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BASIC COUNSELLING

BASIC COUNSELLING FOR HIV AND AIDS PERSONS

LISTENING

**When I ask you to listen to me and you start giving advice,
you have not done what I asked.**

**When I ask you to listen to me and you begin to tell me why
I shouldn't feel that, you are trampling on my feelings.**

When I ask you to listen to me and you feel you have to do something to solve my problems, you have failed me, strange as that may seem.

Listen! All I asked is that you listen, not talk or do – just hear me.

**Advice is cheap: a small bit of money will get you an 'advice' column
in the local newspaper.**

**And I can read that for myself! I am not helpless. Maybe discouraged and faltering,
but not helpless.**

**When you do something for me that I can and need to do for myself,
you contribute to fear and weakness.**

**But, when you accept as a simple fact that I do feel what I feel, no matter how irrational, then I can quit trying
to convince you and get about the business of understanding
what is behind this irrational feeling.
And when that is clear, the answers are
obvious and I do not need advice.**

Irrational feelings make sense when we understand what is behind them.

**So, please listen and just hear me! And, if you want to talk,
wait a minute for your turn;
and I'll listen to you!**

Author Unknown

What is Counselling?

It is a process of dialogue and interaction between two or more persons aimed at facilitating problem-solving, understanding, and increasing motivation for quality of life.

Counselling is designed to:

- Provide support in times of crises.
- Promote change when change is needed.
- Propose realistic action in the context of different life situations which may bring about difficulty.
- Assist individuals to accept information on health and well-being, personally and/or for loved ones, and adapt to its implications.

Counselling is an agreement between the **counsellor** and the **client** (or person being helped) and is based on two-way communicating and talking.

The Counsellor Should:

- Listen to the client with respect, empathy and compassion.
- Create an environment of trust.
- Help the client to talk about himself/herself and the situations involved.
- Give information to help the client solve his/her problems. It is important to note that a counsellor DOES NOT solve the problems for the client.

The Client Should:

- See his/her need to approach someone outside of himself/herself to help in problem-solving.
- Explore his/her problem situation.
- Seek to understand his/her situation better.
- Make decisions that will solve problem situations.
    - Take actions that are based on decision, to solve problem situations.

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Aims of HIV and AIDS Counselling

Support:

- Helping either the infected or affected person with the emotional, relational, psychological, spiritual, and physical tools whereby he/she can live a quality life for as long as is possible.
- Helping the affected or infected with social support systems available.
- Helping the infected with "who and how to tell" regarding his/her status.
- Helping the infected with possible negative fall out because of his/her status.

(Example: possibility of rejection and fear of them by others, losing job, etc.)

Education:

- Disseminate information about HIV and AIDS in order to reduce fear and ignorance.
- Dispel misunderstanding and myths.
- Give practical helps in maintaining quality of life for as long as possible.
- Change negative attitudes about HIV and AIDS.
- Help with life skills on sexual behaviour in order to prevent the spread of HIV and AIDS.
- Bring awareness to the infected and affected about the nature of the disease, what to anticipate, the medical, psychological, and social factors to be considered, as well as the long-term financial implications of HIV and AIDS.

HIV and AIDS Counselling Situations

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1. **Pre-test counselling** - is recommended for all persons taking an HIV test. This counselling is usually a one-time session and is particularly aimed at helping the client with the following:
    - Why the test?
    - How the test will be helpful? (Use information on 'Testing' in Chapter 9 to help the client understand testing).
    - Alleviate fear about the test.
    - Explain what the test does, and the possible results.
    - Prepare the client for both an HIV-negative (HIV-) and an HIV-positive (HIV+) test result and the ramifications of a possible positive test result.
    - Length of time to wait for test result.
    - Where to come for HIV test result.

Note: The counsellor should always obtain follow-up measures to ensure that the client comes back for the test result. Many times individuals will come for the test, and out of the fear of a possible positive test result, will not return for the results of the test. The counsellor should always maintain a way to contact the client to be sure he/she returns for the results of the test.

Note to Local Churches: Numbers of local churches are finding the pre/post-test counselling to be a very effective way to share the gospel. Many church buildings are not utilised during weekdays. The Pastor of the local church sponsors some of his congregants to take a 'recognised' pre/post-test counselling course that is accepted by the Ministries of Health. He then offers the church building as a testing site where people can come on a specific day for counselling and an HIV test. Counsellors in this situation are usually free to incorporate spiritual guidance, and offer hope in Jesus Christ to those being counselled and tested. Many churches involved in this community service are finding that many people accept Christ as a result. Many members of the extended family

are also brought to Christ and into the local church as a result of this creative ministry to the community.

2. **Post-test counselling** - is counselling given to the person whose test result has been received. This session should accomplish the following:

   The Negative Test Result

   - Explain the meaning of both a negative (-) and positive (+) test result and the implications of both.
   - Adequately explain the client's negative status.
   - Discuss possibility of being in the 'window period'.
   - Assist in making plans for a 2nd confirmatory test.
   - Help the client to incorporate no-risk sexual behaviour life skills so as not to have to worry about HIV infection.
   - Explain that a negative test result is only relevant for as long as at-risk sex is not engaged in.

   The Positive Result

   - Explain the meaning of both a negative and positive test result and the implications of both.
   - Sensitively prepare the client for a positive test result.
   - Adequately explain the client's positive result.
   - Discuss the implications of his/her positive test result (for example: in own life, in the life of his/her family, accepting his/her status, coping skills, personal care, life skills, changes that need to be made – for example: in sexual expression, support resources, medical care, and treatment, etc).
   - Assist the client with "who should I tell" decisions and their implications.
   - Link with HIV support systems.
   - Discuss having sex again, if it should be engaged in…what about risk to sexual partner.
   - Possible need to deal with sexual identity matters in the case of 'same sex' exposure to HIV.
   - Help client make a plan regarding family matters.
   - Possible HIV and AIDS community involvement.
   - Choices and lifestyle plan for staying healthy for longer.
   - Eventually, preparation for symptomatic illnesses, facing a terminal illness and all of the implications in the preparation for full-blown AIDS, dying, etc.

Who Might Be the Client Needing Counselling?

This could be anyone, even like you or me, that faces HIV and AIDS and needs support in living with HIV either for himself/herself or for a loved one. Thus, the client could be a person who is: heterosexual (opposite sex persons), homosexual (same sex persons), bi-sexual (either sex persons), and persons from any racial, socio-economic, ethnic, or religious background. Here are some:

- The "worried" who may feel they have been at risk for exposure to the HIV virus
- Rape and/or molestation victims
- Teenagers and young adults (who are the highest risk group)
- Patients who visit a health care institution/STD clinic/TB clinic
- IV drug users who have exchanged needles
- Children who could have been exposed through needle pricks, sexual abuse, or perhaps born HIV positive because their mother was HIV infected
- Couples getting married who want to make sure there is no risk of infection being brought into the marriage
- Women of childbearing age

Possible Feelings of the HIV-Positive Person Being Counselled

- Reluctance to talk about sexual matters
- Embarrassment of being in this position
- Not knowing who to tell
- Not knowing how to tell
- Not knowing what the future holds, fear of unknown
- Not admitting or taking ownership of being HIV positive
- Fear of getting sick, fear of dying
- Despair about provisions for medical and health treatment, particularly if money is scarce
- Fear of losing employment, life insurance, life provisions
- Confusion and fear of rejection
- Battling with sense of loss
- Feeling ashamed, resisting having to be dependent upon others
- Acute distress, feeling 'out of control'
- Feeling numb and emotionless
- Feeling of doom, depression, etc.
- Not wanting to eat, cannot sleep
- Low self-worth, etc.

The emotions of the HIV-positive client often go "up and down" and are totally mixed up for a while, and this is natural. These feelings will change often, and go from one extreme to the other. It is important for the counsellor to help the client deal with these emotional feelings.

What Are Some of the Emotions of the HIV-Positive Client?

These feelings about HIV and AIDS can be:

SHOCK **N**o matter how much you prepare, it is a shock to hear that you are HIV positive which will eventually turn into AIDS.

DENIAL At first, some individuals will be unable to believe that they are HIV positive. They may rationalize like this, "The test must be wrong," "It can't be true," "How can I be positive when I feel so good?"

ANGER Some people get very angry when they find out that they have HIV. They blame themselves, blame the person who infected them, or blame God. Some individuals are so angry at the one who infected them, they want to go out and infect other people out of vengeance.

BARGAINING Some try to make deals. They think, "God will cure me if I stop having sex," or "The ancestors will make me better if I slaughter a goat," or "If I go and see a special doctor, he will give me a magic cure."

LONELINESS Persons with IV and AIDS often feel very lonely. Their sense of loss is magnified particularly in relationships with others. They need to be given the assurance that they are not alone, that especially God has never left or forsaken them…ever!

FEAR People living with HIV and AIDS often fear many things:

- Pain
- Shame
- Other people knowing they are infected
- Of not being able to be intimate
- Of not having sex
- Of leaving their spouse, children, and friends

SELF CONSCIOUSNESS Some HIV-infected persons feel everyone is looking at hem or talking negatively about them. This makes them want to hide. They sometimes feel rejected by others…that they are ugly. That they want to reject themselves…do away with themselves (maybe suicide).

DEPRESSION Some people with HIV and AIDS feel there is no good reason for living. They feel useless. Sometimes they will stay at home, not eat, talk to anyone, or punish themselves, etc. Depression can make this person weak in mind and body.

HOPE People with HIV and AIDS can have hope about many things:

- Hope that they will live a long time
- Hope that scientists will find a cure
- Hope that the doctor will be able to treat each sickness as it comes
- Hope because they are loved and accepted for who they are
- Hope because of their belief in God and life after death

- Hope because they know they are accepted by God and are forgiven for any failure, even if sexual that caused the HIV infection, because God loves them

The Counsellor's Non-Verbal (Non-Speaking) Manner

The manner in which the counsellor approaches the HIV-positive client is very important. It can either help them both or it can be a negative experience and not helpful. Some of the following can help the counsellor focus attention on his client in the best possible way:

Squarely: Face the client squarely and up front. This posture conveys the message "I am available for you and I will listen."

Receptively: Adopt a receptive rapport. This indicates that you are interested in what the client has to say.

Lean forward: Lean slightly towards the client which indicates "I am interested."

Eye contact: Maintain comfortable eye contact.

Relax: Be at ease and relax, with yourself and the situation.

The REDA Model of Helping

This is an acrostic which assists the counsellor in the process of helping the HIV and/or AIDS client. Thus, it is suitable for responding to a wide range of sexual health problems including HIV and AIDS. The **REDA** model stands for:

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- **R apport**
- **E xploration**
- **D ecision**
- **A ction**

Each of the stages has aims and tasks for the counsellor. Here is a simple outline:

1. RAPPORT

AIMS: To establish a co-operative working relationship

TASK: Welcoming
Introductions
Contract – explains the purpose of the session, confidentiality and time aspect
Helping the client to relax enough to talk

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SKILLS: Being at ease, being comfortable, having ability to set others at ease, and clarity of setting the tone. Ability to know when to listen.

2. EXPLORATION

AIMS: To assist the client in identifying the nature of the problem for which help is being sought. To understand what the problem means

to the client. For the Christian counsellor, he/she also wants to include into the aims, to be able to lead the client into a daily walk and discipleship with Jesus, and to have a lifestyle that pleases God.

TASK: Obtaining as complete a picture of the problem as possible. Identifying the most pressing aspects of the problem. Understanding the client's general situation. At this stage, the Christian counsellor needs to ascertain as to whether or not the client has accepted Jesus Christ as Saviour and Lord, and about the client's spiritual walk.

SKILLS: **People Skills:**

a) Attitude:
- Unconditional positive regard for the client
- Personal respect for the client
- Empathy and compassion

b) Non-verbal communication:
- Knows how to come across in manner that helps client to open up and share problems and solutions
- Knows 'how' and 'when' to listen

c) Verbal Communication:
- Ability to address situations with simplicity and ease
- Minimal verbal response
- Ability to paraphrase client's responses
- Ability to probe and get client to talk
- Ability to reflect…consider all that has been said
- For the Christian counsellor, to be able to discern the right time to bring in spiritual relationship with God, and God's ability to help the client solve his/her problems. The Christian counsellor cannot force his/her beliefs on the client, but needs sensitivity to lead the client to Christ and Biblical solutions if the client is willing
- Not to show shock at any problem, no matter how twisted, the client may have or been involved in
- Clarifying…ability to make clear what can seem like confusion
- Checking out…ability to verify and coordinate information
- Interpreting…ability to see into what the client is "really" saying, even though it may be masked or hidden
- Confronting…where necessary to help the client solve the problems at hand, yet not pushing the client further than he/she is able to handle
- Never to convey hopelessness, no matter what the problem may be. Helping the client to realise there are always solutions to problems if the right solutions are found

- Informing…ability to give information and assistance when it is needed in order to see the desired result
- Summarising…ability to collect all the information and help the client to be able to simply absorb it
- Feedback…ability to share responses and communication back and forth

- Follow-through…ability to make and communicate a plan whereby the client can carry through with problem solving and incorporate accountability in those areas
- To be able to also direct the client to support systems that can help him/her follow through on decisions and solutions to problems

Communication Skills:

The do's and don'ts in getting the client to talk:

a) Do pause.
b) Do show interest.
c) Don't ask 'yes/no' trick or leading questions.
d) Don't criticise.
e) Don't bring the client back to the point at hand too quickly.
f) Don't raise personal matters, particularly sexual ones, too soon.
g) Do help client to know that his/her problems are not unusual.
h) Don't be threatening.
i) Do listen.

3. DECISIONS

Having explored the problem and its meaning to the client, the counsellor can now offer new perspectives and begin to focus attention towards what can be done about the problem, with short and long-term solutions.

AIMS: To assist the client in planning a course of action and embark upon it. To help equip the client (emotionally, spiritually, mentally, relationally, and with the necessary life skills)to be able to solve his/her problems satisfactorily.

TASK: Introducing different ways of looking at the problem. Helping the client to participate and initiate solutions to the problem, and providing new and relevant information regarding the problem and the solutions.

SKILLS: Particularly for the Christian counsellor, It is important that the counsellor know Biblical principles regarding decisions to be taken that can help the client decide on the basis of 'what pleases God'. The Christian counsellor cannot force his/her biblical belief system on the client. However, he/she should be clear as to what the biblical position is in principle. This way the Christian counsellor can guide

the client into making right decisions. The counsellor must also have the skill to be able to help the client who resists the Christian ethos, as much as is possible.

4. ACTION

Having guided and helped the client to make important decisions in problem solving, the counsellor must help the client to be able to make an achievable action plan to carry out solutions to the problem.

AIMS: To assist the client in planning a course of action and embark upon it. To also incorporate an accountability whereby the client will be able to measure his/her progress.

TASK: Identifying an appropriate course of action. Supporting the client to do this in manageable steps. Guiding the client to support systems to be able to achieve decisions taken. Evaluating action taken. Reviewing goals in follow-up. Homework to be done. Bringing conclusion.

SKILLS: An ability to lead the client to an action plan that can be accomplished in the client's living environment and within the financial means available to the client.

Identifying Problems and Barriers During Counselling

1. The Client:
    - Culture
    - Perceptions
    - Habits
    - Education
    - Family situation
    - Resources available to the client
    - Religious persuasion
    - Primary language ability, mother tongue

2. The Counsellor:
    - Culture
    - Identifying with a client that is so unlike himself/herself. Example: the client is from a very rural area with little education and an animated belief-system, it might be difficult for the counsellor who is from the urban centre and highly educated, to identify with the client.

Pre-Test Counselling

1. RAPPORT

AIMS: To establish a relationship of trust between the counsellor and client. To effectively carry out the test and test results in a manner that will help the client live his/her life in the best way possible in the future.

TASK: Introducing/Welcoming

Establishing a contract to include:

- First session date
- Subsequent sessions, time, and venue
- Duration of visits
- Cost factor
- Test results duration
- Confidentiality

Helping the client to relax and start to share why he/she wants to be tested. Possible fears, etc. Explanation of the test and ramifications of the test.

2. EXPLORATION

AIMS: To explore the client's story, problem, possible reasons for taking the test.

TASK: Explore until you have a complete picture of the client's reasons, problems. Complete understanding of reason for the test, and or anxiety levels connected with it. Identify the client's living environment, and how it possibly relates to his/her coming for the test. Identify the important needs of the client and problems that need to be solved, particularly those immediately surrounding the reasons for the test.

SKILLS: The Counsellor needs to use those skills that are particularly "people" and "communication" orientated. The counsellor needs to explore and identify immediate problems the client has.

3. DECISION

AIMS: To lead the client in a positive direction to make important decisions about his/her lifestyle, as well as the HIV test. To help prepare the client should the test result be positive.

TASK: Give necessary/basic information about HIV/AIDS and test to client. Assist client with steps he/she needs to take about lifestyle change.

SKILLS: Know how to direct client so the sessions result in change where change is needed. Skills to be able to guide the client to decision-making. Ability to motivate the client in areas where problem solving is needed. Counsellor needs to be able to stay focused and be motivational.

Things the Counsellor Should Inform the Client About Concerning the 'Decision' Stage

- The difference between HIV and AIDS
- The different stages of HIV infection. The variances of HIV infection and that it does not work the same in every body:
    - Window period
    - HIV positive, but well
    - AIDS-Related-Complex (ARC) symptomatic illnesses beginning to appear
    - Full-blown AIDS
- How the HIV virus is transmitted; how it is not transmitted
- No cure but:
    - Healthy lifestyle (diet, addictive behaviours of smoking/alcohol/drugs, etc.)
    - Mental and emotional health
    - Safer sex practices
    - Other general precautions
- Treatment for symptoms and opportunistic HIV infections (Note: The counsellor must be aware of the treatments and medicines available in that particular area. Some areas have more medical assistance available than others.) It is important that the counsellor does not offer medical and medicine availability that IS NOT readily available in that particular area. Another factor that the counsellor must discover is the cost of such medicines and medical care, and the ability of the client to pay. If the client is disadvantaged where he/she cannot possibly pay, the counsellor must explore options to either obtain financial subsidy or to refer the client to financial resources that could help. Medicines should not be suggested that are out of reach for the client. This would set the client up for false hope and disappointment.
- What problems may be encountered if HIV positive:
    - Loss of work
    - Loss of income
    - Medical and dental services (needed?) (refused?)
    - Loss of insurance
    - Differing feelings – depression, sense of loss, etc.
    - Victim of prejudice, stigmatised or rejected
    - Loan benefits may be withdrawn
    - Negativity from family members, or spouse
- Find out about the client's family system, other support systems, who he/she will tell
- How the client deals with stress
- The HIV testing procedure itself, antibodies, etc.
- Implications if pregnant
- Implications if other STDs are present

4. ACTION

AIM: To help the client to follow through with decisions brought about as a result of needing the HIV test. Example: these may be sexual behaviour change to prevent risk of infection in the future. To help the client, even if fearful of test results, to return for the test results at a future appointment with the counsellor. To give support after decision making.

TASK: Refer the client to the nurse for the HIV test. Arrange appointments. Getting the client to make return appointment and engaging a positive environment that will alleviate any fear to return for test result. The counsellor needs to be aware that many clients come for the test but fail to return for the results, out of fear. The task of a good counsellor is to motivate and convince the client positively, that he/she will want to return for test results.

SKILLS: Ability to show the positive side of HIV testing, longevity of life, etc. that test results allow. Ability to motive without instilling further fear and judgement.

What is Bereavement Counselling As It Relates to HIV Counselling?

This counselling is given at a time of loss (death or separation for example). It is to give total support to help the client during the bereavement process. It allows the client to verbalise different emotions and feelings. It is to assist the client in an open and honest way. Therefore, bereavement counselling means to talk about loss, death, and dying issues.

Phases of Bereavement

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These are similar to the phases of grief outlined in Section 14 on "Death and Dying" in this manual.

Phase 1: **Awakening Stage**

This is the first stage of the bereavement process. The client is diagnosed to be HIV positive, or may think he/she is HIV positive.

Emotions = shock, dismay, disillusionment, loss of control, hopelessness, anger, blame, etc.

Phase 2: **Denial Stage**

Client doesn't realise the seriousness of the disease. The client can think "this isn't really happening to me" or "it isn't really that bad" because there are no immediate symptoms or negative effects at this stage. The client can tend to push it off or take the results lightly.

Phase 3: **Aggression Stage**

Aggression and rebelliousness are often a result of underlying anger. Maybe anger at oneself or the person who may have possibly infected him/her. Sometimes the client may want to go out and infect others (projected anger) so he/she does not feel alone in the disease. As irrational as it may sound, the counsellor must be able to recognise these tendencies. These feelings in the client are normal and can relate to the intense struggle the client is feeling knowing he/she is going to die earlier than expected. The client may also give up on having any 'order' to his/her life due to feeling hopeless…no long-term planning for life anymore. The person may be angry at God, feeling God is doing this to punish him/her. This can produce aggressive behaviour toward God and negative behaviour which 'gets back at God'. Example: a person is infected by his/her spouse even though faithful in the marriage, or infected through a blood transfusion. This person could blame God and engage in behaviours that are negative

and that are really projected anger toward God (drinking when he/she knows they shouldn't).

Phase 4: **Negotiation Stage**

The client may try to 'negotiate away' the HIV-positive results, thinking "God, if I am good You will make this status go away." This negotiation phase usually is characterised by making promises (promises to a spouse, to God, etc.). This process is to ask God for a longer time to live or to achieve certain goals in life. Example: If I stop sleeping around God will cure me.

Phase 5: **Depressive Stage**

Depression occurs. The person thinks a lot of his loved ones as well as of himself/herself. Sometimes the person is quiet most of the time, doesn't want to talk to people or engage in daily activities. The person may be, in fact, "saying good-bye" to life, his loved ones, etc. The person may cry a lot at this stage…and that is OK. The counsellor must be sensitive enough to get the client to 'open up and talk' by gentle, appropriate touches (e. g. pat on the arm, touching the hand, etc.). Sometimes touching and quietness says more than words at this stage. The counsellor must always assess the feelings of the client so that any gestures like touching are entirely appropriate, and do not make the client feel that you pity him/her.

Phase 6: **Acceptance Stage**

The person comes to the stage where he/she accepts his HIV positive status and the illnesses that may be showing themselves. He/she has made peace with God, and his/her loved ones, and has accepted his/her status, etc. The counsellor must be sensitive to the fact that the client has gone through a lot of suffering to come to this point of peace. This tranquility should not be taken for granted. The client is accepting the status because he wants to live the rest of his/her life in peace, and die in peace, rather than being 'happy' about the status. There is a marked difference between 'being content' with the status, and 'coming to terms' with the status. Withdrawal as compared to the client's normal lifestyle, may still be marked. However, there will be a remarkable sense of well-being rather than fighting the HIV-positive status.

It is important for the counsellor to know that not all HIV-positive clients will follow ALL stages or necessarily in the above order. However, it is important for the counsellor to recognise the stage of the HIV + client and to help him/her come to the acceptance stage so they can live a quality life for as long as possible. In counselling the HIV+ person in these stages, guidelines given in Chapter 14 "Death and Dying" will be helpful. Remember: the client, in facing his/her own HIV-positive status, is facing a similar situation about himself/herself as he/she would with losing a family member.

Practical Guidelines for the Counsellor

- Don't let the client be too dependent upon you, the counsellor.
- Let the client cry if he needs to.

- Do not try to hide the factor of death down the road. Allow him/her to talk about it as he/she is ready.
- Be careful NOT to say the following to the client:
    - "I know how you feel" (you do not unless you, too, are HIV-positive)
    - "Try to forget it; don't concentrate on your HIV status."
    - "For sure you will live a long life." (perhaps false hope)
    - "Well, at least you will be spared having to worry about problems after you die."
    - If a child is diagnosed HIV positive or dies, "Don't worry, you can have another baby."

Positive Behaviour of the Counsellor Toward the Client

- "Is there something I can do for you?"
- Talk with the person ….befriend him/her, but keep the relationship professional.
- "It must be painful."
- Physical contact, by appropriate, gentle, yet appropriate touching.
- Just be there.
- Listen attentively.
- Be aware that you can make mistakes during the session.
- If you don't know an answer, then do not pretend you do, but assure the client that you will do your best to find the answer.
- Bereavement counselling doesn't mean just to counsel the person, but also to help with daily problem solving and taking to task.
- "It is OK to feel as you feel now."
- "You are very special…never stop being who you are. People need you".

Pre-Test Counselling

- Be compassionate with the client's reactions, by showing empathy. Allow him/her to validate his/her feelings; allow the right to express themselves.
- Reduce anxiety by the counsellor being very calm, yet understanding. A relaxed atmosphere can reduce anxiety in the patient. Also lend reassurance if the patient is not feeling calm.
- Talk about insecurities and other feelings that may accompany such a test.
- Establish their comprehension and general knowledge – why they came, what they understand about HIV, ARC (AIDS Related Complex) and AIDS.
- Assess the risk of their having contracted the infection.
- Assess their understanding about the HIV test, what it entails, what it reveals, what it will exclude, when the test will come back.
- Explain the advantages and disadvantages of being tested. Show how the positive aspects of testing outweigh the negative factors.
- Explore psychosocial reactions:
    - client's coping skills
    - family support
    - other support systems

- Explore sexual behaviour patterns. Educate in behaviour changes and safer sexual practices.
    - Encourage abstinence from sex if unmarried and provide necessary life-skills resources for making that choice
    - If married, encourage non-penetrative, non-genital sex, use of condoms, etc.

- Gently lead the client to consider employment scenarios:
    - Employer's reaction when symptoms appear
    - Safety at work
    - Confidentiality
    - Who to tell, if to tell
    - Possibilities of work loss
    - Other financial considerations
- Pros and Cons of who to tell:
    - How to tell (spouse, etc.)
    - Dealing with loved ones' responses
    - Rejection and negative responses, coping skills
- Maintaining a healthier lifestyle
    - Diet
    - Exercise
    - Stress management
    - Sleep and rest
    - Immediate attention of symptomatic illnesses

Checklist For Pre-Test Counselling

- Introduce yourself
- Explain confidentiality of sessions
- Explain and explore reasons for the test, either it has been recommended or the client wishes it. Explore that
- Ask what client already knows about HIV transmission, prevention, myths, etc.
- Explain facts about HIV and AIDS
    - How HIV affects the immune system
    - How HIV infection is different from AIDS
    - The long incubation period
    - Routes of transmission
    - How HIV does not spread
    - At present no cure
    - Treatment for opportunistic infections
    - The possibility of symptomatic treatment
    - Give hope that there could be a cure sometime in future, but balance it with the reality that we are yet a long way from it
    - Explain that the HIV-antibody test is not a test to find AIDS
    - Explain the "window" period, time between infection and antibody build up
    - Explain false negatives
    - Explain HIV-positive person can spread it immediately upon infection

- Explain policies for coming back and obtaining results
- Explain need for possible 2nd confirmatory test
- Discuss implications of a possible positive result
    - Whom should they tell?
    - How might they cope?
- Discuss support systems, family, and church
- Discuss any other possible at-risk or sexual partners
- Discuss sexual behaviour, possible need for behavioural change, life skills, etc.
- Discuss importance of healthy lifestyle
- If the counsellor keeps the patient's outpatient card, explain what you write on it to preserve confidentiality. Check their understanding
- Explain necessity for them to return for results. Alleviate fear of results
- Arrange follow-up appointment, time, etc.

Checklist For Post-Test Counselling When Test is Positive (+)

- Greet the clients and tell them the result of the test in a calm but honest way
- Give them time to react
- Explain that their reaction is normal
- Check that they understand what the results mean, and the difference between HIV-positive and AIDS
- Ask them what worries them the most about the results. Discuss alternatives for dealing with this worry
- Check their knowledge of HIV transmission
- Explain any facts that they may have forgotten or misunderstood in the first session
- Ask if they will find it difficult to tell their sex partner, spouse, etc.
    - Help them to plan how to do this
    - Invite them to bring in their sexual partner for counselling
- Ask them who else they plan to tell. Identify what emotional support they have from family, church, and friends
- Ask about high-risk behaviour, and discuss how they may change it
- Explain the practical precautions the client needs to take in the home, and also dispel unfounded myths
- If female, find out if client is pregnant, and discuss implications of that
- Give them time to ask questions
- Put the client in touch with local support and further counselling groups
- Explain the medical follow-up that is needed
- Explain the important necessity of immediate medical attention to all/any symptoms
- Early treatment prolongs life
- Discuss coping skills
- Arrange for further appointment

Basic Facts for Post-Test Counselling When Test is Negative (-)

- Giving the results:

- The results may produce feelings of relief and delight which can sometimes lead to reckless repeated behaviour (e.g.sexual behaviour that puts client at immediate risk again).
- In the time allotted, work through the CAUSE of those feelings, what they might mean, and what the news of the negative test result mean.
- Discuss the possibility of a false negative result (possibly client is in the window period) and the need for a second confirmatory test in 3-6 months.
- Be sensitive to the client's reactions.
- Endeavour to motivate the client to carry through on decision-making plans for changes that may be needed in his/her life. There can be a tendency for the client with the HIV-negative test result to walk out of the session having gleaned NOTHING other than the test result. The counsellor should always aim to motivate the client towards positive lifestyle change in the problem areas of his/her life. This will bring long-term results rather than just short-term (negative test) results.
- Help the client to see the importance of making a life plan to avoid further HIV risk, should there be any.
- The REDA model can be used as a framework for post-HIV test counselling.

Counselling People Living With HIV and/or AIDS

"AIDS is the stuff of all our nightmares, triggering many of our deepest fears."

- These words spoken by an HIV-positive patient, sets AIDS apart from any other life-threatening disease, such as cancer.
- Society often reacts to AIDS with stigmatisation, fear, and blame. This is usually not the case with cancer or another terminal illness.
- This complicates the HIV-positive person's process of adapting to, and living with, the diagnosis.
- Except for physical care, one of the most important tasks of the counsellor (nurse or person taking on that role) is to provide psychological and social support to infected people.

The Psychosocial Experience of an HIV Infected Person

- The diagnosis of HIV infection or AIDS is often interpreted by the patient, and those surrounding the patient, as a death sentence. Even some medical institutions (because of the deluge of HIV-infected needing their services) will demonstrate a 'hopeless' response to the HIV-positive patient.
- It evokes severe emotional reactions such as: shock, anger, guilt, anxiety, depression, suicidal thoughts, obsessiveness, and denial.
- HIV-infected people are particularly fearful about being isolated, stigmatised, and rejected.
- They experience loss of control, loss of autonomy, self-blame, and feelings of guilt, all of which cause further anxiety and depression.
- They fear the loss of their ability to care for themselves and their families; they fear the loss of their jobs, their friends, and family. They fear the uncertainty of the future.

Will there be pain or disfigurement, and who will look after them? "Will people be afraid of me?"

- HIV-infected people are often very angry with themselves or others, and this anger is sometimes directed at people closest to them.
  - They are angry because there is no answer to HIV and AIDS and because of the uncertainty that the future holds, particularly for them.
  - They are often also angry with those who infected them, and with society's reactions of hostility or indifference to the HIV-infected.
- Guilt and self-reproach for having contracted HIV or for possibly infecting others or those they love, are commonly expressed.
  - These feelings may be associated with the person's unresolved conflicts about gender confusion (homosexuality) or sexuality in general.
  - Having to tell family members and loved ones that one is HIV positive, often means that one also has to tell loved ones for the first time, about one's intimate life, sexual preferences, or sexual behaviour.
- Most HIV-positive people go through a phase of denial.
  - Denial is an important and protective defense mechanism albeit short-lived, as it can temporarily reduce emotional stress.
  - Denial becomes a coping mechanism.
  - To maintain hope, HIV+ patients should be allowed constructive denial for a time, if they are not yet ready to accept their diagnosis and status.
  - The counsellor should confront this denial if it results in destructive behaviour, such as avoiding medical care, or continuing to engage in high-risk sexual behaviour, or to put sexual partners at risk also.

Psychosocial Assistance to the HIV-Infected Person

- Again, the main function of the HIV and AIDS counsellor is to be there for his/her patients, to listen to their feelings and problems, and to support their self-determination. Counsellors must allow patients to verbalise their fear, anxiety, anger, sorrow, and guilt, or shame, as this gives them opportunity to identify the possible problem areas which need to be addressed and processed in their lives.
- Counsellors must help HIV-positive people to make decisions for themselves and encourage them to do so for as long as possible. The Christian counsellor will want to facilitate directing the patient to biblical solutions that will not only please themselves, but also please God.
  - The HIV-positive person's control over everyday life situations should be reinforced.
  - Counsellors should ensure patients that they can still be productive in the economic, intellectual, and social spheres of their lives, possibly for many future years if right decisions are made now.
  - Patients should, therefore, be encouraged to go back to their work and their life as soon as possible; to live as normal a life for as long as is possible.
    - -The contentions that infected people are unemployable, that they should not be given educational opportunities, (because they are going to die anyway!!) and that they should not be allowed to remain socially active

could result in the collapse of a whole society. This is because it would not only be a totally devastating lifestyle for the HIV-infected, but it would place such demands economically with the immediate loss of people in their productive years (example: Countries would immediately lose a high percentage of their professional labour force and governing leadership if all the HIV-infected were removed from the normal day-to-day jobs).

- A big question that counsellors must assist the HIV-positive person with is: "Can I have sex…what do I do about sex?" Particularly for the Christian counsellor who objects to pre-marital sexual activity, he/she may be ill-prepared for this complex issue. It is not sufficient to just say "Don't have sex anymore". This gives little resource for saying NO to sex. Some of the considerations for intimacy that the counsellor must address with the HIV-positive patient are:

1. If the patient is <u>not married</u> and became HIV through pre-marital sex, the counsellor must walk through all the reasons for sex in the first place. Was it casual, habitual, forced sex, incest, same sex, etc.? All of these possibilities must be explored in the 'discovery stage' with the patient. This often takes time because it can be uncomfortable for the patient to discuss such matters, and most probably it is the first time he/she has ever discussed his/her own intimacy. Out of this 'discovery' will come issues such as:
   -Why did you feel the need to engage in the behaviours?
   -How do you feel your behaviour has impacted your life (positive, negative, both you and your partner)?
   -Do you feel any part of your sexual behavior needs to change…why?
   -If change is needed, what decisions, then steps do you feel are necessary to accomplish that change?
   -In the case of illegal sex (incest, child abuse, rape) the counsellor must know the current local laws that apply to reporting by the counsellor and legal steps that must be adhered to in:
      -protection for the potential victim
      -counsellor/patient laws
   -Now that you are HIV infected and risk infecting others through sex, let's look at possible alternative ways to channel your sexual activity (these must be explored).
   -No further sex, non-penetrative sex, non-genital sex, etc.

2. If the patient is same sex, the counsellor must explore what it is that the patient feels about his/her gender of origins (born male or female and how comfortable they are with their birth gender). Often in gender confusion where HIV infection is thought to have been contracted through homosexual sex, the patient has struggled for a long time with sexual confusion. These issues will likely have to be pursued in future counselling.

3. In the case of the married person being unfaithful, and perhaps where other children are involved from these sexual unions, the resolutions to these problems are much more complex. It is not enough for the counsellor to say to

the patient, "Stop having sex with that person". The counsellor must direct the patient to responsible decision-making with regards to the "other" person, welfare of any children involved, and ways of bringing the best resolution for everyone concerned. The Christian counsellor will obviously look to the Biblical principle that governs solutions to these problems and seek "righteous" solutions in the best way possible. Other issues for married HIV-infected might be:

-if married partners are both HIV infected, the use of condoms to lessen cross infection is important. This lessens the possibility of reinfecting the spouse with a different HIV virus strain or more of the virus. It also lessens the possibility of pregnancy which would not be desired. The counsellor needs to be able to give instruction to the married couple on these options, their risks, and what might be best for them when it comes to their sexual intimacy. The counsellor should also be able to explain confidently about these options.

The counsellor must have worked through these issues <u>first.</u> It is important that the counsellor not take a simplistic approach and skim over the surface just to avoid dealing with these complex issues. Christian counsellors must be careful that out of their own belief system, they might come across as being judgemental, accusatory, or condemning. The Christian counsellor must be able to motivate the patient to HEART CHANGE because he/she wants to change. This will only be done through demonstrating the love of Jesus, and through compassion and understanding of the problems that led the patient to this point. The counsellor who avoids dealing with these issues (because more than likely the HIV-positive patient is positive because of some kind of sexual experience) will likely not lead that patient to resolve these important issues in his/her life. This puts the HIV + person at further risk, and also places future sexual partners of the HIV-positive person at great risk for infection. The Christian counsellor can ask God for wisdom in 'where' and 'how' to present the person of Jesus Christ as the HIV-positive person's best friend, and how He can meet every need that he/she will encounter, as he/she turns over his/her life to Jesus. Christians who counsel HIV and AIDS patients have a wonderful evangelistic opportunity. Involvement by the church brings practical help to a growing segment of the community that is seeking help…those that are HIV-positive and/or into full blown AIDS.

<u>A NOTE OF CAUTION</u>: Particularly in developing countries where there is a great lack of professional and qualified counsellors, there will be a greater need for trained lay Christian counsellors to help. Local churches will be able to give training to specific lay people so that the HIV/AIDS-related needs in the community are more adequately met. The church can and should take the lead in the issues surrounding AIDS and not leave it up to government only. However, there are two cautions here:

1. That the church not fail to adequately train lay counsellors so that they are properly equipped
2. That the church not misrepresent our qualifications in preparing lay counsellors.

It is very important that the lay counsellor be just that…a <u>lay counsellor</u> and not pretend to be professional. The lay counsellor can be confident in having a compassionate heart for the HIV-infected, albeit limited training, and wanting to be a friend to the HIV-infected person. However, it is important that the lay counsellor not move into areas outside of

one's expertise and training. This could lead to giving wrong advice to the HIV-infected and AIDS patients who don't need that on top of the problems they already have. The lay counsellor's best function is to "listen", and to stick to common-sense problem solving, even using the REDA model. However, it is strongly advised not to try to give answers concerning areas where the counsellor really does not have the expertise.

Practical Suggestions to Counsellors, Nurses and Support Persons to the HIV-Infected

1. Compile a list of problems along with the patients' input.
2. Try to find possible solutions to these problems with the patients. Encourage them to come up with their own solutions. This is necessary so that they will take ownership in carrying out the solutions to their own problems.
3. Make a list of the patient's qualities and possible limitations in terms of problem solving. For example: their coping skills, sense of self-worth, personality style, communication style, sense of humour, family support system, economic and financial resources, job resources, educational background, etc.
4. Examine and discuss possible solutions to problems they are presently encountering and likely will encounter as a result of their HIV-positive status. Assess each one in terms of the patient's capabilities.
5. Identify the ways in which they dealt with specific problems in the past, and help them to develop new ways, if necessary.
6. Encourage the patients to make their own decisions and to take control over their lives whenever and wherever possible.
7. Take note of relationship problems between the patient and his/her loved ones, friends, and family, as well as between the patient and other health providers.

Note: Living with HIV and AIDS sometimes gives rise to serious emotional problems, such as depression, suicide, and obsessiveness. If the patient seems unable to cope, the counsellor, nurse, or lay counsellor should not hesitate to refer the patient with serious emotional trauma to professionals with expertise to help the patient. The lay counsellor should not continue without professional input if the patient seems not to be responding positively within a reasonable time into the counselling.

A Paraphrased Testimonial of an HIV-Positive African Young Man

My doctor gave me the news. My first reaction was one of relief. The confusion and fight I felt before the test seemed over for the moment. All the various symptoms in my body could now all be explained. No more worried now about IF I would develop AIDS. I now was moving into full-blown AIDS.

The next day on my way to work I began to realise the full meaning of my status. What would lie ahead? I had moments throughout the day of denying it was really happening to me. Me…I wanted to believe I would be well in a few days. I really didn't feel very good so I went and told my supervisor that I would be off sick for a couple of days. I briefly wondered if there had been some mistake. Maybe I had been misdiagnosed. My mind was racing. I could not concentrate on anything for more than a few minutes. Ninety percent of my thoughts were 'death' related or reflections on what life choices I had made. I had so many "what if" thoughts…mistakes, broken dreams. Where would

it end? What would my funeral be like? What sickness would finally kill me? Would my family still love me or would they hate and blame me?

Suffering and fear were what I felt. I tried to imagine how long I could keep my job, and be well enough to work. My biggest concern was telling my parents. They were both old and I could not know for sure what this news would do to them. I felt guilty about how they would feel.

Some reactions surprised me, others made me angry. I tried to imagine how I would feel if I were on the other side. One work friend sent me a note that said, "I know there is nothing I can say or do to change what's happening with you. But my heart is with you. I love you just the way you were and you are. Nothing has changed in that regard. I am here for you. If you want to laugh, scream, kick the wall or cry, I will be with you if you want. Be yourself." Those words were some of the greatest comfort to me. The one that stood out that made me the most angry was a neighbour. He wouldn't talk to me all of a sudden. I could see his children run across the street if I approached, like I was infectious to them! I heard them laugh and I knew it was because of him that they acted like that. I felt bad and mad at the same time.

The early weeks of 'real' illness were the most challenging so far. I remember after I was diagnosed with pneumonia that they found several lesions in my mouth. I was afraid to see the doctor for fear that he would find something else wrong. What if I died right then? But, he explained that I wouldn't and then he rubbed my sore feet and that meant so much. I just needed someone to touch me and it seemed that lots were now avoiding me. Why me? It was the same old me…why was I so lonely?

I remember the day when I was replaced at work. How would I pay my bills? That was very worrying for me because I always sent some money home for the family and the old people. Now what would happen? I could hardly bear the thought that they would have to care for me. I was the first-born and it didn't seem right. Guilt again! It meant so much the day my Father walked over to my rooming house and said he had come to take me home. He then put his arm around me and he wasn't afraid. I was so proud of my Father before, but even more I wanted to be like him when I became old. Old? I guess I would never have that chance, for I would die in my 20s.

I went home and experienced varying degrees of depression, rage, gratefulness, helplessness, and resignation. Looking back, I see it was my attempt to control what was happening to me that I had no control over.

When AIDS set in, I remember thinking, 'If I am going to die, I am going to die.' But, I wanted to say 'when' and 'how.' I could accept weight loss but I couldn't accept the skin infections that for me, started to come. I didn't want diarrhoea. There was no way that my mother was going to see my private parts at my age. I wasn't an infant! And, I was terrified that, at times, I would lose my mind.

I remember the doctor telling me, 'Don't try to answer all the questions. Things will fall into place; take one day at a time and it will get easier.' He was right. Fourteen months have passed since my diagnosis. I continue to experience up and down days…one day

I'm very good and another few days bad. But the peaks and valleys of my illness are less dramatic for me. I feel tired of fighting. Yet, I'm coming to accept that I can't change things. I look out my window and I see a bird. It has so many colours…it's sitting there on a branch with the wind on its back blowing the feathers. I don't think I noticed that before now, but today I do. The small things make me grateful. Grateful for just one more day. Grateful for my loved ones who love me…just me. Yes, the diarrhea did come and that day I felt so sick I didn't care if my mother did have to clean me up. I couldn't hold it and I wasn't embarrassed…I just felt sick. I have grown to accept what I can and cannot do. But, I'm still grateful for one more day to see the sun, feel the wind. I try to enjoy something joyous every day. The mere fact that I am alive today allows me to reflect, but the guilt is gone. I've come to terms with my mistakes. Would I do things differently if I had them to do again? For sure. But, I can't go back; today may be my last day so I'm going to watch for that little bird and see if he comes back today. Just today!

Counselling and Assisting the Dying Patient

- The counsellor working with the HIV-infected persons and their family/friends, will encounter many of the situations described in Chapter 14 "Death & Dying". It is important that the caregiver have a good knowledge of culturally expected, and accepted ways of expressing loss and grief. The caregiver must also respect and support the spiritual beliefs of the patient, family and friends, and facilitate the traditions that the family holds dear. Where specific practices seem to conflict with Christians, this is where they can demonstrate the love of Jesus practically, rather than having a confrontive and judgemental manner. The Christian caregiver can walk in wisdom, looking for just the right opportunity for non-Christian family members to seek their input. When the time is right, they will have opportunity in a loving way, to share Jesus Christ in a manner that it will be heard, and hopefully received. However, forcing one's beliefs, especially during a time of loss and grief, is not wisdom and will only bring distrust and resentment by loved ones.

Case Scenario of a Mother Whose Son Is HIV Positive

She watched as her son fell into a deep coma, a sleep from which he wouldn't wake up. She remembered when he was tiny, growing up, and how he would cry when he fell and hurt his knee. Now she watched him lying there and knew, as a mother, what he needed (and what she needed also). She felt that if she could crawl into bed with him, just like when he was tiny, tousle his hair, and sing him to sleep he would be all right. But, she didn't do it because she feared what the nursing sisters would think. It would not be acceptable because he was nineteen years old now and what would they say? But, he kept groaning in his coma and he couldn't talk. The Mother wanted to soothe him, but she couldn't. It wasn't long and he slipped off into another world…death had taken him. To this very day the Mother regrets that she sacrificed her son's dying need to be soothed and her need to console her son, because of what others would think. She never had the chance to bring closure to her dying boy…the nurse's opinion won!!!!

Counselling people dying with AIDS demands a great deal from caregivers.

- Most of the time, such counselling involves young people who are dying in the prime of their life.
- Because of the stigma associated with the disease, these people often die a lonely death without the compassion which, for example, a cancer patient might receive.
- Counselling for the dying has no fixed pattern or schedule.
- Each process is different and the caregiver's role varies according to the specific needs and demand of each patient.
- The overall attitude of the caregiver towards the dying person must be one of respectful care and dignity. The patient must be permitted to make his/her own choices in life for as long as possible.
- Sensitivity to the specific needs of each dying person remains the key to success in helping them right to the last.

A Dying AIDS Patient Gives the Following Advice

"***As in life, people with AIDS facing death have a right to do it their own way. Do not pry or force patients to feel your feelings or 'face' death your way. It is a disservice to force patients to give up their feelings, even if wrong, or to give false cheery hopes to them. Sometimes I just want people to listen to me. Sometimes, I do not want to talk or think about AIDS. Sometimes I do not want to talk at all. I just want you there! If you stay, contribute what you can, but being there for me helps the most. I can't say how I will feel tomorrow. Maybe you can't come tomorrow. But, permitting me to be me helps me not be afraid. You cannot fail that way. Thanks for your commitment to helping all sick people, like me!"***

Counselling and the Local Church

In very practical ways, the local church can minister to the non-Christian community by involvement in practical counselling, and offering their church building as a community testing site on specific days.

The possible HIV-infected person who comes for pre-test counselling, receives the HIV test, and then returns for results and post-test counselling, is in a very needy position for spiritual guidance. This person is also more likely to respond to accepting Jesus Christ as Saviour and Lord. The Christian church must get involved and do her part to give this practical assistance.

Some practical ways of involvement are:

- Training up specific lay workers in the church to do lay, pre/post-test counselling. (Note: Do this in such a way that it is recognised by the local health authorities.)
- Offer your counselling services to the community at no charge, or at a very nominal charge as a community-care service. Practically demonstrate that the church cares.

- Nursing sisters, and/or doctors can also help with counselling and testing services.
- Offer the church venue as a testing station for the local community, and enlist Ministry of Health input relative to testing kits, testers, etc.
- Offer HIV/AIDS family support systems, friendship evangelism of HIV/AIDS families, etc.
- Offer teen support systems.
- Offer behavioural change support teaching groups. (For example: offer specialised groups where biblical teaching and support is offered free to cover subjects like: alcohol abuse, sexual addiction, unfaithfulness in marriage, abuse, etc.)
- Offer home-based care support for symptomatic patients.
- Offer clinic or hospital visitation for sick.
- Offer childcare for HIV-infected parents who need some help.
- Offer support for the dying and the bereaved, and counselling…lead the sick to Jesus; lead the bereaved to Jesus.
- Offer counselling and practical physical support for single parents.
- Endeavour to offer Christian homes to orphaned children whose parents have died of AIDS.
- Take the message of sexual purity and AIDS prevention to all of the local schools in the community, reaching every school-age child in your community.
- Offer AIDS-prevention education to community businesses, school professionals, etc., free of charge and allow this to be a tool of evangelism.
- Offer parent support and "raising moral children" training to non-churched parents who struggle with a changing society for their children. Lack of traditional values and peer pressure make the parenting process difficult.
- Offer support to mothers of child-bearing age whose husbands are being unfaithful, with options and assistance to deal with the infidelity that could result in their becoming HIV positive. Matters concerning possible unborn children and surrounding issues also need to be addressed.

There is much that the Christian church can do through the needed, open door of community counselling services for HIV and AIDS-affected and infected. May the church not lose the opportunity to do so!!

A PRAYER FROM THE CHURCH

Lord Jesus, for so long we've been silent!

This dreaded, unthinkable killer…AIDS…is here, right amongst us.

Lord, help us to be silent no longer.

May we hear Your voice and do Your deeds.

You did not wait until hope was gone before you got involved with us.

No, you involved Yourself in our lives even while we were yet sinners.

Help us, Lord, to be involved in probably one of the greatest disasters that threatens our children and grandchildren…that of AIDS.

We commit ourselves to involvement. That by every means…even AIDS we will win some in our community to You.

Your mission: to bind up the broken-hearted, to pray for the sick, to bring hope to the oppressed is our mission, too.

Help us, Lord Jesus, because we are willing to get involved.

AIDS is our problem because it is Your problem.

Thank you for helping us, Lord. Amen!