicated to becoming a home or care center where people can go to die. A church congregation or people in a community may decide to build or convert a building into a comfortable environment where people who have no way to be at home and nowhere to go can come and receive hospice care. In some areas, a section of a hospital will be given over to hospice care.

3. Who Does Hospice Care?

Hospice care can be given by anyone who is caring and concerned about the person who is sick and dying. It is best done by someone who has had some training in the matters addressed by this manual. Ideally, hospice care is most effective when there is a team made up of family or friends who are close to the person, a health professional, someone skilled in counseling, and someone who can address spiritual needs.

Hospice care can be given by anyone who is caring and concerned about the person who is sick and dying. It is best done by someone who has had some training in the matters addressed by this manual.

In many areas of the world, the situation in the local communities is not ideal for hospice care. In some places, many people in the community die from AIDS every month. There may not be enough people to make up the hospice support team. At times there may be only one person available who can help out. However, with just a small amount of help, that one person can make a very large difference in the comfort and peace of the person they are caring for.

- **Community volunteers**. In some parts of the world, AIDS and other epidemics have taken the lives of the family members who would normally be by the side of the person who is ill. It is an admirable fact that many communities have responded to the challenge. They are forming groups of volunteers who receiving training to give hospice care, and organize themselves to help meet the needs of the people in need in their communities.

- **The church's response**. Some churches have also responded to the needs of people facing end-of-life issues, and are reaching out in compassion to offer care and assistance. This is done in a variety of ways: by organizing a facility or home where people can go for end-of-life care or by organizing volunteers to offer home care. As will be addressed in later sections, financial resources of those who are dying are often greatly depleted, and church projects that help support those in need are often of great help.

4. What Materials are Needed?

When setting up hospice care either in a home or facility it isn't necessary to invest large amounts of money in medical equipment. This goes back to the basis of hospice care: providing care in a home like setting. Many of the items that are needed in hospice setting are probably already present in a home or can be purchased locally.

Some items that are usually used on a daily basis in hospice care are included in the following list. The items necessary for daily living are similar across the globe. While the function of the items are similar, what they items look like and cost vary from region to region.

> ***When setting up hospice care either in a home or facility it isn't necessary to invest large amounts of money in medical equipment.***

Bed

It is not necessarily to have hospital beds to care for a sick person. Some people will be accustomed to beds with frames and mattresses; some people are accustomed to sleeping on a mat on the floor. The most important thing is to keep the person as comfortable as possible, especially if they aren't able to get out of bed. Use linens appropriate to local culture (sheets, blankets, pieces of cloth, etc.), and change them frequently so the person isn't forced to sleep in a dirty bed. If the person soils the bed with urine or feces, place a piece of plastic sheeting that doesn't tear easily between the mattress and linen, to protect the mattress or mat. (Wash the plastic with a cloth each time the bed linen is changed.) Of great importance is the use of two or three pillows or cushions to support their head and limbs.

Keep a small table or chair next to the bed within arm's reach of the person, where he or she can place necessary personal items. This may include reading materials, a radio, a phone, a source of light, tissues or handkerchiefs, drinking water, etc.

Personal Hygiene

Some homes or hospice centers will have full bathing facilities with water from a faucet or shower. Others will bathe using a basin or bucket of water to wash the body. Soap, lotion, and towels to dry the body are necessary for each individual being cared for. If the person can't get out of bed, he or she might still be able to wash his or her body. If not, the caregiver can bathe the person in the bed. Using two basins of water (one for washing, one for rinsing), and keeping the person covered with a sheet or piece of cloth, the caregiver can systematically wash, rinse, and dry the body. The bed linen should then be changed so the person isn't forced to lay in a wet bed.

If the person is sick and vomiting, it is necessary to have clean basins next to the bed. Keep fresh water and a clean towel at the bedside so the person can rinse their mouth after vomiting.

Keep plenty of disposable tissues around if the person is coughing. If disposable tissues are not available, use handkerchiefs or rags that are only used for this purpose. Dirty tissues or rags should be placed in plastic bags, and safely disposed of out of the reach of people or animals or burned. If the person is coughing up sputum, they may prefer spitting directly into a plastic bag or into a jar or can filled with sand that can then be disposed of out of the reach of people or animals.

Toilet Needs

Again, some homes or centers will have full toilet facilities with flushing toilets. Others will have toilet areas located outside the house; often these are latrines or pit-style toilets. It is important that a sink or washing basin is located close to the toilet for hand washing. Some areas always have toilet paper available; in other areas this isn't always done, but some method or product is necessary to cleanse and dry their anal area, especially if they are suffering with diarrhea. If toilet paper can't be flushed, there needs to be a receptacle in which to place the toilet paper so it can be safely disposed of or burned.

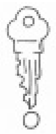
It is important that a sink or washing basin is located close to the toilet for hand washing.

If a person can't walk or get out of bed, they still need to urinate or have bowel movements. Some type of sturdy receptacle or bucket can be placed next to the bed, and the person can transfer from bed to the toilet with the help of the caregiver. If a woman can't get out of bed, the caregiver can help her raise her hips and place a bed pan or sturdy plastic basin for urination or defecation. A man can use a urinal or a plastic bottle for urination.

A simple bedside toilet can be made using a small bench and a sturdy bucket with a lid. Cut a hole in the bench and place the bucket under the hole. The bucket can then be emptied and washed after use.

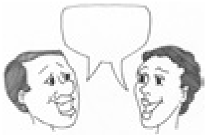
CHAPTER 11

Setting up a Hospice Home Care Program



Key Points

1. **Description of a Hospice Home Care Program**
2. **Advantages of Home Care**
3. **Organizing a Hospice Home Care Program**
4. **Working With Volunteers**
5. **Program Evaluation**



Role-Play

Person in late stages of AIDS: *"I just can't go back in the hospital one more time. I don't care what happens to me; I just want to be at home. I want my children nearby. I just can't be in that place once more."*

Spouse of person with AIDS: *"Well, I'm just not sure if I can take care of you. That's what worries me. What if something happens and I don't know what to do? Then what?"*

- What do you see?
- What is happening?
- Does it happen in our situation?
- Why is it happening?
- What can we do about it?

Questions for Discussion

- What are your feelings about taking care of someone who is dying at home?
- What are the positive things about dying at home?
- What are the negatives?
- Are there things in your culture that would make volunteer home care difficult?

1. Description of a Hospice Home Care Program

Home care can mean different things, but whatever form it takes, it relies on two strengths that exist everywhere in the world: the family and the community. When one of these elements is missing, home care hospice programs are not likely to succeed.

Care at home is usually provided by family, friends or neighbors, church members, or interested community members. Often people are reluctant to sign on as volunteers for home care because they feel they don't have the skills to care for a sick person. They may even fear becoming infected by caring for someone with AIDS.

Home care may require specific caregiving skills, but there is more to it than providing physical care for a sick person. It also includes a willingness to help meet the very basic physical needs, such as food, clothing, and housing.

> ***Home care may require specific care giving skills, but there is more to it than providing physical care for a sick person.***

In the early years of the HIV epidemic, fear, stigma, and lack of acceptance of people with AIDS kept people from getting involved in home care. Though this still exists, people are becoming more informed about HIV/AIDS. The tendency to hide or deny the disease is lessening. This is bringing about a larger number of volunteers willing to reach out to help those who cannot help themselves.

Questions for Discussion

- What are some advantages to home care, in your opinion?
- What are the disadvantages?

2. Advantages of Home Care

There are advantages of home care for persons with AIDS. Some of the advantages listed in the World Health Organization's *AIDS Homecare Handbook* are:

- Good basic care can be given successfully at home.
- Many people who are dying would rather do so at home, especially when they know there is no cure in the hospital.
- Being in a familiar environment with friends and family often brings comfort.
- Home care means that hospitals will be less crowded.
- It is usually less expensive for someone to be cared for at home.
- If the sick person is at home, family members can carry on some of their responsibilities without having to be at the hospital all the time.
- Sometimes hospital care is simply not possible.

3. Organizing a Hospice Home Care Program

A group, fellowship, church congregation, or community needs to take responsibility to initiate the hospice outreach. There should be some type of board or committee who takes responsibility for all the operations of the home care program.

Setting Goals

After a committee has been formed, the members need to decide what its goals are and how far reaching the program will be. Examples of goals may be:

- Raising up volunteers to do the care giving.
- Raising funds to support families giving care.
- Offering respite care (times of relief for family members doing the care).

Questions for Discussion

- How will you know if there is a need for the hospice program in the community in which you wish to work?
- What kinds of things do you need to know before beginning?

Assessing the Need

When determining if a community needs a hospice program, it would be helpful to ask questions about what is being done by other groups. There may not be a need to start another program if someone else is already meeting the needs.

In order to know if the community needs a hospice program, the committee will have to do a *needs assessment*. This includes finding out how many people are dying in homes, how much family support is available, how many volunteers will be needed to care for these individuals, and what kinds of needs are most prevalent, i.e. food, practical helps, hands-on physical care, etc.

A sample needs assessment form is given in Appendix E. If this form isn't suitable, it can be adapted to ask the questions that will help obtain the needed information. A house-to-house survey form can be found in Appendix F.

Objectives and Mission Statement

Once the goals have been decided upon and the needs assessment done, objectives and a mission statement should be formulated which clearly say exactly what the proposed hospice program hopes to achieve. These should be written in a way that allows for evaluation of the objectives. This is the best way to know if the program is effective and doing what it said it would do. See Appendix G for help in writing objectives.

4. Working With Volunteers

Most home care programs function on a day-to-day basis thanks to the service of volunteers. Volunteers are often neighbors, church members, or interested community members. Sometimes people who have experienced a loss and who were (or were not) helped during their struggle want to give back and help others. Some feel it is a God-given call to help; others simply see the need and want to serve.

The number of volunteers needed depends on the scope of care being planned by the hospice program. The needs assessment that has been done should help determine how many volunteers are needed.

Recruiting Volunteers

Once the mission of the group is clear, persons in the organizing group who speak well and can promote the need should seek to speak at church gatherings, community functions, parent meetings, etc. The mission of the hospice should be clearly given. Flyers can be posted at meeting points.

Screening Volunteers

Though the program does not want to discourage volunteerism, there must be some mechanism of screening so that unscrupulous people are not signed up as volunteers and given entry to homes where they may exploit the families they are sent to serve. In smaller communities, most people know each other and this step may not be necessary, but for the protection of the program and the recipients of care, it is best to have:

- An application form (See Appendix H for a sample form).
- An interview process (See Appendix I for sample interview format).
- A reference check procedure (See Appendix J for sample reference form).

Training Volunteers

Once volunteers have been recruited and screened, they will need to be trained. Using this manual or a similar publication is helpful. The training can usually be done in a week or less. However, follow-up training may need to be done if the volunteers feel that they need more skill or information for the tasks they are being asked to do.

Organizing Schedules

The committee in charge of organizing the program should set up a volunteer schedule so that regular visits are made to those who are enrolled in the hospice program. Volunteers can sign up for the days and hours that they can serve.

Formulating Teams

As stated in the introduction of the manual, the ideal hospice program uses a team approach to address the needs of the person dying at home.

As stated in the introduction of the manual, the ideal hospice program uses a team approach to address the needs of the person dying at home. A medical person, a counselor, a spiritual leader, and volunteers to do different tasks would make up a team. Some of the team would visit less frequently, whereas the volunteers may be visiting every day. However, if the professional members of the team are not available, the volunteers can still make a very big difference in making the end-of-life process less traumatic for the patient and family.

Support Groups for Volunteers

Caring for the terminally ill and their families can be very draining, both emotionally and physically. The volunteers should be encouraged to attend monthly support groups to be able to communicate their feelings and receive encouragement. (Refer to Chapter 2, "Preparation to Become a Caregiver.")

Dropouts

Occasionally volunteers will find that caring for someone who is dying is too difficult for them, and will find it impossible to continue to volunteer. Others will realize that they did not understand how difficult the task would be and feel they need to leave the program. Others may become frightened by the seriousness of the symptoms of the ill person, and others may simply not show up.

Affirmation of Volunteers

The work the volunteers are doing is very difficult. It is important to affirm their work by expressing how much they are appreciated. If the organization sponsoring the hospice program has the resources, it would be good to reward the volunteers occasionally with a special dinner or something special that would show that their work is appreciated.

Evaluating Volunteers

Even though the volunteers are giving their time without pay, it is important that their work is monitored and evaluated. The best method of doing this is to ask the patient and family how they feel about the service being offered by the volunteers that come to their home. A sample evaluation form is given in Appendix K.

5. Program Evaluation

All programs need to continue to make efforts for improvement. They need to determine if the original objectives of the program are being accomplished. Sometimes, especially if the program grows and expands, it is beneficial to have an outside, objective group come in to evaluate how the program is doing (for example, a church board or group of community leaders).

The objectives and mission statement of the program should be reviewed every six months.

The objectives and mission statement of the program should be reviewed every six months. As the program grows, a governing board should be set up and written evaluation reviews submitted to the board.

The review should include:

- Accomplishments (statistics—numbers enrolled in program, etc.).
- Obstacles.
- Strategies to overcome obstacles.
- Lessons learned.

Though there is much more that needs to be known before offering hospice care, this lesson has given some of the considerations that should be taken into account before starting this ministry. Often this type of outreach starts spontaneously as neighbors reach out to neighbor in Christian love and concern. As people follow each other's example, a hospice program may emerge. There is no better foundation than one built on "serving and loving each other—just as Christ loves and serves us."

> ***"Giving always means receiving. Each person I've assisted has given me more than I gave."***
> ***—Interfaith Volunteer Caregiver, Sedona, Arizona, USA.***

CHAPTER 12

Setting up a Hospice Facility

Key Points

1. **Determining the Need for a Hospice Facility**
2. **The Purpose of a Hospice Facility**
3. **Advantages and Disadvantages of Facility Care**
4. **Organizing and Equipping a Hospice Facility**
5. **Church-Based Hospice Facilities**
6. **End-of-Life Issues**

> ***"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."***
>
> **—A person dying with AIDS**

1. Determining the Need for a Hospice Facility

After doing a community needs assessment, it may become evident that there are numbers of people who have no family to care for them at home. These people may not be in a housing situation that suits their special needs as they become sick. It may also be found that there are not enough volunteers to go out and provide care in a home-based hospice program.

Another option for providing care for someone in their final months or weeks of life is to create a facility with the specific objective of housing and caring for those who are dying of AIDS.

There are always expenses involved in building, renovating, buying, or renting a building to use as a care center. However, providing care in a centralized location may be more efficient than going from house-to-house because a number of people can be cared for at the same time and in the same place.

Volunteers may still be needed and can be used for this type of care as well. However, if financial resources are available, people might be hired to do the caretaking.

Some community centers have been turned into hospice units. In some places hospitals have given over a section or wing of a hospital building for hospice purposes. Churches have also built or made space available for the same purpose.

2. The Purpose of a Hospice Facility

Ideally, the hospice facility should provide a home-like atmosphere. In fact, some hospice programs start in a family home where there is a person with AIDS, and then another sick person is taken in. Neighbors begin stopping by to offer help, and suddenly the idea of a care center develops.

Whatever or wherever this takes place, the principles are the same: to provide a peaceful, comfortable atmosphere with caring people who can offer physical, spiritual, and emotional support and care. While able, people who come to a hospice center are given tasks and responsibilities to carry out as long as they can. People with enough energy may want to help to take care of those who are bedridden. In Christian hospice, a spiritual environment is provided with someone available to offer spiritual encouragement through prayer and Scripture reading. A pastor should be available to offer his or her pastoral support during moments of crisis.

> ***In Christian hospice, a spiritual environment is provided with someone available to offer spiritual encouragement through prayer and Scripture reading.***

3. Advantages and Disadvantages of Facility Care

Advantages:

- Efficient use of volunteers and other support personnel.
- Less feeling of isolation—persons of “like difficulty” being together .
- Spiritual support more available.

Disadvantages:

- May be perceived as self-contained and self-supported, making it more difficult to find volunteers willing to commitment to volunteerism.
- More expensive: facility, meals, beds, supplies, etc.
- May need to meet government regulations.
- May seem to have a stigma attached as “a place to go to die.”

Questions for Discussion

- What are the advantages of a hospice-type facility?
- What are the disadvantages?
- Would such a facility be acceptable in your culture? Why or why not?

4. Organizing and Equipping a Hospice Facility

Just as in a home-based program, a needs assessment should be carried out before setting up a hospice facility. Objectives and a mission statement need to be written. Policies and procedures and volunteer screening need to be put into place. A budget must be drawn up and fundraising strategies planned prior to opening of the facility. Checking for government regulations is critical. Please refer to Lesson 10 for ideas on the organization of a hospice program.

> ***Just as in a home-based program, a needs assessment should be carried out before setting up a hospice facility.***

The Layout of the Facility

When creating a care facility in existing buildings, there may be some limitations in how the center is laid out. Ideally, the facility should be laid out to provide privacy for each person, space for individual rooms, a sitting and eating area, toilet facilities, and a food preparation area. A lockable storage area is important because medicines and supplies will usually be kept on-site. If buildings have to be constructed, they should be constructed in a style which fits the local context. For example, if all buildings in that particular locale are mud and thatch, then this building should also be mud and thatch. (See Appendix L for sample floor plans of simple hospice facilities.)

Ventilation and Fresh Air

Of most importance in the layout of a hospice facility is the ability to allow for ventilation and fresh air. This is very important when persons have TB, since a non-ventilated room can lead to a higher incidence of transmitting the bacteria to others. If an existing structure is to be used, it would be good to determine if windows could be added to permit adequate airflow.

Food Preparation

Some programs will have food brought in from others. If resources permit, food may be prepared on-site. Well-balanced nutritional meals that are not spicy or greasy are preferred. If food preparation will be done at the facility, a kitchen separate from the living area of the residents may be preferable, since the smells of food often cause increased nausea and discomfort to those who are very ill with AIDS.

Beds and Furniture

Beds and furniture may be donated by families, church members, or community members or may be constructed out of local materials. Hospital beds are not necessary. Mattresses may or may not be used, depending on the area; in some countries, people prefer sleeping on mats on the floor. Linens that are appropriate to the local culture will also be needed. Two or three pillows or cushions are essential for the comfort of a person who cannot get out of bed.

Toileting and Bath Care

Toilet and bath areas are necessary in any center. These should be in keeping with local standards, using local materials.

Medical Equipment

Expensive medical equipment is not usually necessary in a community-based hospice center. The types of equipment needed include basins or buckets for bathing and other toileting needs if the person cannot get out of bed. The objective is to make a person as comfortable as possible, not provide medical care. A doctor or nurse may be engaged to make regular visits to the facility to check on the patient and prescribe whatever medications will be indicated to keep the pain at a minimum.

Records

Records should be kept on each person in the facility, just as in the home care program. A notebook or some means of recording when medicines are given, when vomiting occurs, and anything pertinent to the patient's condition is all that is needed.

Comfort measures such as turning those who cannot turn themselves, giving water and food, keeping the bed dry and clean, and help with dressing, walking, etc., should all be available.

5. Church-Based Hospice Facilities

The development of a hospice center is an excellent way to demonstrate the love of Jesus. It is an excellent outreach of the church to the community. Some churches have formed hospice facilities and, as the practical love of Christ has been shown, have had opportunity to lead terminally ill people into a relationship with Jesus and instill a new hope into their lives.

6. End of Life Issues

At some time every person will face the end of life. For some, it will seem to be much sooner than it should be, and it may not be an easy death. But all of us, regardless of when we die or how we die, share a common hope that when death comes it will be peaceful and as free of pain as possible. We hope to face death surrounded by those we love, while feeling safe, comfortable, and cared for with the peace of our Lord in our hearts, with an assurance of eternal life in heaven. Hospice care which stresses living fully until the end, dying with dignity and comfort, and being surrounded by loving and caring support may provide at least some of what we all hope for.

APPENDIX A

Life Review

Life review is the process of looking back at the past. It allows the patient to remember a time when he felt strong and capable and perhaps allows him to come to terms with unresolved conflicts and disappointments. Life review serves as a means to finish unfinished business.

How can I help someone reminisce?

1. While you're with the patient, your time and thoughts should be focused on the patient.
2. Keep the patient's recollections confidential.
3. Keep the conversation flowing, and focus on the feelings surrounding events rather than on the events themselves.
4. Be sensitive to the patient's capabilities, needs, and feelings.
5. Allow silence and emotion.
6. Focus on the patient's reminiscing, but your occasional sharing of a similar experience can help the patient feel more connected to you.

Steps for reminiscing

1. Think of some open-ended questions you might ask to start the conversation.
2. Listen actively. Make eye contact and remember body language. Ask follow-up questions and restate key points.
3. Help the patient take satisfaction in the life he or she has led.
4. If the patient gets stuck on one particular story, help him or her find the real meaning and resolve it by getting beyond the actual event.
5. If the patient just hints at a subject, ask questions designed to get further information and encourage him or her to talk about the memory.
6. Not all memories are happy ones. Reassure the patient that we all make mistakes and we are all human.
7. If a stressful memory comes up, remember that your role is to listen supportively, not be judgmental, and not to solve the problem. If you feel the patient would like or needs to discuss the memory at a level you are not comfortable with, do not hesitate to seek the help of professionals.

APPENDIX B

Spiritual Assessment

Part 1

Name: ____ ID# ______________________

Patient Religious Preference: ______________________________ ☐ Active ☐ Inactive

Caregiver Religious Preference: ____________________________ ☐ Active ☐ Inactive

Questions asked of ☐ Patient ☐ Caregiver

1. How would you rate your spiritual health?

   ☐ Good ☐ Fair ☐ Poor ☐ Uncertain

2. How would you classify your spiritual life? Do you see yourself as being:

   ☐ Deeply spiritual ☐ Somewhat spiritual ☐ Not at all

3. How much is your spiritual life a source of strength and comfort to you?

   ☐ Very much ☐ Moderately ☐ Not at all

4. How do you view your relationship with God?

   ☐ Meaningful/important ☐ Not meaningful ☐ Cause of discomfort

   ☐ Other ___________________________

5. How important to you is reading Scripture?

   ☐ Very much ☐ Moderately ☐ Not at all

6. How important to you is personal prayer?

   ☐ Very much ☐ Moderately ☐ Not at all

7. How active were you in your faith community?

   ☐ Very much ☐ Moderately ☐ Not at all

8. Which sacraments, traditions, or ceremonies are important to you?

   ☐ Communion ☐ Anointing with oil ☐ Someone to pray with you

   ☐ Other ____________________________

9. Which of these have you felt recently?

☐ Anger ☐ Confusion ☐ Guilt ☐ Peace ☐ Hopeful ☐ Discouraged

☐ Disappointed ☐ Cheated ☐ Abandoned ☐ Supported ☐ Loved

☐ Abused ☐ Accepted ☐ Denial ☐ Content ☐ In Control

☐ Out of Control ☐ Forgiven ☐ Unforgiven ☐ Forgiveness of others

10. Is there any other particular problem bothering you? ______________________________

____

____

11. What was your childhood religious training and any other relevant past religious history?

____

____

12. What do you hope for? ____

____

____

13. What gives meaning to your life now? ________________________________

____

____

Part 2 (To be filled out by pastor/spiritual caregiver)

Strengths

☐ Good support system ☐ Sense of humor ☐ Flexibility

☐ Resolved spiritual/religious issues ☐ Helpful spiritual/religious issues

☐ Other: ____

Needs for Intervention

☐ Anger ☐ Guilt ☐ Unresolved spiritual/religious issues

☐ Grief and loss issues ☐ Spiritual alienation/isolation ☐ Anxiety/fears

☐ Forgiveness ☐ Absence of peace ☐ Reconciliation

☐ Other: ____

Spiritual Discomfort

☐ None ☐ Moderate ☐ High

Comments

Additional Comments

Plan of Spiritual Care

Signature of pastoral/spiritual caregiver: ____________________

Date: ____________________

APPENDIX C

List of Suggested Scripture Readings

(The following readings are particularly appropriate for use in spiritual care for the terminally ill.)

Old Testament

Job 7:11–21	Job complains to God
Ecclesiastes 3:1–15	For everything there is a season
Isaiah 26:1–4	God will keep them in perfect peace
Isaiah 38	Hezekiah's prayer in distress
Isaiah 40:1–11	Comfort my people
Isaiah 40:28–31	Those who wait for the Lord shall renew their strength

Psalms

Psalm 6:2–4, 6–9	Lord, heal me, for my soul is struck with terror
Psalm 23	The Lord is my shepherd
Psalm 27	The Lord is my light and my salvation
Psalm 42:1–5	As a deer longs for flowing streams
Psalm 46:1–5, 10–11	A very present help in trouble
Psalm 51:1–12, 15–17	Create in me a clean heart, O God
Psalm 63:1–8	In the shadow of your wings I sing for joy
Psalm 77	I cry to God to hear me
Psalm 86:1–7	In the day of my trouble I call on you
Psalm 91	My refuge and my fortress, my God in whom I trust
Psalm 103:1–5	Bless the Lord, O my soul
Psalm 130	Out of the depths I cry to you, O Lord
Psalm 143:1–2, 5–6, 10	Give ear to my supplications

New Testament

Matthew 5:1–12	The Beatitudes

Matthew 11:28–30	All who are weary and are carrying heavy burdens
Luke 8:4–-48	The woman with hemorrhages
John 3:16–17	God so loved the world
John 10: 11–18	I am the good shepherd
John 14:1–6, 25–27	Let not your hearts be troubled
Romans 5:1–11	Hope does not disappoint
Romans 8:14–23	Present sufferings are not worth comparing with the glory to be revealed
Romans 8:26–28	The Spirit helps us in our weakness
Romans 8:31–39	If God is for us, who is against us?
Romans 12:1–2	Present your bodies as a living sacrifice
2 Corinthians 1:3–7	Sharing in sufferings and in comfort
2 Corinthians 4:16–18	Visible things are temporary; invisible things, eternal
Philippians 4:4, 6–9	Rejoice in the Lord always; have no anxiety
Hebrews 2:14–18	Christ was tested in every way
James 5:13–16	Is anyone among you suffering?
1 Peter 1:3–9	Born anew to a living hope
1 John 3:1–3	We are children of God
1 John 4:16–19	There is no fear in love
Revelation 21:1–7	God will wipe away every tear

APPENDIX D

Last Will and Testament

LAST WILL AND TESTAMENT OF________________________________. BE IT KNOWN, THAT I, ________________________________, OF________________________________, County of____________________________, in the State/Province of______________________, being of sound mind, do make and declare this to be my Last Will and Testament expressly revoking all my prior Wills and Codicils at any time made.

I. PERSONAL REPRESENTATIVE:

I appoint _____________________________ of _____________________________ as Personal Representative of this my last Will and Testament and provide if this Personal Representative is unable or unwilling to serve then I appoint _____________________________ of _____________________________ as alternate Personal Representative. My Personal Representative shall be authorized to carry out all provisions of this Will and pay my just debts, obligations and funeral expenses. I further provide my Personal Representative shall not be required to post surety bond in this or any other jurisdiction, and direct that no expert appraisal be made of my estate unless required by law.

II. GUARDIAN:

In the event I shall die as the sole parent of minor children, then I appoint ___________________ as Guardian of said minor children. If this named Guardian is unable or unwilling to serve, then I appoint ____________________as alternate Guardian.

III. BEQUESTS:

I direct that after payment of all my just debts, my property be bequeathed in the manner following:

____

____

____

____

____

____

____

Page ___ of ___ Testator Initials _________________

Execute and attest before a notary.

IN WITNESS WHEREOF, I have hereunto set my hand this ______ day of _________________, ________ to this my last Testament.

____ Testator Signature

1V. WITNESSED

The testator has signed the Will at the end and on each other separate page, and has declared or signified in our presence that it is his/her Last Will and Testament, and in the presence of the testator and each other we have hereunto subscribed our names this ______ day of _________________, ________.

Witness Signature ____________________________ Address ________________________

Witness Signature ____________________________ Address ________________________

Witness Signature ____________________________ Address ________________________

STATE/PROVINCE OF _________________ COUNTY OF ________________________

We, _______________________, _______________________, and _______________________, witnesses, respectively, whose names are signed to the attached and foregoing instrument, were sworn and declared to the undersigned that the testator signed the instrument as his/her Last Will and that each of the witnesses, in the presence of the testator and each other, signed the Will as a witness.

Testator: _______________________________ Witness: ________________________________

Witness: ________________________________

Witness: ________________________________

STATE/PROVINCE OF ____________________ COUNTY OF ______________________

Page _____ of _____

On ________________________________ before me, _________________________, appeared ________________________________ personally known to me (or proved to me on the basis of satisfactory evidence) to be the person(s) whose names(s) is/are subscribed to the within instrument and acknowledged to me that he/she/they executed the same in his/her/their authorized capacity(ies), and that by his/her/their signature(s) on the instrument the person(s), or the entity upon behalf of which the person(s) acted, executed the instrument.

WITNESS my hand and official seal.

Signature ____Signature of Notary

Affiant: ________________

Known ________________

Produced ID ________________

Type of ID ________________

(Seal)

Disclaimer: We do not and cannot assure you that any document is legally acceptable in your jurisdiction. You must consult with an attorney prior to using or signing any legal document.

APPENDIX E

Assessment of a Community for Hospice Need

Assessment Question	*Where to Find Answers*	*Findings*
What is the approximate number of persons with AIDS (PWA) in the defined community?	Department of Health, UN/WHO office	
How many families are dealing with someone who is very sick or dying with AIDS?	House-to-House Survey	
What kinds of assistance do families or PWAs say they need most? (i.e. Hands-on care, finances, food, etc.)	House-to-House Survey	
How many persons are very sick with AIDS and have no family to help them?	House-to-House Survey	
How many hospice programs are there in the defined community?	Department of Health, Registry of NGOs	
Are the above hospices, if they exist, meeting the needs of the community?	House-to-House Survey	
What are the other forms of assistance being offered to PWAs, if any?	Department of Health, UN/WHO office	
How many PWAs are in the hospital in a given week?	Hospital director	

APPENDIX F

House-To-House Survey

(Fill out one form per household)

Name ____

Address ____

Number of persons in household _____ Mother present ☐ Father present ☐

Number of children living in the home _____

Number of persons very sick in the home _____

Does the family know what sickness it is? ______________________

Is the person(s) receiving medical treatment? Yes ☐ No ☐

What type of difficulties is the family encountering due to the sickness? __________

____

Is the family receiving any type of home care visits from anyone or any group? ______

____

Would the family like to be visited by volunteers who could help out with the sick person or the family needs, if such volunteers were available? Yes ☐ No ☐

What type of assistance from a volunteer would be most helpful? ____________

____

____

____

____

APPENDIX G

Writing Objectives

There are different kinds of objectives which serve different purposes—learner objectives (which are behavioral) and project or program objectives (which are more activity-oriented and have specific outcomes).

For the purpose of a hospice program, you should construct project objectives.

These need to be specific and be expressed in measurable terminology, stating what activity will be done, who will do it, how it will be measured, and in what time frame. These objectives can be of a great assistance in evaluating where you are with the project and whether you are meeting your original expectations in timely fashion. External evaluators will usually want to see your objectives and discuss the outcomes with you.

When writing objectives:

WHO: Refers to the person(s) carrying out the action.

WHAT: What is the actual activity that will be done (when) and how it will be measured.

MEASURED BY WHAT: Identifies how well the activity must be done in order to demonstrate acceptability and what tool or method will be used in the measurement.

WHEN: Refers to the time component and must be realistic and specific. (It is realized that ideal and actual are relative when it comes to time.)

Words which are considered to be useful for measurable objectives which describe action and can be measured are:

Ex: The church of Bedudu (WHO) will construct a mud-thatch home hospice center (WHAT) in the acceptable standard of the building to house 12 persons with AIDS and 2 helpers (dimensions of the home adequate to house 14 people by local standards) by 2013 (time line).

To write
To conduct
To solve
To choose
To name
To trace
To adjust

To contrast
To select
To differentiate
To find
To list
To explain
To match

To state
To compare
To classify
To locate
To build
To do

EX: A house-to-house survey, using a government-approved survey tool, will be conducted from April to October, 2013, by the Miller House appointed project assessment team to determine how many families and persons are dealing with or are sick or dying from AIDS in the communities of Zyswha, Kitchwa, and Goodge, India. (Note what will be done, who will do it, what specific tool, what specific area. The next objective should discuss how the information will be utilized and what action will be taken based on that information.)

Words which should be avoided as they are subjective and difficult to measure are:

To know
To recognize
To perceive
To learn
To think
To be familiar with
To enjoy
To remember
To understand
To comprehend
To believe
To have knowledge of
To be acquainted with

APPENDIX H

Volunteer Application Form

Name ____

Address ____

Telephone ____________________

Date of birth ____________ Place of birth ____________________

What type of work do you do? ____________________________

Do you read and write? Yes ☐ No ☐ Highest education ______________

What languages do you speak? ____________________________

How much time can you give to volunteering?

☐ 1-2 hours each day

☐ 1-2 hours 2–3 days per week

☐ Other ________________

Why do you want to volunteer in this program? ______________________

____

Have you volunteered in another program in the past? ____________________

____

Please check the types of activities that you think you can do.

☐ Help do household chores.

☐ Help turn, bathe, and give medicine to the sick person.

☐ Help take care of the children of the sick person.

☐ Help prepare meals for the sick person or family.

☐ Help run errands for the family or sick person.

☐ Provide spiritual care for the sick person or family.

☐ Provide counseling for the sick person (qualifications ________________).

The persons you may care for may be sick with AIDS or TB or other diseases. How do you feel about caring for someone with these types of illnesses?

____

____

Though the risk is slim, are you aware that you could be at risk for becoming infected?

Yes ☐ No ☐

Are you willing to take this risk? Yes ☐ No ☐

Have you ever been arrested for a crime? Yes ☐ No ☐

If yes, were you found guilty and detained? ________________________________

Please provide the name of two other persons who know you and can provide references for you.

Name: ____
Address: ____
Phone: __________________________ Relationship to you: ____________________

Name: ____
Address: ____
Phone: __________________________ Relationship to you: ____________________

Signed: ____

Date: ________________________________

APPENDIX I

Interview Questions for Screening Volunteers

1. Where did you first hear about the hospice program?

   ____

   ____

   ____

2. Why did you decide to respond?

   ____

   ____

   ____

3. Have you been a volunteer before? Yes ☐ No ☐

   Where? Tell me about that experience.

   ____

   ____

   ____

4. Tell me what you expect this experience to be?

   ____

   ____

   ____

5. What do you think would be the most stressful part of your role as a hospice volunteer? Why?

   ____

   ____

   ____

6. Have you had any experience dealing with the terminally ill? Yes ☐ No ☐

   Where? Tell me about that experience.

7. How recently have you lost someone in your own family or someone close to you?

8. Do you feel that you have had time to grieve that loss?

9. Are you aware of and understand the risks involved in this type of care? How do you feel about that aspect of your role?

10. How do you feel about someone with AIDS?

11. What do you feel is the best thing you have to offer someone who is terminally ill?

12. How busy is your schedule? Do you feel that you really have time to do this?

13. Do you have any questions?

APPENDIX J

Contacting References

It is important to follow up on the references provided by the applicant. Asking open-ended questions will elicit the most response. The following may be helpful:

- How long have you known the applicant?
- What can you tell me about this person?
- How would you describe the applicant?
- Why do you think the applicant would make a good hospice volunteer?
- Is there any reason why the applicant may not be particularly suited for hospice work?

APPENDIX K

Volunteer Performance Evaluation

Evaluating Supervisor: ____

Name of volunteer: ____

☐ 3-month evaluation

☐ 6-month evaluation

☐ 12-month evaluation

Rating Scale

1 = unacceptable practice or behavior

2 = needs improvement

3 = fair

4 = good

5 = very good

6 = superior

N/A=not applicable

Professionalism

____ Understands the objectives of the program and practices accordingly

____ Shows respect to the patient and family

____ Speaks kindly and appropriately to patient and family

____ Maintains confidentiality

Responsibility

____ Arrives at home or office at scheduled times

____ Arrives on days scheduled; notifies family or supervisor if delayed

____ Carries out assigned activities as scheduled

____ Is careful and protective of patient and family's property

Effectiveness

____ Carries out assigned tasks thoroughly and completely

____ Willing to ask questions when in doubt

____ Documents progress and medications carefully and correctly

____ Goes beyond what is expected

____ Demonstrates a caring and kind attitude toward patient and family

Recommendation to continue services of volunteer

____ Highly recommend

____ Recommend

____ Needs monitoring and another review in one month

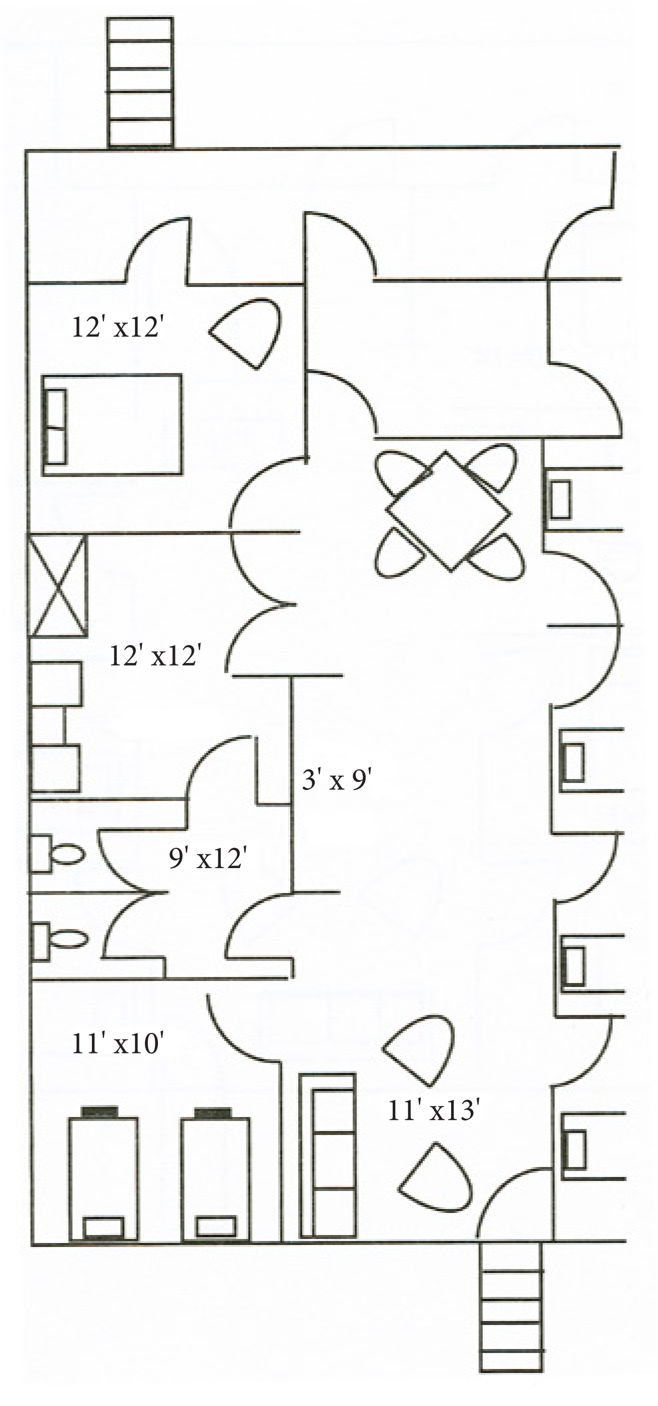
____ Recommend volunteer discontinue service

APPENDIX L

Facility Layouts

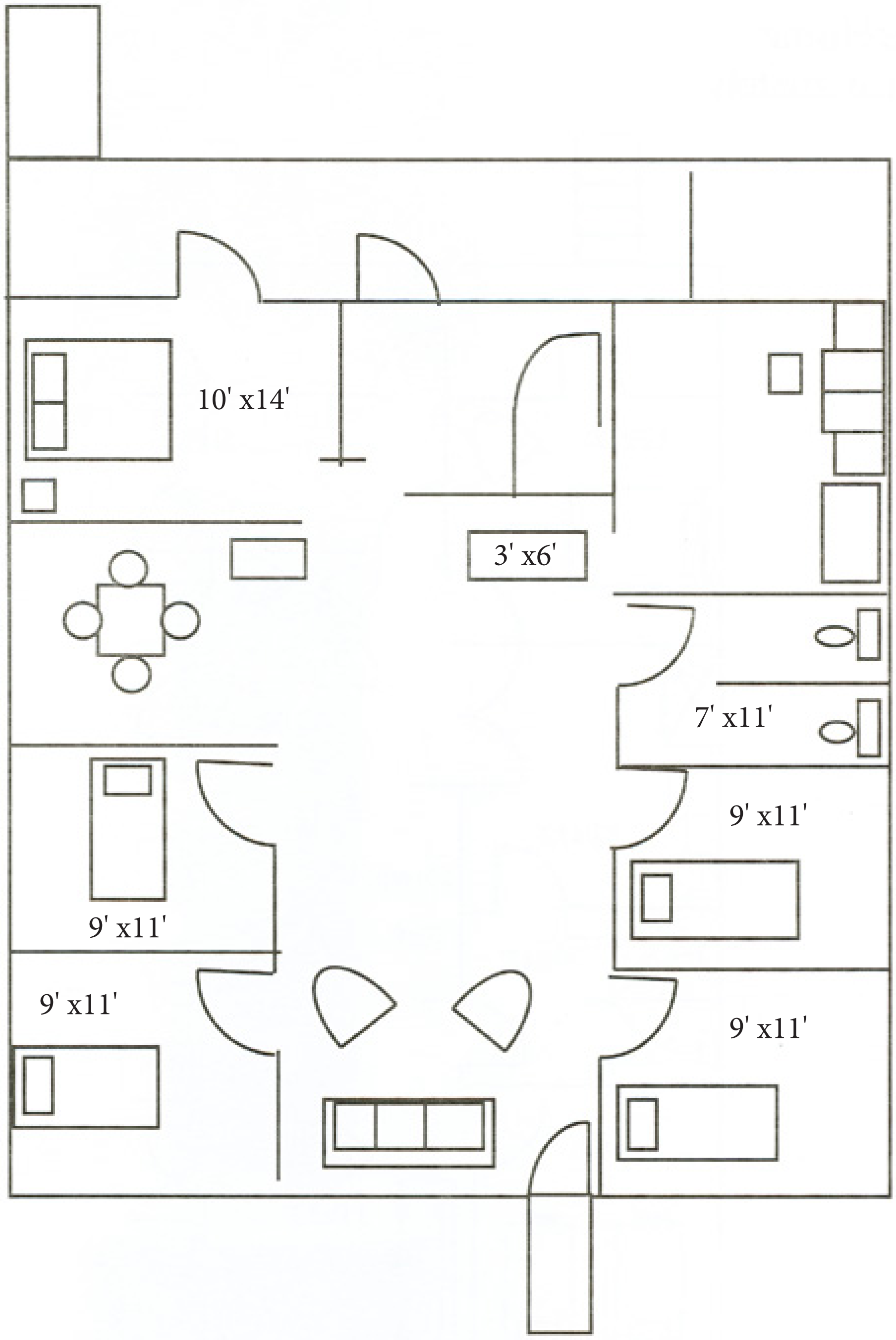
Hospice Care Home

(37'X53' Approximately)



Hospice Care Home

(37'X42' Approximately)



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