



Republic of Kenya

HOME BASED-CARE FOR PEOPLE LIVING WITH HIV/AIDS

**NATIONAL
HOME-BASED CARE
PROGRAMME AND SERVICE
GUIDELINES**

**National AIDS/STD Control Programme
Ministry of Health**

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National Home-Based Care Programme and Service Guidelines

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ABBREVIATIONS AND ACRONYMS

ACCs	AIDS Control Committees
ACU	AIDS Control Unit
AFB	Acid fast bacilli
AIDS	Acquired immune deficiency syndrome
BD	Twice a day (referring to medication)
CACC	Constituency AIDS Control Committee
CBO	Community-based organization
CBD	Community-based distributor/distribution
CSF	Cerebral/spinal fluid
CHW	Community health worker
CMV	Cytomegalovirus
CNS	Central nervous system
DACC	District AIDS Control Committee
DHMT	District Health Management Team
GIT	Gastro-intestinal tract
HBC	Home-based care
HIV	Human immuno-deficiency virus
IEC	Information, education, and communication
INH	Isoniazid
IV	Intravenous
MTCT	Mother to child transmission
MCH	Maternal/child health
NACC	National AIDS Control Council
NASCOP	National AIDS/STD Control Programme
NGO	Non-government organization
ORS	Oral rehydration salts/solution
PACC	Provincial AIDS Control Committee
PHC	Primary health care
PLWHA	Person living with HIV/AIDS
STD	Sexually transmitted disease
TB	Tuberculosis
TBA	Traditional birth attendant
TDS	Three times a day
TOT	Training of trainers
TT	Tetanus toxoid
WHO	World Health Organization



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To all of you, and to all others, too many to be mentioned here, who contributed in one way or the other to this effort to improve the quality of care and the quality of life of persons infected and affected by the HIV/AIDS epidemic, we express our gratitude. Your contribution will have an impact on millions of lives across Kenya.

Ministry of Health
Republic of Kenya



FOREWORD

The small emblem that appears above and on the cover of this *National Home-Based Care Programme and Service Guidelines* carries a big message about the commitment of the Government of Kenya to reduce the impact of the HIV/AIDS epidemic. The separate elements of the emblem will be familiar to most of us, yet they are combined in a new and significant way.

Today almost everyone will know that the red ribbon represents AIDS. And the family is just that a family, but with the red AIDS ribbon superimposed to indicate that HIV/AIDS is not an affliction of individuals only, it affects everyone. The heart is widely recognized as a symbol of love and caring. The green, too, is significant. Green is regarded by many as the colour of hope. Thus the small emblem portrays an AIDS-stricken family surrounded by a heart full of hope and caring. That is the message of home-based care.

Home-based care is an approach to care provision that combines clinical services, nursing care, counselling, and social support. It represents a continuum of care, from the health facility to the community to the family to the individual infected with HIV/AIDS, and back again. The Government is committed to home-based care as a viable mechanism for delivering services because it has important benefits for everyone on that continuum.

The *National Home-Based Care Programme and Service Guidelines* spells out the basic components of home care services, the programmatic standards, and the requirements for service delivery. In Part I, the guide opens with a description of HIV/AIDS and its impact on the human body and the human community, and presents the case for home-based care. Part II walks us through the process of designing and setting up a programme to deliver home-based care services, including such elements as the importance of a needs assessment, the composition and functions of the home care team, relationships between public and private sector efforts, and procedures for monitoring, evaluation, networking, and resource mobilization. This part of the guide is intended to be flexible enough to accommodate a variety of approaches to service delivery, but prescriptive enough to ensure programmatic effectiveness and service quality.

Part III gives details of the service components: clinical management, nursing care, and counselling. Here we look at treatment regimens for various AIDS-related conditions, including guidelines for what to do at home and, importantly, when to seek help. The counselling component is particularly important, given the emotional and spiritual upheaval the disease causes, and here we are reminded that the care in home-based care does not end when a person succumbs to the disease it must be extended to the survivors, especially children. Throughout, the guide stresses the importance of community involvement. Finally, a set of annexes provide complementary information, including a glossary, a comprehensive bibliography, and a list of the contents of home care kits, as well as a list of some of the many people and organizations who have participated in the development of the guide.

The audience for the guide is multifaceted: It includes mid level programme managers and mid and operational level health workers such as MOH personnel, ACU managers, NGO and other HBC service managers, and district/local health management teams. Others are Provincial/District/Constituency AIDS Control Committees, supervisors of community health

workers, and trainers of trainers. There are related documents for other players in the delivery of home-based care services, including a training curriculum and reference handbook for community health workers and other health service providers.

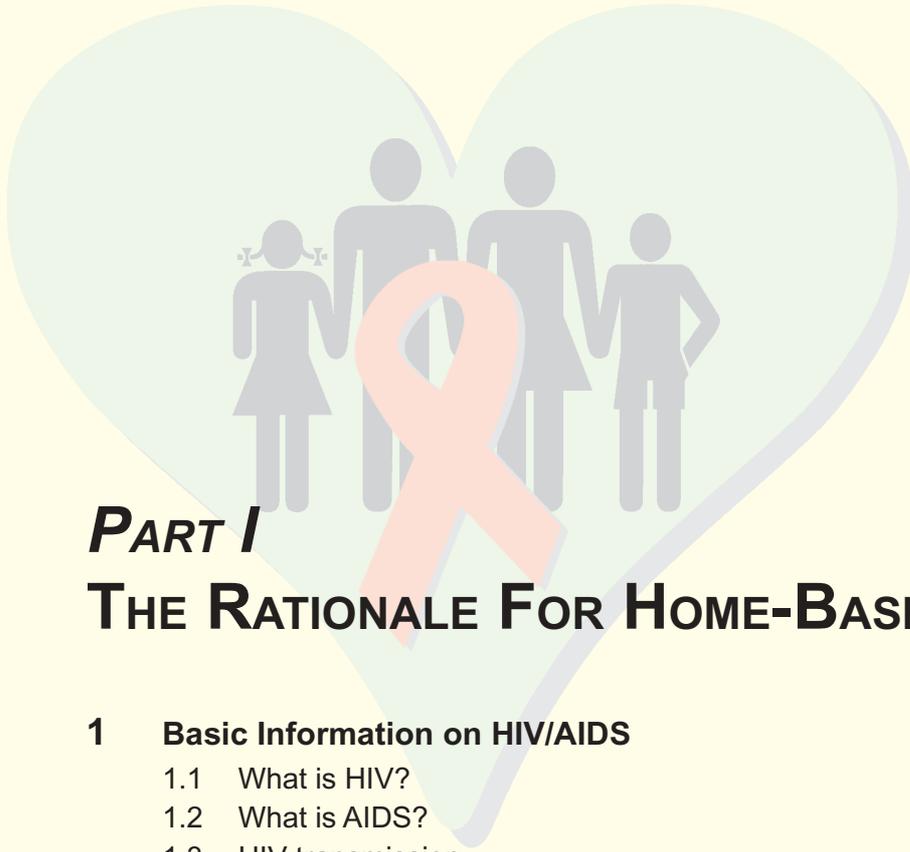
The need is urgent, as people and organizations in all of these categories are striving to improve the quality of life of persons living with HIV/AIDS and their families. There are hundreds of thousands of such Kenyans, struggling to come to terms with their HIV-positive status and to cope with the illness and disability that come with AIDS. They need all our care and compassion, and the Government is committed to looking beyond prevention to the quality of life of persons living with HIV/AIDS.

Home-based care will help us do just that, as it helps us change attitudes towards persons living with HIV/AIDS and towards the disease itself. Home-based care recognizes that a diagnosis of HIV does not necessarily mean death is at hand, and it helps reduce the stigma attached to the disease. Home-based care can provide the support that will enable HIV-positive persons to extend their productive lives for many years, living positively in the fullest sense of the word.

Nevertheless, the disease remains without cure and without a vaccine, and is ultimately fatal. We must continue our prevention efforts with utmost diligence. Here, too, home-based care has an important role. When community members provide care to their family members, neighbours, and colleagues, they not only increase access to care, but become involved in prevention activities. Everyone benefits.



Dr. Richard O. Muga, MBS
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May 2002



PART I

THE RATIONALE FOR HOME-BASED CARE

1 Basic Information on HIV/AIDS

- 1.1 What is HIV?
- 1.2 What is AIDS?
- 1.3 HIV transmission

2 Home-Based Care as an Intervention in HIV/AIDS

- 2.1 What is home-based care?
- 2.2 Objectives of home-based care
- 2.3 Principles of home-based care
- 2.4 Home-based care needs at various levels
- 2.5 Roles of the various players in home-based care

3 Components of Home-Based Care

- 3.1 Clinical care
- 3.2 Nursing care
- 3.3 Counselling/Psycho-spiritual care
- 3.4 Social support
- 3.5 Entry into the home-based care system



1

BASIC INFORMATION ON HIV/AIDS

The HIV/AIDS epidemic in Kenya began in the early 1980s. Twenty years later there is still misunderstanding about what exactly HIV/AIDS is, how it affects the body, and how it is transmitted. Despite massive research around the world, it is important to note that as of today there is no vaccine for HIV/AIDS and no cure, and it is ultimately fatal.

1.1 What Is HIV?

HIV stands for **human immuno-deficiency virus**. This is the virus that causes acquired immune deficiency syndrome (AIDS). The virus destroys the human immune (defence) system, making the body vulnerable to other infections. When the virus enters the body, it binds itself to specific defence cells. As it enters the cells it destroys them. As more of these cells are destroyed, the body becomes too weak to defend itself against infections.

The virus knows no gender, age, race, or religion. It can attack anyone and **you cannot tell who has the virus just by looking at them**. You might not even know that you have the virus, and this means you can transmit it to other people without knowing.

1.2 What Is AIDS?

AIDS stands for **acquired immune deficiency syndrome**. It is acquired because it is not inherited the virus that destroys the body's immune system is spread from one person to another. A syndrome is a group of signs and symptoms denoting a disease, in this case, the collection of signs and symptoms resulting from lowered immunity due to HIV. As the virus multiplies and more immune cells are destroyed, many infections and complications occur. These infections are referred to as **opportunistic infections**. They are called opportunistic because they take the opportunity provided by the lowered immunity.

A collection of signs and symptoms caused by infections and other complications arising from

HIV infection is referred to as AIDS. AIDS may occur 3—10 years after HIV infection when the human immune system becomes severely weakened and this leads to various life-threatening conditions.

After infection with HIV, the immune system of the body develops antibodies. These antibodies are detectable in the blood and other body fluids within 6—12 weeks after the infection. Before 4—6 weeks, the body will not have generated enough antibodies to be detected by HIV antibody tests. This period is known as the **window period**. It is important to note that **the person is infective despite the negative test result**. HIV infection is only confirmed after a person has developed antibodies and goes through an HIV antibody test. Positive tests confirm the infection except in children below 18 months old. Until this age the child could have acquired the antibodies from the mother and not the virus.

1.3 HIV Transmission

HIV is spread in three ways:

- Sexual intercourse
- Blood (and other body fluids)
- Mother to child

1.3.1 Through Sexual Intercourse

In Kenya, this is the commonest mode of HIV transmission. The virus is found in all body fluids of people infected with HIV, with high quantities of the virus in genital fluids (semen and vaginal fluids). The amount of virus is even greater in the genital fluids if there is co-infection with other sexually transmitted diseases (STDs) like gonorrhoea, syphilis, and chancroid. Ulcerations arising from these STDs allow HIV to enter the body easily during sex with an HIV infected person. Therefore, the presence of other STDs increases both the transmission and the risk of acquiring of HIV/AIDS.

1.3.2 Through Blood

This happens when a person comes in contact with blood or blood products (or other body fluids) from an infected person. This occurs through the following ways:

- Blood transfusion from an infected person.
- Blood contaminated needles, syringes, razor blades, and other sharp objects, including unsterilized instruments used in cutting like traditional circumcision or scarification.
- Lifesaving and emergency contact where there is blood, e.g., accident victims.
- Organ transplants from HIV-infected donors.
- Body fluids and discharges like saliva, pus, diarrhoea etc.

1.3.3 Mother-to-Child Transmission

Mothers who are infected with HIV can transmit it to their unborn or new-born babies. The transmission from mother to baby can occur during pregnancy, at the time of delivery, or after delivery through breast milk.

About 30 to 40% of babies born of HIV infected mothers become infected. Most of these babies develop AIDS related symptoms within the first year of life and many die before their fifth birthday.

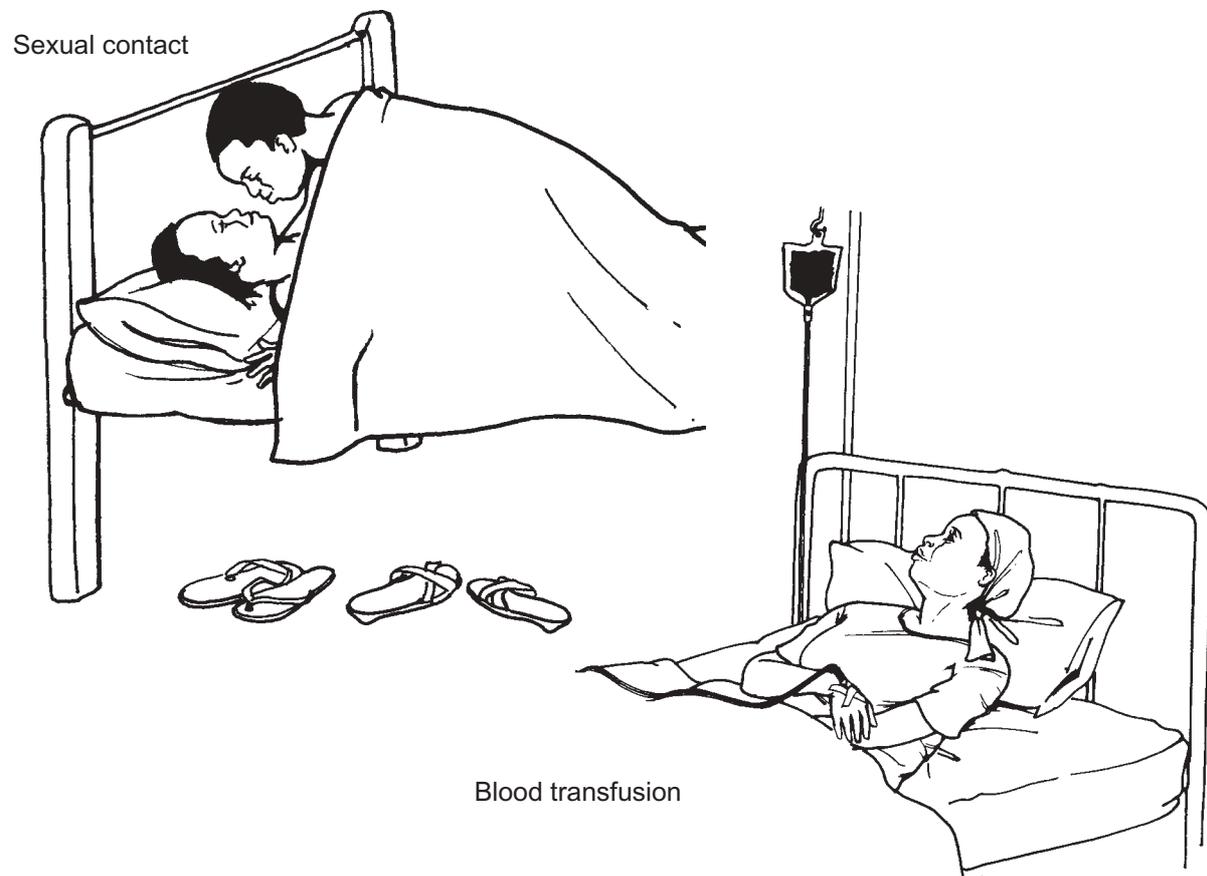
How HIV is not spread

HIV is *not* spread through casual contacts with an HIV-positive person. These casual contacts include:

- Living in the same household with an infected person
- Shaking hands, hugging, or light kissing
- Sharing foods, plates, and cups
- Using the same public transportation
- Sharing bathrooms and toilets

HIV is not spread by insects like mosquitoes and bedbugs.

Figure 1.1: How HIV is spread



Mother to child



During pregnancy



During breastfeeding



During labour and birth



2

HOME-BASED CARE AS AN INTERVENTION IN HIV/AIDS

The increasing number of people developing AIDS calls for partnership among family members, health care workers, local communities, community-based organizations (CBOs), non-government organizations (NGOs), and the persons themselves in providing care and support to those infected and affected by the HIV/AIDS epidemic. Home-based care programmes are being developed as the best option for caring for people with HIV/AIDS. The National AIDS/STD Control Programme (NAS COP) of the Ministry of Health, drawing on experiences from Kenya and elsewhere throughout the world, has developed these guidelines to ensure the effectiveness of home-based care programmes in Kenya.

2.1 What Is Home-Based Care?

Home-based care is the care of persons infected and affected by HIV/AIDS that is extended from the health facility to the patient's home through family participation and community involvement within available resources and in collaboration with health care workers.

Home-based care is a holistic, collaborative effort by the hospital, the family of the patient, and the community to enhance the quality of life of people living with HIV/AIDS (PLWHAs) and their families. It is comprehensive care across the continuum of care from the health facility through to community/home level. It encompasses clinical care, nursing care, counselling and psycho-spiritual care, and social support (see Figure 2.1).

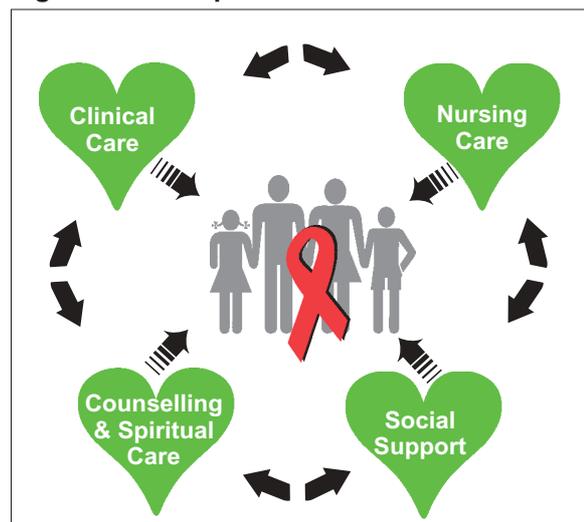
These are complementary, and actors in each should understand the role of the others on the team. The components are expanded here and services are explained in detail in Part III:

- **Clinical care:** Includes early diagnosis, rational treatment, and planning for follow-up care of HIV related illness.

- **Nursing care:** Includes care to promote and maintain good health, hygiene, and nutrition.
- **Counselling and psycho-spiritual care:** Includes reducing stress and anxiety for both PLWHAs and families, promoting positive living, and helping individuals to make informed decisions on HIV testing, plan for the future and behavioural change, make risk reduction plans, and involve sexual partner(s) in such decisions.
- **Social support:** Includes information and referral to support groups, welfare services, and legal advice for individuals and families, including surviving family members, and where feasible provision of material assistance.

The operational concept here is **effective referral and networking between health and social sectors**, involving government, NGOs, CBOs, private institutions, and the families and communities of PLWHAs.

Figure 2.1: Components of home-based care



2.2 Objectives of Home-Based Care

1. To facilitate the continuity of the patient's care from the health facility to the home and community.

2. To promote family and community awareness of HIV/AIDS prevention and care.
3. To empower the PLWHA, the family, and the community with the knowledge needed to ensure long-term care and support.
4. To raise the acceptability of PLWHAs by the family/community, hence reducing the stigma associated with AIDS.
5. To streamline the patient/client referral from the institutions into the community and from the community to appropriate health and social facilities.
6. To facilitate quality community care for the infected and affected.
7. To mobilize the resources necessary for sustainability of the service.

2.3 Principles of Home-Based Care

To ensure that the foregoing benefits are realized, home-based care should be regarded as a holistic system of care with provisions for:

- Ensuring appropriate, cost-effective access to quality health care and support to enable persons living with HIV/AIDS to retain their self-sufficiency and maintain quality of life.
- Encouraging the active participation and involvement of those most affected, the persons living with HIV/AIDS.
- Fostering the active participation and involvement of those most able to provide support the community at all levels.
- Targeting social assistance to all affected families, especially children.
- Caring for caregivers, in order to minimize the physical and spiritual exhaustion that can come with the prolonged care of the terminally ill.
- Ensuring respect for the basic human rights of PLWHAs.
- Developing the vital role of home-based care as the link between prevention and care.
- Taking a multi-sector approach to care and support.
- Addressing the reproductive health and family planning needs of persons living with HIV/AIDS.
- Instituting measures to ensure the economic sustainability of home care support.
- Building and supporting referral networks/linkages and collaboration among participating entities.

- Building capacity at all levels household, community, institution.
- Addressing the differential gender impact of the HIV/AIDS epidemic and care for persons living with HIV/AIDS.

2.4 Home-Based Care Needs at Various Levels

Home-based care needs can be identified as those specific to the PLWHA, to the family, and to the community within which the PLWHA lives. These needs may be physical, spiritual/pastoral, social, or psychological, but will vary from person to person and from one community to the other. These needs should be identified when a PLWHA is being enrolled into a home-based care programme, for example while still in hospital, so as to ensure proper planning and integration of activities. Early identification also ensures adequate resource mobilization and the sustainability of activities initiated.

2.4.1 Needs of PLWHAs

Persons living with HIV/AIDS have physical, spiritual, social, and psychological needs that must be met in order to enhance both the quality and the length of their lives.

Physical Needs

- Drugs for treatment of opportunistic infections and prevention of mother to child transmission.
- Clinical care, including medication and regular check-ups in case of onset of new symptoms to ensure immediate management.
- Clothing, housing, food, fuel/energy, water, education for children, and income.
- General nursing care, including attention to toilet needs, observation of vital signs, care of wounds, personal and oral hygiene, and comfort.
- Nutritional needs, that is, provision of an affordable and locally available balanced diet.
- Physical therapy, exercise, massage.
- Information, education, and communication (IEC), including up-to-date, accurate information on HIV/AIDS and safer sexual behaviour, on writing a will, and on preparing for the eventuality of death, all of which aim to help the PLWHA to live more comfortably and cope with the HIV infection.

Spiritual/Pastoral Needs

Strengthening existing faith and helping the PLWHA in spiritual growth boosts the spiritual aspect of life. This plays a great part in encouraging the person to have a positive view of life and to forgive others and self for any misconceptions and blames. The PLWHA will therefore be able to:

- Accept forgiveness by others.
- Forgive others.
- Have reassurance that God accepts them.
- Allow religious groups to offer support.
- Have freedom of worship according to faith, which should be respected by the health worker and the care providers.
- Call a religious leader of choice for sacraments and fulfilment of other needs.

Social Needs

PLWHAs need company and association without stigma or discrimination. Recreation and exercise at clubs/groups of their choice should be facilitated by family and community members. PLWHAs need to be considered as people of value and having rights to be respected. They should not be cut off from activities they enjoy, e.g., political rallies, church/mosque/temple, and spiritual gatherings.

The social needs of PLWHAs include:

- Respect.
- Love and acceptance from others.
- Company of those around them.
- A source of income/income-generating activity.
- Right to own, inherit, and bequeath property.
- Confidentiality regarding their condition by all who know about it.
- Help with the activities of daily living.

Psychological Needs

Love, encouragement, warmth, appreciation, reassurance, and help in coping with the infection are some of PLWHAs psychological needs. Religious groups, volunteer groups, and other related support groups can all play a part in meeting these psychological and counselling needs. They can:

- Instil hope so that the PLWHA can continue with daily activities as long as possible.
- Maintain confidentiality and unconditional acceptance and love.
- Provide supportive counselling to live positively.

2.4.2 Needs of the Family and Caregivers

Families and caregivers, too, have physical, psychological, and social/spiritual needs that must be met in order to maintain family solidarity and well-being.

Physical Needs

The physical needs of the family are more or less the same as those of the PLWHA, except for personal needs that are specific to the PLWHA's condition. Family members will need proper STD/HIV/AIDS education and demonstrations on the care they will be expected to provide. Because the burden of caring for someone who is very ill or dying is constant and heavy, the family may also need help with household, farm, or other chores.

Psychological Needs

The family of a PLWHA needs a lot of support, encouragement, and acceptance from community members so that they may be motivated and encouraged to care for the PLWHA without fear of being isolated. They should be adequately prepared for:

- The deterioration and eventual death of the PLWHA.
- How to give un-smothering love and acceptance.
- Where and how to meet others who are going through the same experience of caring for similar PLWHAs. This gives the family members a sense of hope and a drive to go on.
- The importance of observing confidentiality, e.g., keeping matters relating to the PLWHA in confidence.
- The very real possibility that they themselves may need to seek counselling to help them cope with the situation.

Social and Spiritual/Pastoral Needs

Families don't stop being members of the community when someone gets infected with HIV/AIDS. More than ever, such families need:

- Respect and help with activities of daily living when need arises.
- Acceptance of the PLWHA and help with enabling the PLWHA to socialize and interact in the community.
- Solidarity with the PLWHA and the family.
- Spiritual comfort, including taking the initiative to involve the PLWHA and family in spiritual growth through worshipping and praying together.

2.4.3 Needs of Orphans

- Acceptance by those around them resulting in a sense of belonging.
- Basic needs like food, shelter, clothing, education, love.
- Legal interventions in cases of property inheritance.
- Protection from exploitation.

Figure 2.3: Needs of the PLWHA and the family

Social needs



Physical needs



2.5 Roles of the Various Players in Home-Based Care

All of those involved in home-based care have a role to play in the delivery of the service. Some aspects of the roles are unique to the specific players, but others may overlap to some extent. Every function is important, and none should be thought inferior to others, because they all make vital contributions to the total home-based care system.

2.5.1 Role of the Health Facility

- Initiate and market the HBC process by recruiting the PLWHA to the programme, identifying needs at various levels, and preparing the PLWHA for discharge home.
- Prepare the family caregiver for the caring responsibility at home.
- Make initial diagnosis, institute relevant nursing and medical care, help identify psychological and social needs.
- Initiate referral and networking systems, which may change over time as the PLWHA's condition and needs change.
- Care for terminally ill PLWHAs depending on their wish.

2.5.2 Role of the Home Care Team

Home care teams, supervised by a medical or social work professional, may be associated with a local or health centre or community organization. They are organized to provide a variety of services to PLWHAs and their families. The community health worker is a key member of the team. These teams:

- Manage AIDS-related conditions.
- Provide home nursing care.
- Arrange voluntary HIV counselling and testing.
- Provide supportive counselling.
- Refer for clinical and other services.
- Educate PLWHA/family on HIV/AIDS.
- Arrange spiritual/pastoral care.
- Mobilize material support.
- Train home-based caregivers.

2.5.3 Role of the Family and Caregivers

- Learn to accept and adjust to the situation, including that of the terminally ill with AIDS.
- Collaborate with other care providers, e.g., religious institutions, support groups, health and social institutions.

- Be able to volunteer or agree on other possible caregivers to be involved in providing the services in the family. This becomes shared responsibility on issues of referral and networking.
- Learn to consult with the PLWHA on matters concerning them.
- Involve the PLWHA in all care activities and any other family activities without discrimination.
- Emphasize the need to prepare for death as inevitable and sensitize the PLWHA about the importance of ensuring the continuing care of family members who are left behind.
- Encourage and help the PLWHA to write a will.
- Remember that being present is a major support.

Figure 2.4: The role of the family



2.5.4 Role of the Community

- Accept the situation of the PLWHA and learn to collaborate and work with existing agencies around to meet the needs of those infected, e.g., religious groups, women's groups, and other social and health agencies.

Figure 2.5: The role of the community



- Help in the formation of support groups, which in turn would lobby and advocate for the rights of the PLWHA.
- Be with the family members and provide company.

2.5.5 Role of the PLWHA

- Identify the primary or alternative caregiver.
- Participate in the care process, but not passively, especially in making decisions on own welfare.
- If possible, give consent on caregivers and where the care will be provided, e.g., home or hospital especially during the terminal phase of the disease.

- Prepare a Memory Book to provide their children with family history and a tangible record of caring.
- Write a will.
- Identify own spiritual/pastoral needs.
- Be open to the caregiver and share any worries.
- Take personal responsibility to prevent further transmission of HIV.
- Advocate for behaviour change.

2.5.6 Role of the Government

- Create a supportive policy environment.
- Develop policies and guidelines.
- Develop and maintain standards.
- Provide/coordinate training.
- Provide drugs and commodities.



3

COMPONENTS OF HOME-BASED CARE

Home-based care goes side-by-side with prevention and should therefore be an integral part of health care structures. In this way it will offer quality of life to persons living with HIV/AIDS and contribute to the reduction of HIV transmission.

To ensure that HIV/AIDS patients get comprehensive care it is essential to integrate care activities at all levels individual, family, community, and health and welfare systems. Investing in care at home can decrease the social impact of AIDS, enhance preventive measures, prevent spread of secondary infections, and help strengthen the existing health care systems. In order for home-based care to work, there is need to provide the essential drugs and supplies required for HIV/AIDS care including protective clothing and disinfectants.

The components of comprehensive care are:

- Clinical care
- Nursing care
- Counselling and psycho-spiritual care
- Social support

3.1 Clinical Care

Clinical management of HIV/AIDS includes early diagnosis, treatment, and follow-up care of opportunistic diseases and conditions associated with HIV/AIDS infection.

3.1.1 Clinical Care Requirements

- **Trained clinical personnel:** Doctors, nurses, clinical officers, and other paramedical staff involved in patient management, e.g., physiotherapists, laboratory technologists, social workers, etc.
- **Drugs for opportunistic infections:** Anti-fungals, antibiotics, anti-diarrhoeals, analgesics, anti TB drugs, rehydration solutions, herbs, effective local remedies.
- **Anti-retrovirals:** These have known benefits and should be made available as far

as possible, including for prevention of mother-to-child transmission.

- **Supplies of various types:** Gloves, soap, waterproof sheeting, draw sheets, sheets (for emergency), etc.
- **Dressing materials:** Cotton wool, gauze, strapping, cleaning lotions, etc.

3.1.2 Linkages with Home Care

- Identification and training of community health workers, within the system and from community organizations, to ensure a smooth referral network between health facilities and community level for the management of opportunistic infections.

Figure 3.1: Clinical care component



- Documentation of home-based care activities by each implementer at all levels to avoid duplication.
- Team work and networking among all health care providers at both the health facility and the community levels.
- Proper supply of drugs and nursing supplies to health facility and community health workers who may be doing outreach or home visits within a given community.
- Understanding of the referral system by care providers, the family, and the PLWHA to avoid wasting time when referral is necessary.
- Formation of support groups for caregivers.
- Supervision of community health workers in the use of simple drugs and supplies within their home care kits.

3.2 Nursing Care

Nursing is The art of assisting individuals, sick or well, to do those things they would do if they had the strength, knowledge, or will, or to a peaceful death . Nursing care for people living with HIV/AIDS is aimed at alleviating physical and psychological symptoms as well as maximizing the level of function of the affected person. A systematic assessment of the needs of the sick individual and provision of care to meet those needs is important in achieving the nursing aims. While the PLWHA is still in the hospital, recruitment into a home-based care programme for patients and relatives who can benefit and preparation of a hospital discharge plan should be taken as a priority.

Total nursing care should be maintained at all levels: health facility, home, and the community. The common presenting problems requiring nursing care are:

- Diarrhoea
- Difficulty in swallowing (dysphagia)
- Difficulty in breathing (dyspnea)
- Swelling of body parts (oedema)
- High temperature (fever)
- Nausea and vomiting
- Nutritional deficiency
- Skin or mucous membrane lesions
- Unkempt mouth and body
- Neurological impairment
- Pain

Nursing also incorporates palliative and terminal care (see Chapter 12).

Figure 3.2: Nursing care component

In the health facility



At home



Nursing care intends to meet the following needs to the extent possible:

- Symptom control
- Comfort/reassurance
- Nutrition
- Coping with loss and change
- Preparing for death
- Personal and environmental hygiene
- Medication and follow-up
- Pain management

3.2.1 Nursing Care Requirements

- Nurses and health care workers trained in HBC.
- Community health workers (CHWs) and family members trained to provide care.
- Home care kits containing gloves, cotton wool, disinfectants, and basic medicines.
- Equipment and supplies for general nursing procedures.
- Time and transport.

3.2.2 Linkages

- Planned discharge from health facility and a clear follow-up and supervision system in place.
- Coordination of communication between the health facility and the home where the PLWHA and the family caregivers are.
- Referral system to the nearest health facility, care and support services, or back to the home.
- Liaison with other health team members and the village health committees.
- Formation of a network that brings together all the parties involved in the care and support of people affected by AIDS at all levels, ranging from policy makers to caregivers to PLWHA self-help groups.

3.3 Counselling/Psycho-Spiritual Care

Counselling is a professional helping relationship that assists people to understand and deal with their problems. It includes psychological/emotional support, anxiety reduction, promotion of positive living, and help

with making informed decisions about HIV testing, life, and living. Good counselling also involves: accurate information about the subject, active listening, self-awareness, and an understanding of the counselling process. In the context of home-based care there are several types of counselling:

- Pre- and post-test counselling (VCT)
- Behaviour change counselling
- Group counselling
- Family counselling
- Supportive counselling
- Crisis counselling
- Spiritual/pastoral counselling
- Death and bereavement counselling

The objectives of counselling and psycho-spiritual care in home-based care are to:

- Control the spread of HIV/AIDS through information dissemination, promotion of safer sex, advocacy for behaviour change, and encouragement of better health seeking behaviour.
- Help PLWHA to come to terms with the infection and to adopt a positive living attitude.

Figure 3.3: Counselling component



- Help the client/PLWHA make well informed decisions about sex and sexuality.
- Offer psychological and spiritual support to PLWHAs and their families.
- Help PLWHAs to assess and talk about what their life has meant to them through their belief systems, whatever they may be.
- Help PLWHAs accept the need to talk to family members about their condition and future plans.

3.3.1 Counselling/Psycho-Spiritual Care Requirements and Issues

- Confidentiality: This is a traditional, professional, and ethical requirement of the health professional. It is the necessary privacy given to personal information about clients/PLWHAs.
- Acceptance: This consists in the non-judgemental acceptance of the PLWHA and recognition of the PLWHA's own personal belief systems.
- Training: This involves integration of counselling into all training curricula (multi-sector) for health workers, social workers, teachers, community health workers (CHWs), trainers of trainers (TOTs), and PLWHAs.
- Monitoring and supervision: This entails follow-up of all those offering counselling services to provide technical support and ensure quality.
- Multi-sector approach and collaboration/networking.
- Establishment of hotline service and counselling support services for PLWHAs and their families.
- Establishment of voluntary counselling and HIV testing centres.
- Political will and support.

3.3.2 Linkages

- Liaison with and involvement of all other actors, stakeholders, and partners in the care of PLWHAs health care workers, counsellors, spiritual leaders, local NGOs and CBOs.
- An inventory of all stakeholders and counsellors at all levels.
- A hotline for counselling information.
- A system of networking at all levels.

3.4 Social Support

Social support, for HIV infected people, is the creation of an enabling environment for the PLWHA by all involved in providing care. It

Figure 3.4: Social and psychological component



involves information dissemination and referral to support groups and welfare, economic, and legal services. There is need to understand the social side of health, which in general includes:

- Knowledge of local socio-cultural beliefs and practices related to HIV/AIDS treatment in order to educate people on the positive and negative aspects.
- Recognition of gender issues in the care of PLWHAs.
- Patterns of health-seeking behaviours and support systems of the community.

The primary issues in social support include the following:

- Burden of care on women.
- Confidentiality, acceptance, solidarity, and stigmatization.
- Protection from loss of job and insurance.
- The role of traditional healing.
- Societal concept of the epidemic.
- Income-generating activities and resource implications.
- The impact of the extent and quality of support on the PLWHA's quality and quantity of life.

- The impact of environmental factors on individual and community health, for example, mosquito and rodent control, industrial or other pollutants of air and water.
- Early involvement of relatives and other support groups, social workers, and children's department.

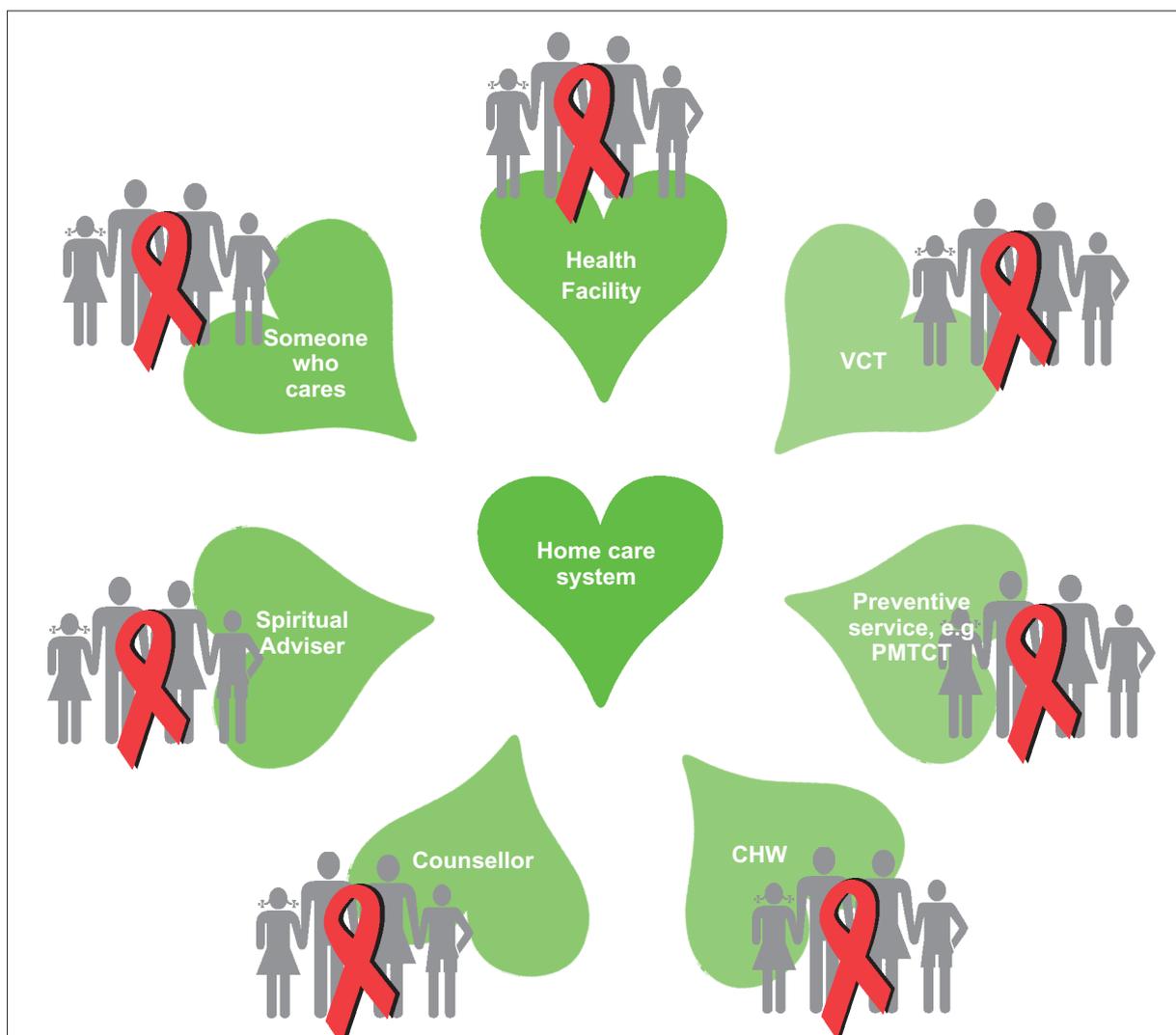
3.5 Entry into the Home-Based Care System

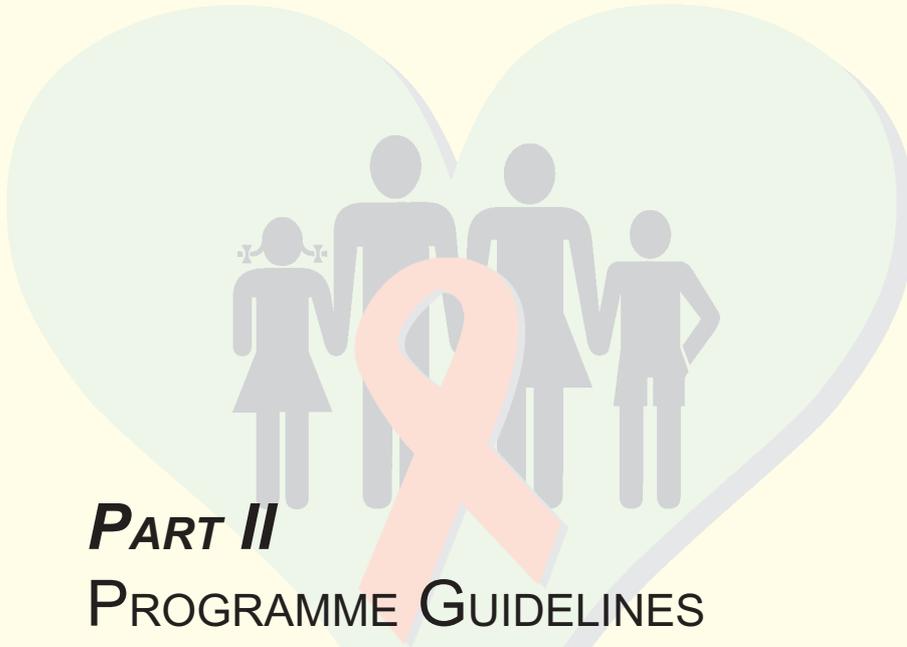
Because home-based care represents a continuum of care from the health facility into the home and back again, there are many entry points along the way (Figure 3.5). A person who is hospitalized may be identified as a candidate for home care at the time of discharge. An

individual who has gone for voluntary counselling and testing may apply for home care services if the test result comes back positive. Other counsellors, spiritual leaders, and simply caring friends or relatives may recommend a PLWHA for home care services.

It really doesn't matter so much how the person gets into the system. The important thing is to provide the services that will contribute to improved quality of life and better health longer for the PLWHA, and to the emotional and physical stability of the family. For maximum effectiveness, home care programmes should have provisions for identifying potential candidates that are not biased in favour of any particular entry point.

Figure 3.5: Possible entry points into a home-based care system





PART II

PROGRAMME GUIDELINES

4 Planning and Setting Up a Home-Based Care Programme

- 4.1 Needs assessment
- 4.2 Establishing programme priorities
- 4.3 The public sector framework

5 The Home-Based Care Team

- 5.1 Roles of HBC team members
- 5.2 Identifying team members
- 5.3 A model home care team
- 5.4 Orientation, training, and certification

6 Resource Mobilization

- 6.1 Types of resources needed for effective and sustainable care
- 6.2 Sources of the required resources
- 6.3 How to mobilize the identified resources
- 6.4 Sustainability

7 Referral and Networking Systems

- 7.1 Why referrals are necessary
- 7.2 Appropriate referral points
- 7.3 Constraints/limitations in referral and networking
- 7.4 Solutions to referral constraints
- 7.5 The referral framework

8 Monitoring and Evaluation

- 8.1 What is monitored and evaluated in home-based care
- 8.2 Objectives of monitoring and evaluation in home-based care
- 8.3 How monitoring and evaluation are done in home-based care
- 8.4 Constraints/limitations to monitoring and evaluation
- 8.5 Solutions to constraints



4

PLANNING AND SETTING UP A HOME-BASED CARE PROGRAMME

There are a number of issues to take into consideration before setting up a home-based care programme. Among these are the HIV prevalence in the community, the services that are already available, and the recognized need for home-based care services.

The home-based care programme can be either health facility based, meaning that it is mainly coordinated from the health facility, or community based, meaning that it is mainly coordinated from the community. Regardless, the programme must comprise all four components identified by NASCOP: clinical care, nursing care, counselling/psycho-spiritual care, and social support. It is also essential to have clear objectives, a viable management plan that spells out the roles and responsibilities of all the players, and a strategy for mobilizing required resources.

Because the emphasis in home-based care is on community participation, community members and representatives of community institutions can come together to discuss these issues, compile background information, and develop objectives and strategies that are appropriate to their community. Depending on the model used, this process can be facilitated by the health facility or by community leaders or community-based organizations.

4.1 Needs Assessment

One of the first steps in the planning process is to conduct a needs assessment. A needs assessment is important because it helps us to **know** and **understand** the problem or the actual situation that needs to be addressed through a community home-based care programme. This helps us ensure that the programme will effectively address all the issues at hand.

The following information, among others, will help assess whether there is need for a home-based care programme in the community:

- The extent of HIV infection in the community (prevalence).
- Factors enhancing the spread of HIV in the community, e.g., traditional practices, the prevalence of sexually transmitted diseases, the presence of major transport facilities.
- The existing health and other care services and how effective they are in providing care to the PLWHAs, e.g., hospitals, NGOs, CBOs, private organizations, etc.
- The additional resources that are or could be made available from the community.
- The utilization rate and effectiveness of existing services in meeting people's needs.
- How existing resources and networks could be used.
- Environmental factors that may have an impact on health, e.g., mosquito breeding areas, a dusty quarry, an abundance of rubbish or trash, a polluted water supply.
- How trained personnel could be brought in to assist in home care, e.g., counsellors, religious leaders within the community, etc.

The assessment does not need to be expensive or elaborate; the answers to a few simple questions should supply the necessary background. Sample questions to be used in needs assessments include:

- What is the prevalence of HIV/AIDS in the community?
- What or who is the source of this information?
- What institutions or organizations exist in this community that could collaborate on a home-based care programme?
- What resources are available from the community that the programme can depend on?
- How have PLWHAs and the community been coping thus far?
- What are the strengths and weaknesses of the community in relation to home-based care? How can the strengths be used for the benefit of PLWHAs and the community?

4.2 Establishing Programme Priorities

The objectives of home-based care were defined in Chapter 2. To recap, they include monitoring PLWHAs and referring them for further medical treatment, teaching families how to provide care at home, teaching PLWHAs to take care of themselves, providing a range of psychological, social, material, and spiritual support to the PLWHA and family, and providing information, education, and communication (IEC) services to promote sustained positive behaviour change to reduce HIV transmission. These objectives form the basis for monitoring and evaluating the programme and can be modified to suit various contexts.

Specific strategies are needed to achieve the objectives. Some questions that can be used as a guide in developing strategies are:

- Will the programme be community based or hospital based? Depending on the answer to this question, decide on the composition of the caregiving team.
- How will you identify the PLWHAs to participate in the programme (e.g., testing)?
- How will the PLWHAs be introduced to the programme?
- Will the HBC team undertake HIV testing?
- If the team will not undertake HIV testing, how will they collaborate with the testing institution? Is there need to improve the relationship?
- What kind of provisions will you make to care for the caregivers?
- Will the HBC team meet the needs of household, non HIV/AIDS patients in the community?
- What alternative services will be available for those who refuse home-based care?
- What mechanisms will be used to refer PLWHAs and families to other caring services (e.g., health facility, counselling, legal aid)?
- What are the possible management plans for the programme (i.e., what is the starting point and what follows)?
- What resources will be required to start and run the programme (human, financial, material)?
- How will you monitor and evaluate your activities (including record keeping, data management, etc.)?

4.3 The Public Sector Framework

Because the HIV/AIDS epidemic is both a health and a development emergency, the Government of Kenya is fighting it on both the health front and the community mobilization front. These two systems consist, on the one hand, of established Ministry of Health programmes and practices and, on the other hand, of the relatively new structure of AIDS control units and committees. NASCOP stresses the importance of public—private coordination and collaboration on programme frameworks and common issues, for example, determining incentives for volunteer members of home care teams.

4.3.1 The Ministry of Health Component

To augment the existing MOH component, NASCOP recommends the establishment of District Home-Based Care Committees. These would be a subcommittee of the District Health Management Board. Their membership would be representative of home care programmes in the public and private sector (including NGO/CBO programmes) and would include PLWHAs. The District HBC Committees would have technical assistance and monitoring and evaluation functions. They would assist local programmes to design HBC systems and would ensure compliance with NASCOP standards and guidelines.

4.3.2 The AIDS Control Component

The government of Kenya sets out the AIDS control framework within the *National HIV/AIDS Strategic Plan 2000—2005*. At the apex is the National AIDS Control Council (NACC), which has overall responsibility for monitoring and supervising HIV/AIDS related activities. Among other functions, NACC mobilizes resources, formulates policy and strategy, develops information systems, and collaborates with international and local agencies. Also at national level, each ministry has an AIDS Control Unit (ACU) to coordinate the implementation of the Strategic Plan within and across sectors. NASCOP is the AIDS Control Unit in the Ministry of Health and the technical arm of the fight against the epidemic.

Three levels of AIDS Control Committees bring the framework right down to the local community. Provincial AIDS Control Committees (PACCs), the coordinating bodies at provincial level, include people from various government departments, the civil society, and the private

sector, as well as persons living with or affected by HIV/AIDS. District-level implementation and monitoring will be coordinated by District AIDS Control Committees (DACCs), with similar memberships to the provincial committees at their respective levels, which will function as the interface between national/provincial levels and the communities.

Perhaps most relevant to the immediate needs of home-based care programmes are the Constituency AIDS Control Committees (CACCs), whose members will be drawn from the same sectors as the district and provincial committees. According to the Strategic Plan, these committees have the following mandate:

- Mobilize communities to play an active role.
- Operate as agents of change.
- Ensure that committees of elders discuss local cultural influences on the spread of HIV/AIDS.
- Promote positive health-seeking behaviours.
- Facilitate the participation of youth in activities aimed at behaviour change.
- Develop sustainable community-owned care and support systems for the affected and infected, including widows, widowers, and orphans.
- Mobilize and ensure proper use of local resources.

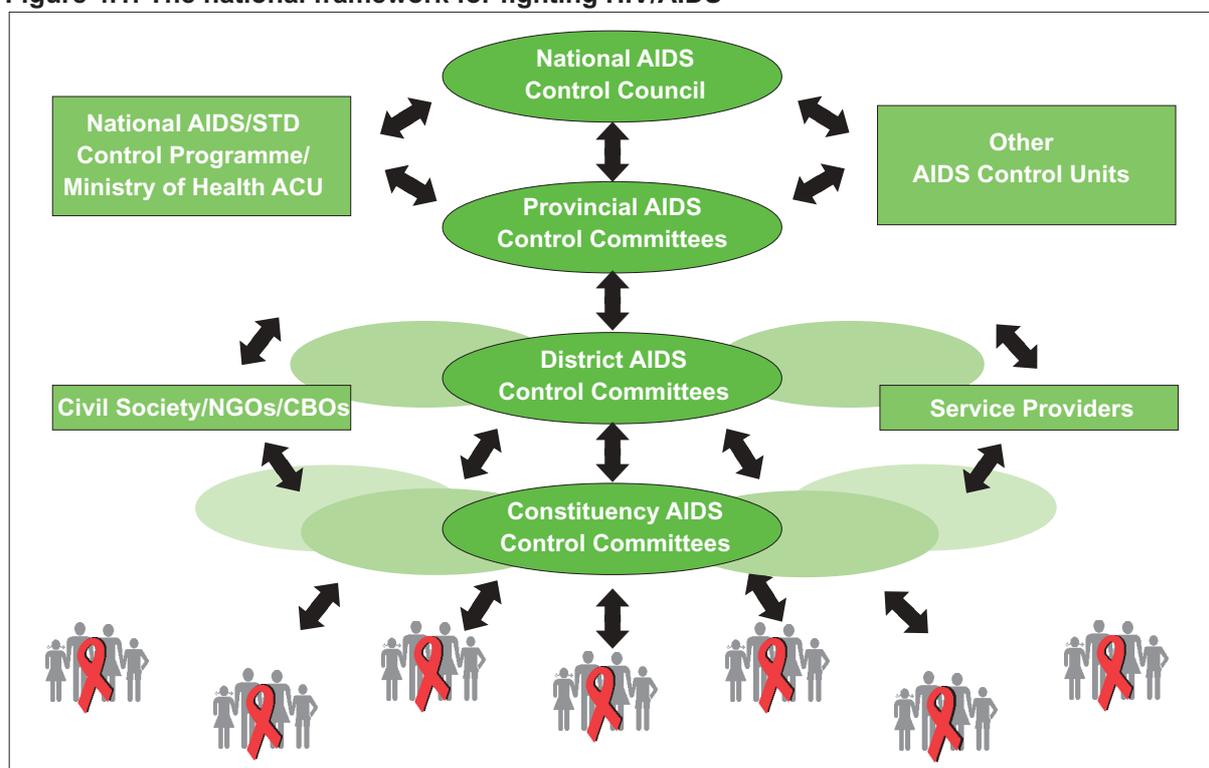
- Promote and strengthen income-generating activities among vulnerable groups.
- Network, collaborate, and coordinate with other AIDS service organizations.
- Establish and implement monitoring and evaluation systems and submit quarterly and annual reports to NACC.

The national AIDS control framework is illustrated in Figure 4.1. At the district and local levels the ACCs will form the community and resource mobilization wings of the national AIDS control effort. The committees will collaborate closely with District Health Management Teams (DHMTs), District Home-Based Care Committees, local and district hospitals, health centres, and NGOs and CBOs that are working in health service delivery.

4.3.3 The Role of NASCOP

NASCOP has the internal function of coordinating AIDS control activities within and between ministries. NASCOP also has the overall mandate of providing technical guidance, standards, and direction to all health care services related to HIV/AIDS. NASCOP is therefore the supervisory body for home-based care programmes.

Figure 4.1: The national framework for fighting HIV/AIDS



Source: Based on Kenya National AIDS Strategic Plan 2000-2005, popular version.



5

THE HOME-BASED CARE TEAM

Home-based care is a collaboration by the health facility, the people infected and affected by HIV/AIDS, and the larger community. Within that collaboration is a wide array of personal and professional expertise that needs to be tapped to make a home-based care programme successful. Members of the team may range from highly skilled doctors and nurses to volunteers. Each member has a role to play, and an effective programme will ensure that the roles are coordinated and complementary. It is therefore important to identify the core home-care team members including the volunteers, and to understand the requirements of the various care providers and the linkages among them.

5.1 Roles of HBC Team Members

The home-based care teams will essentially have a twofold responsibility: primary clinical and nursing care of the HIV/AIDS patient, and mobilization of community involvement and resources. Teams should work under the supervision of or in collaboration with health facilities (hospitals, health centres, etc.), DHMTs, NGOs with recognized oversight capacity, or other capable entities. They should also be prepared to cooperate fully with district and constituency AIDS Control Committees.

5.1.1 Team Membership

Ideally, a home-based care programme or unit would consist of a number of home care teams under the direction of a Team Leader who is a care professional (nurse, clinical officer, counsellor, social worker). Each team would consist, at minimum, of professionals with combined expertise in nursing, counselling, and IEC/community mobilization. These teams would, in turn, coordinate and serve as resources for the community health workers who actually carry out the home-level care functions. (See Figure 5.1 for an illustration of the composition and outreach of home care teams.) The responsibilities and qualifications of the various members of the teams are described further in Section 5.3.

5.1.2 Case Load

Each Team Leader would theoretically be responsible for overseeing the activities of 5 home-care teams, who would each coordinate the activities of 5 community health workers, each with approximately 5 families. This means that each unit could be responsible for as many as 125 persons with HIV/AIDS and their families. Whether this theoretical caseload is feasible will depend heavily on the capacity of the communities to assist, the terrain that must be covered, the availability of transport, and other factors. It will also depend on how well the local/district referral system operates, because this is the heart of the backup support for the home-care providers.

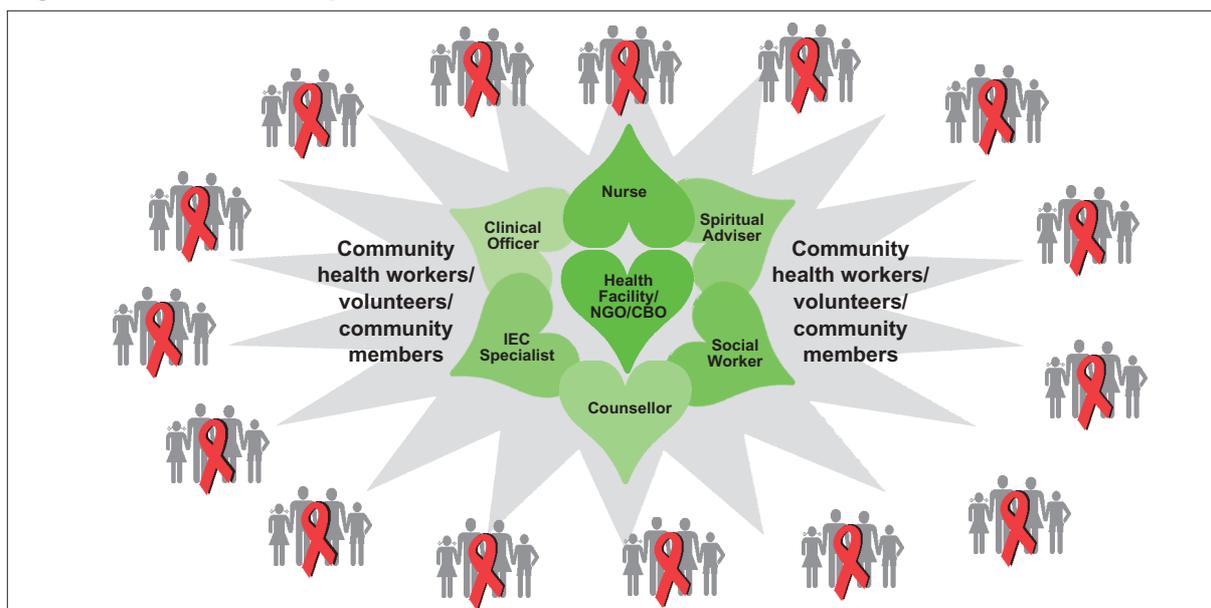
Possible home care case load

- 1 Team Leader →
 - 5 home care teams →
 - 5 community health workers →
 - 5 families
- 125 HIV/AIDS families per unit*

5.1.3 Links with AIDS Control Committees

The public sector ACC structure described in Section 4.3 is, of course, intended to complement the existing health care delivery system, including District Health Management Teams (DHMTs) and the network of hospitals, health centres, and dispensaries. They are also intended to complement the efforts of private sector and mission health facilities, as well as non-government organizations working within communities to identify and mobilize resources and provide home-based care for persons living with HIV/AIDS and their families. It is expected that all such organizations will do their utmost to coordinate their activities and collaborate within the ACC structure to ensure the maximum value of the efforts of everyone involved. The idea, as suggested in Figure 5.2, is to ensure the full benefit of the system reaches PLWHAs and their families.

Figure 5.1: Schematic of possible home care unit



5.2 Identifying Team Members

Since the needs of care recipients are varied they can only be met through a multi-disciplinary care and support system. Therefore the home-based care team should be multi-disciplinary in order to handle the physical, social, psychological, and spiritual needs of care recipients adequately.

The core team members will need motivation, commitment, professional expertise, and preferably relevant experience. The volunteers will need commitment, motivation, and, to some extent, personal experience with family or friends who are PLWHAs or who have died of AIDS. All the team members must be loving and interested in fighting HIV/AIDS and assisting the infected and affected. To be effective, those selected in the home-based care team must be convincing educators who will facilitate change in attitude and behaviour.

In addition, team members should be committed to a lifestyle consistent with HIV prevention

Qualities of a good team leader

- Listens carefully
- Creates a climate of trust
- Acts as a role model
- Delegates tasks
- Shares information readily
- Motivates and empowers members
- Deals promptly with conflict
- Runs meetings effectively and efficiently

messages and willing and able to work hard and for long hours while retaining a sense of humour. They should be empathic and respectful of confidentiality, genuinely committed to PLWHA care, and fully aware of the importance of community education to prevent further transmission of HIV. In recruiting team members, community members must be given priority.

5.3 A Model Home Care Team

Core team members should ideally include a clinician or nurse, counsellor, and social worker, as well as a spiritual adviser. They should all have record keeping and monitoring and evaluation responsibilities, based on their area.

Other members of the team could be volunteers on full or part time basis. They can be drawn from the community and trained by the core team to handle various responsibilities. The positions, qualifications, and responsibilities given below are meant to be illustrative and not prescriptive. It should be noted that the volunteer members of the team are key to extending the capacity of the professionals. Communities are encouraged to find ways to provide incentives to volunteer home care team members to enable them to maintain their commitment.

5.3.1 Team Leader

Qualifications/Requirements

- Must be a trained professional, e.g., doctor, nurse, clinical officer, social worker

- Must have counselling and administrative skills and experience
- Ability/experience in training

Responsibilities

- Overall coordination and supervision of the team members and their activities
- Monitoring and evaluating the progress of the programme
- Report writing
- Financial management, etc.
- Training other team members

5.3.2 Health Worker

Qualifications

- Clinical/nursing experience
- Professional health education training
- Experience with community education
- Counselling skills and experience
- Training experience

Responsibilities

- Educating the PLWHA/family/community
- Advocating for behaviour change, destigmatization of PLWHAs, etc.
- Training other team members

5.3.3 Social Worker

Qualifications

- Training in social work and counselling
- Professional experience in social work or counselling
- Professional experience as a trainer

Responsibilities

- Counselling

- Dealing with all social issues
- Identifying sources of needed non-health services, such as spiritual, legal, etc.
- Training other team members

5.3.4 Community Health Workers

Qualifications

- Highly motivated and willing and able to volunteer
- Able to read and write well enough to use reference materials and make reports
- Willing to be trained in HBC services
- Acceptable to the community

Responsibilities

- Home visits
- Training/supervision/support to caregivers and PLWHAs
- Home nursing as necessary
- Basic counselling
- Record keeping and reporting

5.3.5 Lay Religious Workers and Other Volunteers

Qualifications

- Training and skills in spiritual counselling

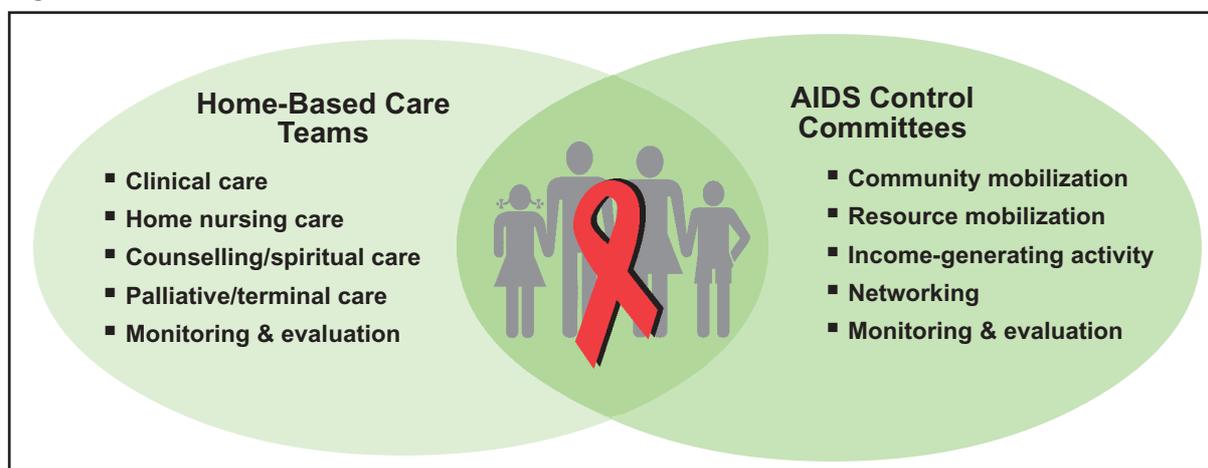
Responsibilities

- Counselling PLWHAs and family

5.4 Orientation, Training, and Certification

The government of Kenya will conduct, or collaborate with others to conduct, training and

Figure 5.2: Collaboration between home-based care teams and AIDS Control Committees



orientation in home-based care. All such training and orientation must be conducted using the training and other materials developed by NASCOP: *National Home-Based Care Programme and Service Guidelines, the Curriculum for Training Community Health Workers to Care for People with HIV/AIDS at Home*, and the *Home-Based Care Orientation Module for Health Service Personnel and Programme Managers*.

At senior levels, the purpose of the orientation will be to acquaint personnel with the issues arising in home-based care programmes, including, for example, the linkages between public and private sector programmes, logistics for supplies and drugs, potential conflicts in confidentiality requirements, etc. This training will also serve as an advocacy vehicle for soliciting the support of people in this cadre.

As summarized in Table 5.1, training and orientation for other HBC team members will also include the following:

- TOT training for health practitioners
- Skills training for health practitioners and community health workers
- Nursing skills training for family members
- Counselling training for health practitioners and community health workers

Participants in skills training programmes will be examined on their ability to perform the required activities. For example, the *Curriculum for Training Community Health Workers to Care for Persons with HIV/AIDS at Home* includes requirements for passing required skill tests.

Testing will be by observed demonstration of skills for health practitioners and community health workers. Having passed the test, trainees will be certified in home nursing skills for community health workers.

Table 5.1: Orientation and training needs for HBC programmes

Personnel	Responsibility	Training needs
National level managers	Programme management, supervision, and integration of AIDS patient care into ongoing programmes	Orientation to HBC guidelines Role of national managers
District/provincial health management teams	Planning, implementation, and evaluation of PLWHA care services	Orientation to HBC Overview of management Needs assessment Evaluation of HBC strategies Orientation to ongoing government and NGO programmes
Health facility level care providers	Management of PLWHA care Provision of care	Orientation to clinical and HBC guidelines Counselling and community prevention and control of HIV/AIDS PLWHA care management
HIV counsellors	PLWHA and family support Prevention and control of HIV transmission	Counselling and communication PLWHA care management Evaluation of counselling services
Community health workers, community counsellors	Provision of HBC care services PLWHA support Counselling Mobilization of community resources	Orientation to basic PLWHA care procedures Facts about AIDS Communication/counselling for HIV/AIDS prevention/control Community organization and networking Management of integrated PLWHA care
Volunteers: Community caregivers, social groups, etc.	Continued care at home and in community Support Networking Education	Facts about HIV/AIDS prevention and control PLWHA care procedures Death and dying Infection control Elements of PLWHA care and support
Family members	Continued care Support Education Counselling Advocacy	Facts about HIV/AIDS Nursing care procedures Drug compliance Counselling Death and dying Infection control Legal rights
PLWHAs	As above for family members	As above for family, plus self-care



6

RESOURCE MOBILIZATION

Resource mobilization entails identifying and using all available services or goods required to meet the identified needs of the PLWHA, family, and community. Resource mobilization is essential to ensure that the set goals at various levels of home-based care are achieved.

There are definite constraints that can affect resource mobilization. These include:

- The financial status of the family and the community. They may not have money to buy drugs and other materials.
- The social stigma attached to HIV/AIDS. This may influence other community members who might shy away from or refuse to be associated with persons with HIV/AIDS and their families.
- Cultural beliefs and fears about AIDS.
- Associating AIDS with witchcraft.

6.1 Types of Resources Needed for Effective and Sustainable Care

Necessary resources can be considered in 3 categories (the 3 M s): manpower (the people needed), material (the goods, services, and financial support), and moments (the time required). These are discussed in turn.

6.1.1 Manpower - People and Their Willingness to Participate

These are the individuals who voluntarily spare their time to assist the PLWHA or the PLWHAs family and children. Persons who can be counted as human resources include:

- Health workers at all levels
- Family members, relatives/friends
- Community leaders like Maendeleo Ya Wanawake Organization leaders

The 3 M s of resource needs

- Manpower
- Materials
- Moments

- Spiritual, political, and administrative leaders like sub-chiefs
- Community volunteers

In late stages of the disease, PLWHAs become too weak to support themselves. This condition calls for continuous assistance from relatives and friends. A volunteer care provider also needs continuous support from the community, morally and materially.

6.1.2 Material - Necessary Goods, Services, and Financial Assistance

AIDS is a long, expensive, debilitating illness. It eventually renders the PLWHA incapable of meeting even the most basic material needs of everyday life. The PLWHA becomes too weak to fetch water or firewood, or to run errands and do shopping. Children may drop out of school for lack of fees, food production and storage will be minimal, and frequent sickness from opportunistic infections will strain the family income. Thus, the material resources required to assist can be in form of food, cooking fuel (e.g., firewood), water, or money for drugs and other purposes.

Friends, family, and members of the wider community could be mobilized to provide food and other needs like drugs or even organize a *harambee*. This will not only assist the PLWHA but also the children or other needy dependents of the PLWHA. It is important for the family caregivers and support groups to know when and where to seek the assistance they need.

6.1.3 Moments - The Time Required

Caring for people who are infected or affected by HIV/AIDS can be very time consuming, and emotionally draining. The caregiver may have little time left to tend to other important aspects of everyday life, like working on the *shamba*, going to the job or office or school, or running errands. The constant demands are very stressful. HIV-positive persons themselves are also under stress, and often in pain. Being

present is a major source of psychological and moral support, and friends and relatives should understand the importance of sparing time not only to help out as needed, but just to be with the PLWHA and the family members.

6.2 Sources of the Required Resources

Resources are required at every level of the home-based care continuum. And, the players at every level should be expected to contribute to the extent possible.

6.2.1 From the Individual

- The home environment
- A home care kit (depending on specific needs)
- Time to devote to care and support
- Sharing of information and experience and advocating for behaviour change
- Cooperation and openness so as to share responsibility and confidentiality

6.2.2 From the Family

- Basic needs, e.g., food, clothing, shelter, medicine
- Time, knowledge, and skills of caring
- Social/psychological support
- Physical care
- Financial support
- Administration of medicine

6.2.3 From the Community

- Social support
- Spiritual support
- Material support
- Financial support
- Time, knowledge, and skills of caring

6.2.4 From the Nation

- Social support through political commitment
- Adequate financial support to national home-based care programmes
- Essential drugs for opportunistic infections at the primary health care level
- Advocacy
- Training and supply of drugs to strengthen the capacity of primary health care providers to properly manage people with HIV/AIDS

6.3 How to Mobilize the Identified Resources

Home-based care is a collaborative partnership in providing care and support to the infected and the affected. The affected in this case are the close dependents of the PLWHA children, spouse, etc. Needs are identified, as well as potential partners who can assist. Examples of partners in home-based care are the individual PLWHA, health workers, community, family member(s), and social leaders.

The CACCs are mandated to take the lead in identifying and mobilizing community resources

Figure 6.1: Resources from the family

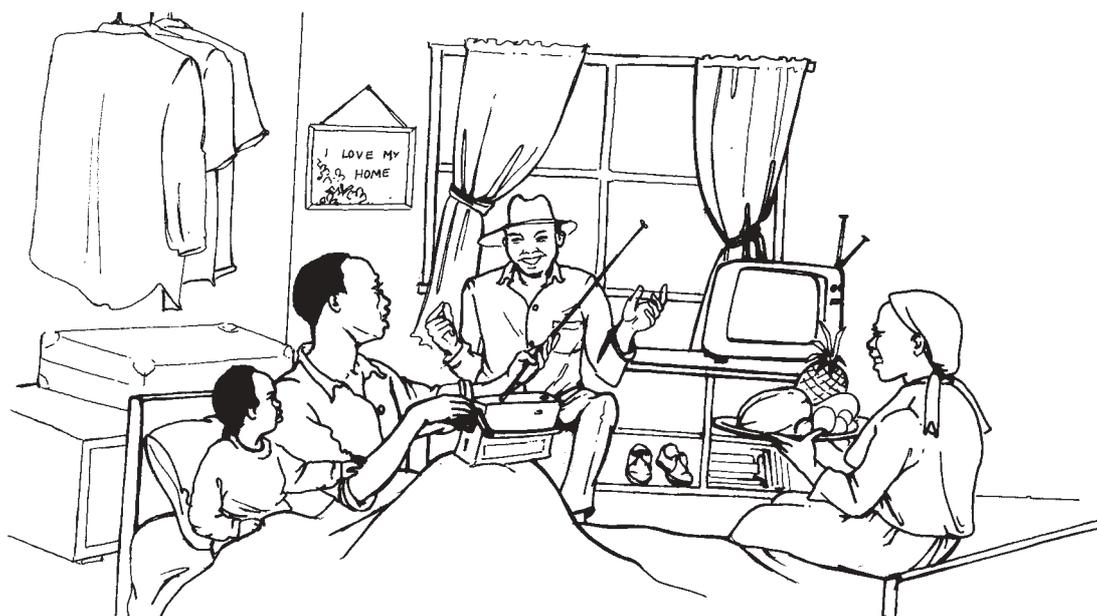


Figure 6.2: Resources from the community



at the local level. They should work closely with private sector and non-government organizations in the area.

6.3.1 Individual

Through counselling and education, the PLWHA will be sensitized to accept the conditions of the HIV status, and to contribute to the extent possible in self-care by:

- Using available resources to assist in making up a care kit that will be availed to the family caregiver to ensure good nursing care.
- Summoning the will to live positively.
- Realizing that home-based care is essential for continuity of care and therefore being ready to consult the health/community health worker to visit at the agreed time.
- Empowering the family caregiver to provide the needed care and attention.
- Learning where to go for information and advice on care of PLWHAs.
- Advocating for acceptance and behaviour change.

6.3.2 Family

The caregiver and the family should be involved and educated about the needs of the individual PLWHA, and to be ready to meet some of these basic needs, by:

- Providing social/psychological support by accepting and not rejecting the PLWHAs because of HIV/AIDS.
- Learning where to go for information and advice on care of PLWHAs.
- Taking the responsibility to administer drugs as prescribed.
- Using available resources to assist in making up a care kit to ensure good nursing care.

6.3.3 Community

Through community counselling and sensitization to accept the PLWHA as one of them and to give social support to PLWHAs and their families, communities assist by:

- Involving the spiritual leader through consulting the PLWHA.
- Providing material support like cooking fuel and water for use in the home.
- While the PLWHA is still strong, accepting them in support groups whereby they will be involved in income-generating activities.

- Using land properly and producing food to ensure the PLWHA is properly catered for.
- Encouraging community members to work together to link with other organizations like donors, NGOs, CBOs, institutions, health facilities, and professionals for referral and networking systems. This will help in providing food, drugs, and IEC materials.
- In case the PLWHA is a parent, ensuring that the children get what they were getting before the parent fell sick. It can be very depressing for the PLWHA to be looking to a future where the children lack food, clothes, school fees, etc.

6.3.4 The Nation

Political leaders who are sensitized on the impact of HIV/AIDS in the community, and committed to do their part to combat the epidemic, will be able to mobilize the general public, who in turn will give social/physical support to the people.

6.4 Sustainability

A number of measures can be taken to promote the sustainability of services to PLWHAs and their families. To ensure this happens, home-based care programmes should make provisions for:

- Helping the community to identify with the problems of PLWHAs through barazas, churches/mosques/temples, and other social gatherings. This will motivate them to accept the sick and the related interventions.
- Encouraging a multi-disciplinary involvement of all government ministries to improve land use and increase food production.
- Participating in and collaborating with the local CACC to ensure the full benefit of community support to PLWHAs and their families.
- Empowering the family and the community to use locally available resources.
- Training community on aspects of care and infection control at home.
- Monitoring and evaluating HBC activities through spot checks and field reports to ensure that programme objectives are met.
- Encouraging regular meetings for the community to discuss issues related to HIV/AIDS.
- Empowering communities to establish income-generating activities to support the provision and replenishment of home care kits for needy PLWHAs/families.



7

REFERRAL AND NETWORKING SYSTEMS

Referral is an effective and efficient two-way process of linking a patient/client from one caring service to another. Referral and networking are essential to ensure continuity of quality care for the PLWHA at all times.

7.1 Why Referrals Are Necessary

Referring a PLWHA will be deemed necessary:

- When services or resources within reach are not able to meet the PLWHA's immediate needs.
- In cases where the acute phase of the PLWHA's care has been dealt with and it is considered safe to transfer care to other caring services/organizations within the community.
- When the caregiver experiences burnout and has no access to counselling services for personal growth.
- When the caregiver has limitations in meeting certain needs of the PLWHA, e.g., based on religious beliefs.
- For better, more competent management in the next stage of referral.
- For specialized care in a hospital setting, especially if the PLWHA is deteriorating.
- For continuity of care from the health facility downwards or from family level back to the health facility.

7.2 Appropriate Referral Points

There are many different referral points, depending on the level and type of care or service required. These include the following:

- Recognized health institutions
- Social support groups
- Spiritual leaders
- Legal agencies and local administration, e.g., for writing wills, settling property

 **Referrals expand capacity and improve care**

disputes, and addressing burial disputes/arrangements.

- Any other relevant agencies depending on the client's needs.

7.3 Constraints/Limitations in Referral and Networking

Despite the importance of referral and networking processes, there are many constraints to their effectiveness, including:

- Competition among various organizations so that they don't disclose what they are doing/ services offered, as they prefer to work in isolation.
- Lack of evenly distributed community home-based care programmes, with the result that some areas lack services and some are overcrowded.
- Lack of resources needed for PLWHAs to travel from one point to another.
- Lack of referral and networking guidelines and standardized referral procedures.
- Ignorance among family members about home-based care due to lack of awareness and proper guidance.
- Fear of breach of confidentiality.
- Stigma and discrimination associated with HIV/AIDS, which makes PLWHAs reluctant to accept referral to certain facilities.
- Poor mobilization and sensitization of partners.
- Lack of confidence in the institution/service where referral is made.
- Lack of updated and proper directory of referral and networking.
- Lack of knowledge by people referring on how and when to refer or network.
- Cultural, social, religious, and economic factors.

7.4 Solutions to Referral Constraints

Health care workers can address the constraints by taking the following steps:

- Hold collaborative meetings among various referral and networking partners.
- Give correct/proper information on referral to the PLWHA and a proper client history to the referral point.
- Ensure confidentiality.
- Lobby and advocate for the rights of PLWHAs.

At a wider level, it is necessary to:

- Establish and distribute a standardized and up-to-date directory on referral and networking points.
- Establish standard referral and networking systems where they do not exist.
- Strengthen the existing referral and networking systems.
- Develop standardized referral and networking procedures involving all the components of care.
- Build national capacity in referral and networking for home-based care at all levels using standardized guidelines.
- Lobby and advocate for the rights of PLWHAs.

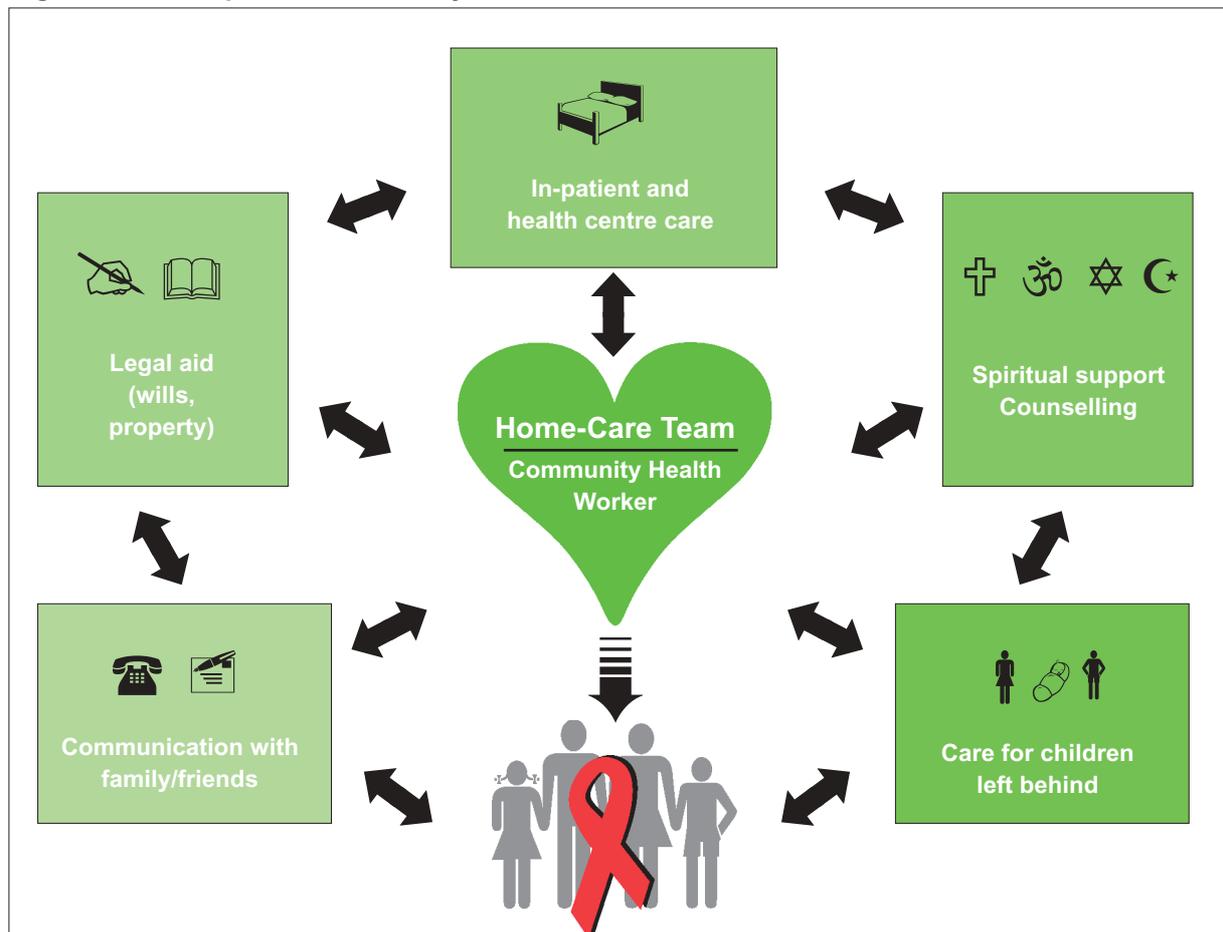
The ACCs at district and local levels will take a lead role in developing the referral network, working closely with NGOs/CBOs operating in the area.

7.5 The Referral Framework

The DHMTs and DACCs will work closely with the CACCs and local home-based programmes to identify appropriate referral points for the range of services likely to be needed by PLWHAs and their families medical, legal, social, spiritual, etc. Within each home-care team a specific team member will be designated as the responsible for ensuring that referrals are done promptly and appropriately. The community health workers on the home-care teams will be trained to recognize the need for referrals, to consult as needed to determine the source of required services, and to assist the PLWHAs and their families to make the necessary contacts.

Figure 7.1 illustrates a simplified home-based care referral system.

Figure 7.1: A simple HBC referral system





8

MONITORING AND EVALUATION

The broad objectives of home-based care, as detailed in Chapter 2, form the basis for programme monitoring and evaluation and can be refined and modified to suit various contexts. In each case, the specific objectives should be clearly measurable.

Monitoring is the ongoing process of reviewing planned activities to ensure they are carried out in such a way that the goals and objectives of a particular intervention are likely to be met. Monitoring can be achieved through spot checks at given intervals throughout the project time frame. **Evaluation** is the process of assessing actual progress toward goals and the impact of programmes on target groups.

Evaluations are usually scheduled to cover specific periods or aspects of programme implementation. For example, a midterm evaluation covers progress during the first half of the timetable, while a final impact evaluation would look at the entire period of the programme. A process evaluation might cover elements of, say, training. Evaluations can be based on activity schedules, reports, budget reviews, client surveys, and other data.

The District HBC Committees are responsible for monitoring and evaluating the various home-based care programmes in their areas to ensure compliance with NASCOP guidelines and standards and to maintain service quality. The DACCs are responsible for monitoring the implementation of HIV/AIDS policies in their respective areas of jurisdiction. At the local level, the CACCs are charged with the development and implementation of monitoring and evaluation (M&E) systems for AIDS related activities within their own areas. CACCs must also submit quarterly and annual reports on activities to NACC.

All home-based care programmes should include provision for M&E to ensure that quality services are provided in a timely, effective, and cost-effective way. This chapter offers broad

monitoring and evaluation guidelines, but individual programmes should adopt or adapt M&E systems that are appropriate to their needs.

8.1 What Is Monitored and Evaluated in Home-Based Care

The whole range of assumptions and activities of the HBC programme should be monitored and evaluated. Questions to ask when deciding what to monitor and evaluate include:

- How many PLWHAs/families are benefiting from the programme?
- How many community health workers and other volunteers have been trained to participate in the programme?
- What is the level of quality, practicability, and effectiveness of the HBC services provided, including for voluntary counselling and testing and prevention of mother-to-child transmission of HIV?
- What is the level of progress of the PLWHA, e.g., social, physical?
- What services and supplies are provided?
- How practical are the HBC interventions?
- What is the acceptance level of HBC by the PLWHAs, family, community?
- How well do referral and networking systems work?
- How effectively and efficiently have the financial resources been used, especially for funded programmes?
- Has the programme complied with monitoring and evaluation requirements?
- What are the short- and long-term effects of the programme (e.g., behaviour change)?
- How has the community responded to the HBC programme?

8.2 Objectives of Monitoring and Evaluation in Home-Based Care

Overall, monitoring and evaluation of HBC activities have the following goals:

- To ensure that guidelines in the provision of HBC are being adhered to.
- To assess the impact of the programme on the affected and the infected.
- To assess the viability of the programme to help in making alterations and substitutions for the success of the programme.
- To help identify constraints and possible solutions.
- To establish proper organizational structures for supervision purposes.
- To enhance accountability and transparency.
- To document programme activities and progress.
- To identify best practices with the idea of replicating them to the extent possible.

8.3 How Monitoring and Evaluation Are Done in Home-Based Care

The processes of monitoring and evaluation in HBC are similar to those for other activities. They include:

- Data collection: Observation, interviews, home visits.
- Literature review: Existing reports/records.
- Meetings: Especially collaborative meetings among stakeholders.

8.3.1 Who Monitors and Evaluates HBC Programmes

Monitoring and evaluation can be either internal or external.

Internal Monitoring and Evaluation

This is done by the programme implementers as part of their planned activities within the programme period. Internal monitoring and evaluation depend on the competence, commitment, and integrity of the implementers. Results can sometimes be very biased and may not be very reliable to work with.

External Monitoring and Evaluation

This is done by outside personnel who have no personal interest in the programme. The fact that the personnel conducting the monitoring and evaluation are external, and in most cases strangers to the project, usually makes results more reliable and gives a less biased picture.

8.3.2 Levels of Monitoring and Evaluation

Monitoring and evaluation can take place at various levels:

- **PLWHA:** This is based on self-assessment of physical and emotional/spiritual condition, quality of life, etc.
- **Family level:** Starting with the caregiver, relatives, and friends. These parties give each other feedback on the progress of the programme based on their assessments of how the PLWHA has been helped.
- **Community level:** This involves all stakeholders, e.g., spiritual leaders, local administration, CBOs, NGOs, etc.
- **Health facility level:** At this level all the professionals implementing the components of home-based care are involved.

8.3.3 A Sample M&E Framework

Within the broad questions considered in Section 8.1, a monitoring and evaluation system can immediately focus in on three main indicators of programme effectiveness:

- Number of PLWHAs/families participating
- Number of community health workers trained
- The quality of care provided to PLWHAs and families

As the programme gains experience, it can begin to consider other elements, such as level of community support, financial sustainability, and impact of prevention messages.

Reporting Requirements

NASCOP will provide guidance on collecting and reporting the data required for ongoing programme monitoring. Day-to-day data

Quality of care indicators

- Is the PLWHA's environment clean?
- Is the bed clean?
- Is the PLWHA displaying a good standard of hygiene?
- Are sores/wounds properly dressed?
- Does the PLWHA report positively on quality of life, relationships, etc.?
- Do family members report positively on quality of life, relationships, etc.?

collection will begin with the community health worker, who will report to the Team Leader through the care coordinator. The care professionals on the team will have

responsibility for routine monitoring of the quality of care of the PLWHA, as indicated by the person's condition and self-assessment.

Minimum M&E Requirements

At minimum, the programme should plan an M&E system that consists of the following:

- **Weekly** reports of home care activities (compiled by CHW)
- **Monthly** assessment of PLWHA's condition (monitored by team professionals)
- **Quarterly** assessment of programme operations to review records and check the effectiveness of referral network (coordinated by Team Leader)
- **Annual** evaluation of programme operations and impact (carried out by an external evaluator) to assess:
 - Community participation
 - Coverage
 - Potential for sustainability
 - Indications of behaviour change

8.4 Constraints/Limitations to Monitoring and Evaluation

Among the problems that constrain proper monitoring and evaluation are:

- Lack of proper records.
- Falling short of schedule or lack of a schedule.
- Inability to formulate or develop M&E tools, e.g., for data collection.
- Lack of proper budgeting.
- Reluctance to undertake the M&E activity.
- Unwillingness of the family and the community to participate in the M&E process.
- Lack of finances.
- Poor organization structure for supervision purposes.
- Improper accountability and transparency
- Delays in presentation of required documents.
- Poor management information systems.
- External factors interfering with implementation of planned scheduled activities.
- Uncooperative beneficiaries in the programme (e.g., spouse threatening care providers, therefore forcing them to withdraw).

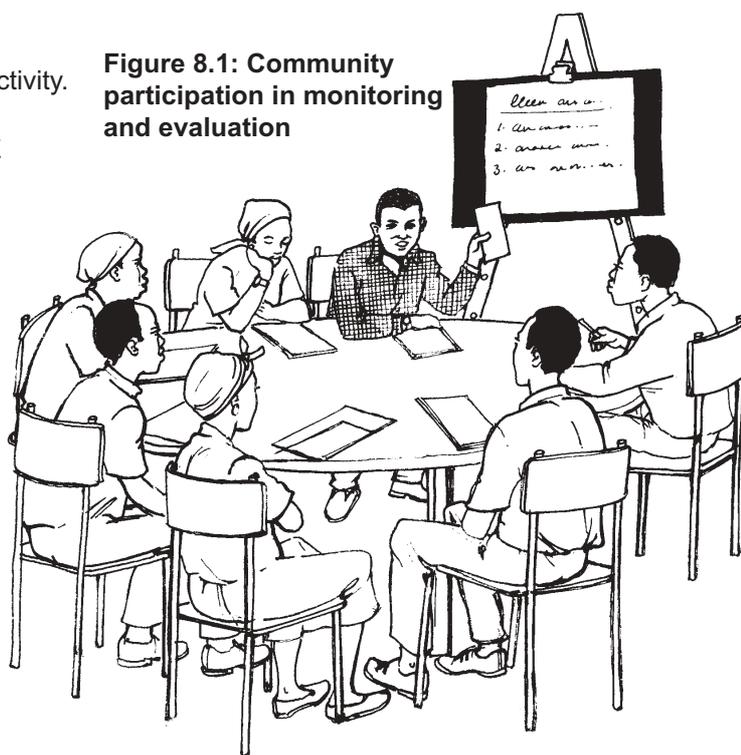
- Care provider burnout as a result of lack of support from the immediate supervisor.

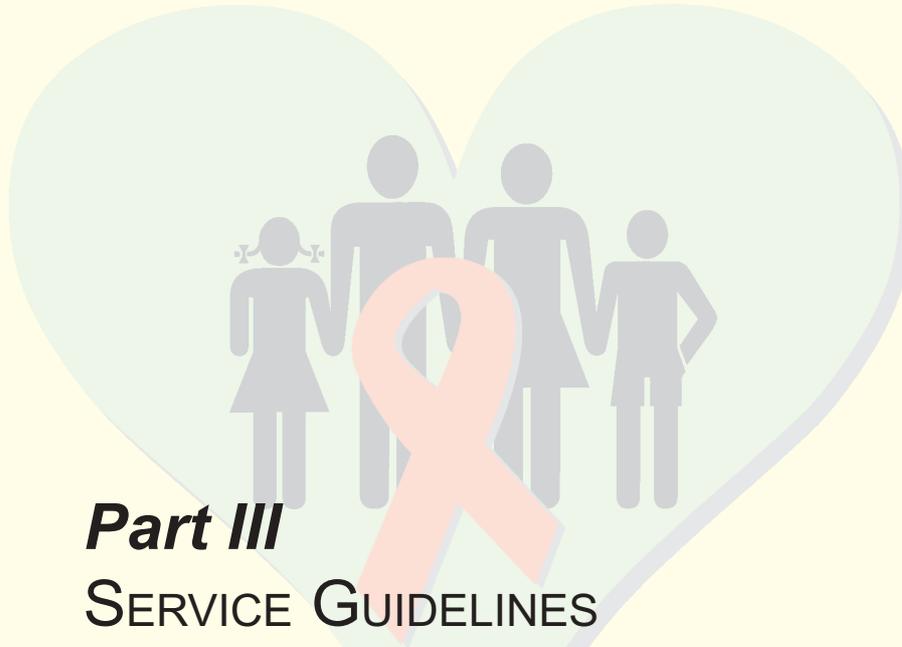
8.5 Solutions to Constraints

Monitoring and evaluation help to identify problems and opportunities in programme management. By the same token, they are themselves facilitated by proper programme management, including:

- Adherence to proper systems for accountability and transparency.
- Proper management information systems.
- Proper organizational structures for supervision.
- Adequate financial and other resource mobilization.
- Proper documentation of project activities.
- Establishment of and adherence to a time schedule for the programme.
- Appropriate IEC for sensitizing the community to undertake the activity and participate in it, i.e., to own it.
- Proper training, education, and motivation for all caregivers at all levels.
- Support from immediate supervisors especially in availing resources necessary to enable caregivers to undertake given activity.
- Proper schedules for meetings of all stakeholders to enable all to be participating without fail (i.e., by avoiding impromptu meetings).

Figure 8.1: Community participation in monitoring and evaluation





Part III

SERVICE GUIDELINES

9 Clinical Care

- 9.1 Objectives of clinical care
- 9.2 Case definition of AIDS
- 9.3 Drug administration
- 9.4 Common symptoms of HIV/AIDS
- 9.5 Skin problems
- 9.6 Respiratory tract infections
- 9.7 Genital problems
- 9.8 Gastro-intestinal tract problems
- 9.9 Central nervous system problems

10 Nursing Care

- 10.1 Components of nursing care
- 10.2 Home nursing
- 10.3 Home care kits
- 10.4 Nutritional needs of PLWHAs
- 10.5 Caring for a child with HIV infection or AIDS
- 10.6 Nursing management of common AIDS conditions in the home
- 10.7 Helping with elimination (toilet) needs
- 10.8 Physical therapy
- 10.9 Infection prevention

11 Counselling and Psycho-Spiritual Care

- 11.1 Spiritual/pastoral care and support
- 11.2 Social support
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12 Palliative and Terminal Care

- 12.1 Palliative care
- 12.2 Terminal care
- 12.3 Networking in the provision of palliative and terminal care
- 12.4 Care after death
- 12.5 Follow-up services for family members left behind



9

CLINICAL CARE

Clinical care in the context of home-based care is the continuation of medical care in the home. The idea is to ensure the continuity of the care and treatment the PLWHA was receiving from the health facility. This is what at times is referred to as the continuum of care. It is collaborative care provision by the health care workers, the family members, and the community.

9.1 Objectives of Clinical Care

The continuum of clinical care in home-based care has the following aims:

- Ensuring early detection and treatment of opportunistic infections and other complications that occur as a result of HIV/AIDS.
- Reducing the suffering from conditions associated with the HIV/AIDS infection.
- Protecting the patient against further infections especially during a long hospital stay.
- Preventing transmission of HIV or other opportunistic infections from PLWHAs to health workers, relatives, and friends.
- Ensuring that drugs prescribed to the PLWHA by the clinician are administered at home according to the regimen of intake.

People with HIV/AIDS take long to heal and therefore prolonged hospital stays are inevitable. Because of their lowered immunity, there is increased risk of acquiring other infections within the hospital setting. This can be avoided if the hospital stay is limited and continuous care is provided at home.

9.2 Case Definition of AIDS

When an individual contracts HIV, they appear completely normal until their immune status starts to go down. The duration between infection and the development of AIDS-related symptoms varies greatly among individuals.

Several signs and symptoms have been used to define AIDS. The World Health Organization (WHO) has grouped them into major and minor signs. The presence of at least two major signs and one minor sign is enough to diagnose AIDS in an adult.

Similar criteria have been established for children. AIDS in children is suspected with at least two major and two minor signs and in the absence of known cause of immunosuppression.

Note that children with malnutrition and respiratory or gastrointestinal infections can present with similar features.

9.3 Drug Administration

Drugs can be administered at home at the same times and frequency they were given to the PLWHA at the hospital. The health care worker should be able to educate and counsel the PLWHA or the family caregiver on the need for drug compliance and the timings. For example, people tend to count the frequency of taking medicines during the day time without considering the many hours of the night. Such

Signs of AIDS in Adults

Major signs:

- Unexplained 10% weight loss in less than 1 month
- Persistent diarrhoea for over 1 month
- Fever for over 1 month

 The presence of at least 2 major signs and 1 minor sign is enough to diagnose AIDS in an adult.

Minor signs:

- Cough for over 1 month
- General pruritic dermatitis
- Recurrent Herpes zoster
- Candidiasis (thrush) of the mouth
- Generalized enlarged lymph nodes
- Disseminated progressive Herpes simplex

— WHO

🚫 Signs of AIDS in Children 🚫

Major signs:

- Weight loss or abnormally slow growth
- Chronic diarrhoea for over 1 month
- Fever for over 1 month

🚫 The presence of at least 2 major and 2 minor signs is enough to diagnose AIDS in a child in the absence of known cause of immuno-suppression.

Minor signs:

- Recurrent common infections like otitis media, pharyngitis, tonsillitis, etc.
- Generalized enlarged lymph nodes
- General pruritic dermatitis
- Candidiasis (thrush) of the mouth or throat
- Cough for over 1 month
- Confirmed maternal HIV infection

— WHO

Figure 9.1: Drug administration and timing



irregular taking of medicines especially antibiotics leads to serious resistance of organisms to drugs. (See Figure 9.1.)

Guidelines for the administration of anti-retrovirals generally and those for prevention of mother-to-child transmission are available from NASCOP.

Guidelines for the administration of pain medication are based on the WHO 3-step analgesic ladder (1: acetaminophen, ibuprofen, paracetamol, aspirin; 2: codeine phosphate; 3: morphine sulphate).

9.4 Common Symptoms of HIV/AIDS

Some of the common symptoms of HIV/AIDS are shown in Table 9.1; others are described in the paragraphs that follow.

Table 9.1: Common symptoms of HIV/AIDS

<p>General symptoms</p> <ul style="list-style-type: none"> General malaise Loss of weight Pain Swollen glands Swelling of the limbs Hair loss 	<p>Gastrointestinal tract</p> <ul style="list-style-type: none"> Diarrhoea Difficulty in swallowing Poor appetite Sore mouth Nausea and vomiting Abdominal pain
<p>Skin and hair</p> <ul style="list-style-type: none"> Itching Boils Rashes, ulcerations, wounds Infections due to bacteria, fungi, and viruses Diffuse hair loss, thinning of the hair, early greying (causes of hair change range from nutritional imbalances to chemotherapy, infection, and HIV itself) 	<p>Central nervous system</p> <ul style="list-style-type: none"> Headache Memory loss and confusion Tingling and numbness of limbs Convulsions, confusion, coma Weakness of one side of the body Anxiety and depression
<p>Chest</p> <ul style="list-style-type: none"> Fever Cough Chest pain Difficulty in breathing 	<p>Genitalia</p> <ul style="list-style-type: none"> Discharge Ulcers Pain on passing urine

9.5 Skin Problems

About 90% of people with HIV infection will develop at least one skin problem in the course of the disease. Knowing these conditions will assist in early case detection and treatment. This will help in counselling for safer sexual behaviour, early detection and treatment of opportunistic infections, and control of HIV spread.

These skin problems can be due to:

- Fungal infections: ringworm, cryptococcus
- Bacterial infections: impetigo, folliculitis, abscesses
- Viral infections: Herpes zoster, warts, Molluscum contagiosum
- Parasites: scabies, body lice
- Atypical presentations of dermatoses: psoriasis, pruritic papular eruptions, seborrhoeic dermatitis, etc.
- Allergies: to drugs, the sun's rays, eczema
- Tumours: Kaposi's sarcoma or lymphomas

9.5.1 Management of Common Skin Conditions

The management of the more common skin problems is summarized in Table 9.2 for both home and facility care.

9.5.2 Other Skin Problems with HIV/AIDS

Other skin conditions the PLWHA may present with include the following:

Molluscum Contagiosum

This is an infection caused by pox virus. It is common in children but immune suppressed adults are more seriously affected. It presents as raised, umbilicated, skin-coloured nodules, which often ulcerate leading to secondary infection.

Hygiene of skin should be observed. Treatment is only necessary for cosmetic reasons or for symptomatic lesions. Treatment can be with phenol cryotherapy with liquid nitrogen. The skin should be kept clean and dry especially if there is secondary infection. Antibiotics are necessary if there is systemic involvement like fever.

Drug Eruptions

May follow use of co-trimoxazole, amoxicillin, penicillin, isoniazid (INH), or Dapsone. Skin reactions can vary in presentation from mild skin

rash to very severe, even fatal, blistering Steven—Johnsons syndrome. This involves blistering of skin and mucus membranes.

What to do at home:

- Stop the medication and immediately refer to the health facility.
- Carry all the medication the patient was on.

What to do at the health facility:

- Depending on the severity, hospitalize and use corticosteroids in severe cases.

Kaposi's Sarcoma

This is the commonest malignant tumour associated with HIV/AIDS. It used to be a tumour affecting the elderly, but with the advent of HIV/AIDS there is an upsurge of an aggressive type that affects much younger people, spreads faster, and is therefore referred to as Epidemic Kaposi's sarcoma.

Kaposi's sarcoma presents as purple-red nodules under the skin, oral mucosa, nose, or even the conjunctiva. The skin lesions in themselves do not often cause problems. Observe skin hygiene in the presence of exudates and secondary bacterial infections.

At the health facility:

- Treat severe or generalized lesions with chemotherapy, e.g., vincristine.
- Consult a medical specialist for the chemotherapy.

9.6 Respiratory Tract Infections

The upper respiratory system includes the nose, sinuses, pharynx, and throat. Infections of the upper respiratory tract that the PLWHA may commonly present with include common colds, sinusitis, sore throat, and tonsillitis.

Lower respiratory tract infections involve the bronchi and bronchial tree and the lungs. The infections may affect some or all the organs at the same time with the most common ones being bronchitis and pneumonia.

General presentations in chest problems are described below.

Table 9.2: Management of common skin problems in HIV/AIDS

Condition	Home management	Hospital management
General skin conditions	<ul style="list-style-type: none"> • Keep skin clean. • Wash with soap and water. • Keep nails short to avoid damaging the skin during scratching. • Use flat part of hand to rub if itchy, not nails. • Cool the skin with water or fan in severe itching. • Apply lotions, e.g., calamine lotion, on weeping lesions. • Use any local herbal remedies that are effective. • Apply petroleum jelly (e.g., Vaseline) or glycerine if the skin is dry. • If it is a child or a mentally confused adult, put gloves or socks on their hands to prevent skin damage due to scratching. 	<ul style="list-style-type: none"> • Give antibiotics if skin is septic and associated with systemic symptoms like fever, general malaise. • Provide strong pain relievers in severe cases, e.g., Herpes zoster. • Keep discharging lesions dry with solutions such as potassium permanganate, salted water, Dettol, hibitane lotion. Avoid greasy ointments.
Fungal infections	<ul style="list-style-type: none"> • Use Whitfield ointment or Nystatin. If no improvement after 2 weeks refer to hospital. • Continue treatment for 10 days after clearance of symptoms. 	<ul style="list-style-type: none"> • Use clotrimazole, miconazole, fluconazole, or ketoconazole • Use oral antifungal, e.g., griseofulvin tablets, for fungal infections of the hair (for 1 month) and nails (for 3 months).
Bacterial infections	<ul style="list-style-type: none"> • Wash the skin with soap and water or salty solution. • May also use antiseptic, e.g., Dettol or gentian violet paint. 	<ul style="list-style-type: none"> • Take a swab for bacterial culture if there is no response to treatment. • In severe infection, administer parenteral antibiotics. Commonly used antibiotics include ampicillin, penicillin, amoxicillin, augmentin, cloxacillin, tetracycline, and erythromycin • For infections that do not respond to the antibiotics listed above, try cephalosporin. • Perform surgical drainage if required for abscesses.
Viral infection (general)	<ul style="list-style-type: none"> • Keep lesions clean with soap and water. • Apply topical antiseptic agents, e.g., gentian violet. <p>➡ Refer to hospital:</p> <ul style="list-style-type: none"> • PLWHA with genital or peri-anal herpes. 	<ul style="list-style-type: none"> • For specific treatment, give acyclovir if available. • Use antibiotics if lesions are infected. • Keep wet or weeping lesions dry with solutions such as potassium permanganate, salty water, or normal saline.
Viral infection (specific)	<p>Herpes simplex / zoster</p> <ul style="list-style-type: none"> • In both Herpes zoster and Herpes simplex, keep the rashes clean and dry. • Apply local topical remedies to relieve pain. • Give paracetamol or ibuprofen for pain. <p>➡ Refer to hospital:</p> <ul style="list-style-type: none"> • PLWHAs for Herpes zoster of face or eyes, or for severe post hepatic neuralgia. 	<ul style="list-style-type: none"> • Give acyclovir if the lesions are fresh or in widespread herpes zoster and also if on the face. • Treat herpes neuralgia with anti-epileptic drugs, e.g., carbamazepine or phenytoin and amitriptylline.
Parasitic infections (scabies)	<ul style="list-style-type: none"> • Apply benzyl benzoate emulsion to the entire body except the face. • Treat all family members even if they have no symptoms. • Clean clothes regularly with soap and hot water and dry them in the sun. Ironing can kill the mites. 	<ul style="list-style-type: none"> • Scabies can be infected and become wounds. Clean with antiseptics like hibitane. • Treat infected scabies with antibiotics if necessary.

9.6.1 Upper Respiratory Tract Infections

Common Cold

An acute inflammation of the airways, nose, paranasal sinuses, throat, and larynx; in some cases may extend down to the bronchi as complication. Symptoms include blockage and running of the nose, sneezing, sore throat, general malaise, and headache. Unless the bronchi have been involved, common colds will resolve in 7–10 days. Give pain relieving tablets like paracetamol if necessary. Encourage plenty of oral fluids.

Tonsillitis

Inflammation of the tonsils and/or the pharynx, usually caused by bacteria, particularly streptococcus, or viruses. Symptoms include painful swallowing, fever, general malaise, muscle pains, and conjunctivitis especially if it is due to viral infection. Children can present with fever, diarrhoea, and vomiting.

What to do at home:

- Give pain killers for pain.
- Encourage plenty of fluids because PLWHAs with fever tend to lose water through perspiration.
- Refer children with sore throats for early treatment because they can lead to serious complications of rheumatic heart disease.

Seek help when:

- There is pus on the tonsils or associated fever and general weakness.

Sinusitis

Inflammation of the sinuses, due either to infections or to an allergic reaction. Symptoms of allergic sinusitis include watery nasal discharge, sneezing, and blockage of nostrils with pale or bluish mucosa. In bacterial infections there is purulent discharge, fever, and frontal headache or tenderness on the sides of the nose. If discharge is from one nostril only, the presence of a foreign body should be ruled out. Management of sinusitis is usually with antibiotics and antihistamines.



**Don't take colds for granted!
They can lead to bigger problems!**

9.6.2 Lower Respiratory Tract Infections

The lower respiratory tract is composed of trachea, bronchi, bronchiole, and alveoli. Inflammation of these structures can present with chest pain, cough, and difficulty in breathing. These structures can be affected singly or in combination. Depending on the structure affected, the infection can be on the bronchi, causing bronchitis, or part or all of lung tissue causing pneumonia.

The management of common chest problems in PLWHAs is summarized in Table 9.3, while treatments for some specific lower respiratory problems are given below.

Bronchitis

Caused by either virus or bacteria. Viral causes include influenza and para-influenza. Bacteria cause streptococcal pneumonia. This is common in children, but adults can be affected too, especially smokers. Patients present with cough that is dry at first and becomes productive later. If wheezing is present then it is due to asthma or, in children, to bronchiolitis.

Management is advice to take plenty of fluids and avoid irritants like cigarette smoking. If cough is disturbing, give anti-cough syrups like Piriton. Note that because most causes are viral, treatment is only symptomatic. If the cough is productive, brownish, and associated with fever and general malaise, then the patient could be referred for review and antibiotic treatment. It is important to realize that HIV infected individuals develop frequent infections and early review and treatment will avoid further complications of bronchitis extending to develop into pneumonia.

At the health facility:

- Give amoxicillin 500 mg x 3 daily for 5–7 days. If allergic to penicillin, then give erythromycin 500 mg x 4 daily for 5–7 days. Other drugs are cotrimoxazole or tetracycline.
- Counsel the PLWHA on drug compliance and the importance of avoiding offending substances like cigarettes.

Pneumonia

Inflammation of the lung tissue due to infection. It can be in one segment of the lung (lobar pneumonia) or diffuse. The organisms often involved are Streptococcus pneumoniae or Haemophilus influenzae. The clinical

presentation of pneumonia in HIV infected persons is similar to that in uninfected persons.

However, lung involvement and the disease are more severe in HIV infected individuals. The PLWHA complains of difficulty in breathing, cough that may be productive, bright yellow or blood stained sputum, and fever. Chest pain may be generalized or more to the affected side in case of lobar pneumonia.

What to do at home:

- Educate people to identify signs and symptoms and refer the PLWHA to a health facility immediately for review and treatment. Because of fever, patients tend to lose a lot of water through perspiration and therefore should be encouraged to take plenty of fluids like *uji, tea*, etc.

Table 9.3: Management of common chest problems

Condition	Home management	Hospital management
Sore throat and tonsillitis	<ul style="list-style-type: none"> • Encourage plenty of oral fluids. • Give paracetamol for pain. • Have PLWHA gargle with warm water mixed with a little salt. • For children, give small frequent feeds; if breastfeeding, breastfeed more frequently. <p>☛ Refer to hospital:</p> <ul style="list-style-type: none"> • If throat or tonsils have yellowish spots of pus. • Children who also have diarrhoea and vomiting (see also Section 9.8.4). 	<ul style="list-style-type: none"> • Treat with penicillin to prevent complications like rheumatic heart disease. • Give rehydration therapy in cases of diarrhoea and vomiting. • Manage retro-pharyngeal abscess.
Cough	<ul style="list-style-type: none"> • Distinguish between productive (wet) and dry cough. Wet coughs can be due to infection. • Reduce irritants, e.g., smoking. • Elevate with pillows to semi-sitting position if this helps relieve the difficulty in breathing. • For a cough that is dry and irritating: Soothe the throat by drinking tea; use a safe home-made cough syrup; try commercial remedies if affordable. <p>☛ Refer to hospital:</p> <ul style="list-style-type: none"> • If the cough does not respond to home remedies and lasts more than 2 weeks. • If cough involves other symptoms, e.g., spitting up blood, pain in the chest, or breathing difficulties and fever. 	<ul style="list-style-type: none"> • If cough persists for over 2 weeks, investigate for the various causes of cough, e.g., sputum for AFB, chest X-ray. • Use bronchoscopy if diagnosis is doubtful or there is no response to treatment. • <i>Treatment depends on the cause of the respiratory symptoms.</i> • Elevate to semi-sitting position if it is of benefit to the PLWHA. • Investigate prolonged productive cough that lasts more than 2 weeks for tuberculosis.
Chest pain	<ul style="list-style-type: none"> • Apply warm compresses to the area where the discomfort seems to be centred. • If there is pain following a cough, hold a pillow or hand tightly over the area that hurts when coughing. <p>☛ Refer to hospital:</p> <ul style="list-style-type: none"> • If pain is severe. • If pain is associated with deep breathing. 	<ul style="list-style-type: none"> • Investigate to determine cause, then give specific management. • Manage associated anxiety.
Difficulty in breathing	<ul style="list-style-type: none"> • Elevate head of bed or lie with pillows to raise the head. • Keep air moving, e.g., by opening windows (but avoid excessive cooling) or minimize number of people in the room. • Reduce environmental irritants, e.g., smoking. • Have someone else there to support the PLWHA by reassuring and monitoring the PLWHA. <p>☛ Refer to hospital:</p> <ul style="list-style-type: none"> • When the condition is severe or if high fever develops. 	<ul style="list-style-type: none"> • Investigate the cause and treat accordingly. • Manage associated anxiety. • Elevate to semi-sitting position if it is of benefit to the PLWHA.

Seek help when:

- There is rise in temperature.
- The PLWHA develops severe pain and discomfort or difficulty in breathing.
- The sputum contains blood.
- The colour of the sputum becomes greyish-yellow or green.
- The cough persists for more than 3 weeks.
- Children develop faster breathing than normal, fever, loss of appetite (not feeding or drinking). Refer children as soon as possible for check-up in the health facility.

At the health facility:

- Put the patient on procaine penicillin 600,000 units BD or crystalline penicillin 2 mega units 6 hourly until the temperature comes down.
- Then discharge home on amoxicillin 500 mg TDS for 5–7 days.
- Other drugs are erythromycin, tetracycline, or cotrimoxazole. Counsel PLWHA and caregiver on compliance with the medications.

9.7 Genital Problems

Opportunistic infections of the genital area and sexually transmitted diseases (STDs) are common in PLWHAs. Common signs of genital problems include:

- Open sores/ulcers in the genital, groin, or rectal areas, which sometimes start as blisters.
- An unusual discharge (a mucus or pus-like substance) from the vagina.
- An unusual discharge from the urethra.
- Pain when urinating.
- A rash in or around the genital area.
- Warts in the genital area or around the anus.
- Swollen glands in the groin.

At the health facility:

- Confirm diagnosis of genital infections through physical examination and specific tests, or syndromic analysis.
- Treat according to the clinical findings and the results of the tests.

What to do at home:

- Use condoms. PLWHAs should be encouraged to use condoms to protect themselves from other STDs and also to protect their partners.
- For women, learn to know the difference between a normal vaginal discharge and one that indicates an infection.
- Also for women, avoid vaginal problems by:
 - ▶ Always using condoms when having any sexual contact.
 - ▶ Keeping the vulva and the anal areas clean by washing with water (but avoid soaps that damage this delicate skin).
 - ▶ After toilet, washing the anus in a direction away from the vagina so that faeces does not get into the vulva/vaginal region.
 - ▶ NOT washing out the vagina or putting anything (e.g., leaves or herbs) inside unless advised by a health care worker.

Some important facts about sexually transmitted diseases

- They increase the risk of acquiring or passing on HIV infection during sex.
- The presence of STDs makes transmission of HIV easier and increases the amount of the virus in the body.
- They may be transmitted to an unborn child during pregnancy.
- They may cause pelvic inflammatory disease.

9.8 Gastro-Intestinal Tract Problems (GIT)

Symptoms involving the GIT in HIV-positive patients are relatively common. Opportunistic infections and complications associated with HIV/AIDS can involve any part of the alimentary tract from the mouth right down to the rectum. Presenting signs and symptoms may be sore mouth, difficulty in swallowing, nausea, vomiting, or diarrhoea. Proper management of gastrointestinal problems is important to ensure that the PLWHA's nutrition is not interfered with.

Dehydration can be a major complication, especially where nausea, vomiting, and

diarrhoea persist unattended. Prevention of dehydration is achieved by ensuring that the PLWHA gets plenty of oral fluids where possible. Intravenous rehydration may become necessary in severe cases.

The management of common GIT problems is summarized in Table 9.4, and treatments for some specific conditions are given below.

Table 9.4: Management of common GIT problems

Condition	Home management	Hospital management
Sore mouth	<ul style="list-style-type: none"> • Explore food preference. • Drink more fluids; watch for dehydration. • Eat small amount of foods often. • Observe oral hygiene, e.g., by using 1% hydrogen peroxide gargles. • Treat oral candidiasis with Nystatin suspension or gentian violet paint. • Rinse mouth with warm salty water or mouthwash after eating or between food. 	<ul style="list-style-type: none"> • Correct dehydration and malnutrition. • Treat the cause of sore mouth. • Counsel the PLWHA on oral hygiene.
Diarrhoea and vomiting	<ul style="list-style-type: none"> • Prevent dehydration and malnutrition. ➡ Refer to hospital: • If PLWHA is dehydrated. • If PLWHA is suddenly unable to eat. • If diarrhoea persists. 	<ul style="list-style-type: none"> • Identify and then treat the cause. • Educate the PLWHA on the prevention of diarrhoea and on drug compliance. • Correct dehydration.
Loss of weight	<ul style="list-style-type: none"> • Eat smaller, frequent meals. • Avoid spicy and oily foods. • Vary foods to make eating attractive. • Identify cause of weight loss. ➡ Refer to hospital: • For unexplained weight loss. • If there is fever, chronic diarrhoea. 	<ul style="list-style-type: none"> • Investigate to identify cause of weight loss and manage according to specific cause, e.g., tuberculosis.

9.8.1 Sore Mouth

In the course of HIV infection, about 90% of PLWHAs present with oral lesions, sore mouth and/or difficulty in swallowing. Some causes are Herpes simplex, candidiasis (thrush), and recurrent aphthous ulcer.

Recurrent Herpes Simplex

Common in HIV/AIDS patients. Presents as grouped blisters mainly on the lips. The lesions ulcerate and form crusts. Other sites can be gums, tongue, or roof of the mouth.

Management is symptomatic, with pain killers, e.g., paracetamol, and hygiene. At the health facility, acyclovir 200 mg to be given 5 times a day for 10 days. This reduces recurrence and duration of the lesion. It is important to note that this drug is best given early when the blisters are still intact and not when crusts have formed.

Candidiasis (thrush)

Due to yeast, *Candida albicans*. Presents as white curd-like plaques on the tongue, inner cheeks, roof of the mouth, or the pharynx. Also causes fissuring in the angles of the mouth (angular cheilitis).

What to do at home:

- Assist in maintaining good oral hygiene.
- Scrub the white plaques using a soft brush 3-4 times a day.
- Unless it is painful, encourage PLWHA to suck a lemon daily, as the acid in lemon slows the growth of the yeast.
- Refer for medication at the health facility.

At the health facility:

- Give topical or systemic antifungals, e.g., Nystatin oral pastille or suspension, ketaconazole, fluconazole.
- Counsel the PLWHA on oral hygiene.
- Educate the PLWHA on nutrition.

Recurrent Aphthous Ulcers

Often occur on oral mucosa. The cause is not known. Though this condition affects anybody and is not related to HIV status, the presentation is more severe and healing is slow in HIV-positive persons.

Good oral hygiene is the major treatment, along with painkillers if necessary. In severe cases, the PLWHA can be referred to a health facility for topical steroids, 1% triamcinolone acetonide applied 3 times a day.

9.8.2 Difficulty in Swallowing

This can be due to obstruction or to pain when swallowing. The distinction should be determined by examination because a patient may not explain properly whether difficulty in swallowing is because of pain or blockage. It is important to inquire carefully so as to help in the early identification and treatment of specific cause. Painful swallowing can be due to inflammation of the pharynx or oesophagus. The commonest cause in HIV/AIDS patients is candidiasis, which is revealed by checking the mouth or pharynx for thrush. Other causes of inflammation can be Herpes simplex, cytomegalovirus (CMV), or chemical burns like alcohol.

Obstruction could be due to tumours like Kaposi's sarcoma, non-Hodgkin's lymphoma, or swollen lymph nodes. The most common is Kaposi's sarcoma, which affects 30–40% of PLWHAs with skin lesions.

What to do at home:

Advise the PLWHA to:

- Take soft foods.
- Avoid hard and crunchy foods.
- Eat bland and not spicy foods.
- Take cold foods/drinks to make the mouth numb and help reduce pain or discomfort.

Seek help when:

- The PLWHA cannot swallow.
- There are symptoms of oesophageal thrush (burning pain in the chest, deep pain on swallowing).

9.8.3 Nausea and Vomiting

Nausea and vomiting are common problems in HIV/AIDS patients. Nausea and vomiting can be self-limiting or may improve on identification and treatment of the cause. Or they may persist for a long time. These conditions may be due to:

- The HIV infection
- Mucosal irritation by drugs or hyper-acidity
- Infections, e.g., candidiasis, cytomegalovirus
- Medications, e.g., steroids
- Blood in the stomach
- Kaposi's sarcoma in the intestines

What to do at home:

- Watch for signs of dehydration, e.g., sunken eyes, dry lips, or loose skin tag.
- Encourage small frequent sips of fluid or oral rehydration solution (ORS) and weak tea.
- Take small frequent amounts of food.

Seek help when:

- Vomiting is frequent and nothing is retained in the stomach.
- Vomiting continues for 24 hours.
- There is also fever.
- The vomit is blood stained or associated with distended abdomen.

9.8.4 Diarrhoea

Diarrhoea is having three or more loose or watery stools in a day. It is a common complaint in people with HIV/AIDS. Diarrhoea occurs in 70–90% of AIDS patients in developing countries and 30–40% of AIDS patients in industrialized countries. It may be accompanied by abdominal cramps and vomiting. When diarrhoea persists for 1 month with unexplained 10% weight loss, it is sometimes referred to as *Diarrhoea wasting syndrome*.

Causes may not be identified in most cases and at times the condition is referred to as AIDS enteropathy. Other causes may be:

- Contaminated foods or water
- Viral: CMV, adenovirus
- Bacterial: e.g., campylobacter, salmonella
- Protozoa: cryptosporidium, Entamoeba histolytica, Giardia lamblia
- Fungal: candida
- Infestations: strongyloides

Other causes of diarrhoea are:

- Metabolic
- Malabsorption, e.g., lactose intolerance
- Medication, e.g., anti-retrovirals, antimicrobials
- Malignancies, e.g., Kaposi's sarcoma.

Diarrhoea is a concern for three important reasons:

- It causes dehydration.
- It can result in malnutrition.
- It can upset the fluid and electrolyte balance.

Disseminated Kaposi's sarcoma of the lower gastrointestinal tract may cause diarrhoea, sub-acute intestinal obstruction, or rectal ulcers.

During diarrhoea more water and salts are lost in the stool than are being absorbed in food and drink. The greater the frequency and amount of diarrhoea, the more fluid and salts are lost. The increased loss of fluid in the body causes dehydration. If dehydration is not corrected, it will cause death or damage to organs like the kidneys and brain.

Signs of dehydration are: increased thirst, dry mucus membranes and lips, sunken eyes, especially in children, and loose skin tag. Children with severe dehydration may have convulsions.

Malnutrition is caused by diarrhoea because of increased motility of the intestines and therefore reduced absorption and increased loss of nutrients in the stools. Loss of appetite may lead to reduced food intake. Management is by preventing diarrhoea from occurring:

- Boiling all untreated drinking water.
- Eating clean and safe foods.
- Observing personal hygiene like washing hands after toilet.
- Covering cooked foods to protect from flies.
- Ensuring raw foods like fruits are washed and dried before use.

What to do at home:

- Prevent dehydration and malnutrition by:
 - ▶ Encouraging more fluid intake than usual.
 - ▶ Giving children under 2 years 50-100mls or 1/4 to 1/2 cup of fluid after each stool.
 - ▶ Giving small frequent amounts of foods to avoid malnutrition especially in children.
- Provide foods that have large amounts of nutrients and calories, e.g., fish or meat or beans plus locally available cereals. Add oils to these foods to increase energy.
- Advise to avoid foods with a lot of roughage, hard to digest foods, and foods or drinks with a lot of sugar.

Seek help when:

- Dehydration does not improve despite the fluid intake.
- The PLWHA is very thirsty.
- There is fever.
- PLWHA cannot eat or drink.
- There is blood in the stool.
- The skin is loose and returns slowly when pinched.
- The diarrhoea persists.

At the health facility:

- Assess the PLWHA to determine the cause of the diarrhoea and the degree of dehydration.
- The commonest cause of diarrhoea in children is bacterial, and therefore antibiotic should be given with good indication.

9.9 Central Nervous System Problems

Central nervous system (CNS) problems in HIV/AIDS individuals can be due to the HIV itself or to opportunistic infections or tumours secondary to the HIV status. The mechanism of HIV/AIDS effects on brain tissue and the nerves is not well understood. HIV infection can cause psychological effects, especially if the person is not properly counselled to cope with the situation. It can also cause mental confusion or dementia and peripheral nerve damage.

9.9.1 Anxiety and Depression

The psychological effects include anxiety and depression. Anxiety is a situation in which one feels nervous and fearful. Depression is a feeling of hopelessness. These PLWHAs come with complaints of many symptoms of illness, headache, fatigue or lack of sleep, loss of appetite, dizziness, lack of concentration. Family members may be the first to report the changes.

Management is through counselling and providing emotional support through friends,

Seek help when:

- The family members feel they cannot cope or the depression is so severe the PLWHA is contemplating suicide.
- There is worsening change in normal habits like refusal to feed, sleeplessness, etc.

family members, or religious leaders. Allow PLWHAs to express their thoughts and feelings and encourage them to talk.

9.9.2 Dementia and Mental Confusion

Dementia or mental confusion could be due to the direct effect of the virus on the brain. Depending on the degree, this can be a serious disability. Patients present with inability to concentrate, loss of memory, slow thinking, poor short-term memory, and personality change. In late stages, about half develop motor dysfunctions like weakness of one part of the body, tremors, inability to walk, and incontinence of stool and urine.

What to do at home:

- Prevent accidents like fires and falling over objects.
- Keep drugs, poisons, and sharp objects like knives out of reach.

Seek help when:

- New symptoms occur, like fever, headache, difficulty in breathing, diarrhoea.
- The PLWHA becomes aggressive and violent.

9.9.3 Peripheral Nerve Damage

The effect on peripheral nerves causes a burning sensation, especially on pressure. This makes patients feel even more uncomfortable lying down. Damage to autonomic nerves may cause bladder and gastrointestinal dysfunction, leading to inability to control stool and urine.

What to do home:

- Provide something soft to lie on when they experience pain trying to sleep.
- Give painkillers like paracetamol for pain.
- Discuss with health worker how to manage serious cases of incontinence of urine. Use towel, bed sheet, *lesso*, etc., as a nappy (diaper).
- Keep the PLWHA's skin dry.

9.9.4 Infections

Opportunistic infections of the central nervous system are common. These cause inflammation of the brain cover or meninges (meningitis) or brain tissue (encephalitis) or both the brain and the meninges (meningo-encephalitis). The most frequent opportunistic infections of the CNS are

cryptococcus and toxoplasmosis, which affect 5—20% of AIDS patients. Others are:

- Bacterial: meningococcus, Streptococcus pneumoniae, Haemophilus influenzae
- Viral: Cytomegalovirus, Varicella zoster, adenovirus
- Fungal: cryptococcus, toxoplasmosis, histoplasma
- Parasitic: toxoplasmosis, malaria

Patients with meningitis present with high temperature and stiff neck and may go into unconsciousness within a short time. In children below 2 years the signs may not be specific. They present with high fever, vomiting, irritability, convulsions, high-pitched cry, and bulging of the fontanel.

What to do at home:

- Immediately refer a patient with suspected signs of meningitis to the hospital for proper investigation and management.
- Avoid dehydration due to water lost because of high temperature or vomiting. Encourage plenty of oral fluids like *uji*, tea, soup, or water. In case the patient is vomiting, encourage small sips at a time.

Seek help when:

- The PLWHA has persistent headaches not relieved by painkillers.

At the health facility:

- * Confirm diagnosis of CNS infections through physical examination and specific tests, e.g., lumbar punctures.
- * Treat according to the clinical findings and the results of tests on cerebral/spinal fluid.

9.9.5 Malignancies

Primary CNS lymphoma was rare before the advent of HIV/AIDS. This and other malignancies are much more common now. Signs and symptoms of CNS lymphoma are related to increased intra cranial pressure, e.g., headache, vomiting, and other neurological defects. The course of disease for these and other malignancies is often not normal as a result of the altered immune response. Moreover, cytotoxic drugs cause immunosuppression, so ask if patient is on cancer drugs.



10

NURSING CARE

Nursing care is the care given to a sick person either while at hospital or in their home. It means things done for them by the health care worker or a family member or friend, and may also include things people do to care for themselves.

10.1 Components of Nursing Care

Nursing care in the context of home-based care applies at all levels, from the health institution down to the family, depending on the individual needs of the PLWHA. Nursing care includes:

- Activities to ensure good personal hygiene
- Infection control
- Nutrition
- Administering drugs per prescription to ensure compliance
- Pain management
- Simple wound dressing
- Assisting with toilet and elimination needs
- Physical therapy
- Observing of PLWHA to detect problems: dehydration, dyspnoea, dysphagia, oedema, fever
- Taking the PLWHA to the hospital or health facility when need arises
- Reassuring the PLWHA at all times

The common conditions that need attention normally include:

- Fever
- Diarrhoea and vomiting, which may easily lead to dehydration
- Pain and discomfort
- Chest problems like chronic coughs, colds, and infections
- Skin conditions
- Bed sores
- Nausea, mouth and throat infections

There are both general and specific interventions for the management of these conditions. Table 10.1 gives a brief summary of these interventions at the various levels.

Table 10.1: Nursing interventions at various levels

	General interventions	Specific interventions
By the health worker	<ul style="list-style-type: none"> ● Monitoring vital signs ● Maintaining PLWHA's comfort, e.g., bathing, bed making, assisting with elimination needs ● Caring for pressure areas ● Assisting with oral care ● Nutrition: assisting with feeding when necessary ● Medication: giving oral and injectable drugs ● Relieving pain ● Educating on personal care and hygiene ● Practising infection control in the home and environment 	<ul style="list-style-type: none"> ● Ensuring fluid intake and output and maintaining charts ● Using temperature reducing techniques like tepid sponging ● Dressing wounds ● Administering rehydration fluids (IV and oral)
By the PLWHA/ family caregiver/ community/	<ul style="list-style-type: none"> ● Observing the PLWHA's condition ● Attending to PLWHA's comfort at home ● Bathing and bed making ● Assisting with elimination and toilet needs ● Nutrition: feeding and providing a balanced diet, ensuring adequate fluid intake ● Medication: giving orals and applying local medications ● Educating on health and personal care ● Observing good personal hygiene to prevent infection ● Preventing HIV transmission through the ABC approach (Abstain, Be faithful, use Condoms) ● Avoiding invasive procedures ● Practising infection control principles ● Cleaning and covering open wounds 	<ul style="list-style-type: none"> ● Handling infective materials properly ● Reducing fever and pain ● Managing diarrhoea and vomiting ● Attending to skin problems ● Attending to mouth and throat problems ● Caring for patients with tuberculosis and meningitis, during and after the acute phase

10.2 Home Nursing

This means the nursing care given to sick people in their homes. It may include the things people do to care for themselves, as well as the care given to them by their family or health care workers. The care at home depends on the PLWHA's needs and may include:

- Physical care
- Psychological care
- Social and spiritual/pastoral care

There are routine physical needs that must be addressed and there are needs that depend on the specific symptoms of AIDS in the patient. The routine needs include:

- Nutrition: A well balanced diet with all the different nutrients, vitamins, and minerals.
- Personal hygiene: Daily bath, mouth care, care of nails and hair. Nails should be kept short and clean and hair should be short, combed, and washed regularly.
- Medication: Continuing with prescribed medicines.
- Elimination: Help with elimination (toilet) needs.

10.3 Home Care Kits

The home care kit comprises the basic requirements for nursing the HIV-positive patient outside of the health facility. The kit will actually be at two levels. One level is the materials routinely needed by the individual PLWHA; beyond a certain minimum standard of care and hygiene these will contain medications specific to the individual. At the level of the community health worker, the kit will contain necessary nursing supplies such as soap, dressing materials, and basic medication such as paracetamol. It will also contain reference materials and notebook or diary for record keeping. Figure 10.1 illustrates a simple home nursing care kit, and Table 10.2 lists complete kits at three levels (more details are in the annex).

The health care provider will need to be educated on the importance of replenishing the kit content regularly. Items that are not readily available within the home setting can be improvised with whatever is suitable and affordable, e.g., using plastic paper bags for rubber gloves or old newspapers for draw sheets.

The initial contents of the home care kit will be based on the needs of the PLWHA and

A word about plastic bags

The plastic paper bags used to protect your hands may be those used for bread or by supermarkets, kiosks, vegetable sellers, etc. The bags should be large and soft enough to allow one to work easily, but they should not have any holes in them and they should be strong enough to keep the hands dry. The bags can be tied at the wrist or fastened with rubber bands so they don't come off easily.

determined at the health facility level when the PLWHA is recruited into the HBC programme. Replenishing the kits can be a collaborative effort between the community and the health institution where the PLWHA goes for the required regular medical checks.

Figure 10.1: Home care kit



10.4 Nutritional Needs of PLWHAs

It is almost impossible to put too much emphasis on the importance of good nutrition in the management of HIV/AIDS at all stages. Good nutrition is essential for maintaining strength and the body's immune system, and attention to nutrition should begin as soon as the person is diagnosed with HIV. Thus persons who learn they are HIV-positive should be informed very early that eating well means more than just having a full stomach; it means eating the right combination of foods to provide the nutrients the body needs to function properly.

Sick people have an even greater need for a well balanced diet than healthy persons, but with proper nutrition, PLWHAs can generally stay healthier longer.

10.4.1 Meeting Nutritional Needs

People living with HIV/AIDS have many questions about their diet. Loss of appetite or

Table 10.2: Sample home care kits

Community volunteer kit	Patient primary kit	Patient re-supply kit
Supplies: <ul style="list-style-type: none"> ▪ Gloves (latex, non sterile) ▪ Soap ▪ Toilet paper ▪ Scissors (small) ▪ Razor blades ▪ Waste disposal bags ▪ Jik ▪ Surgical spirit ▪ Plastic apron ▪ Plastic sheeting ▪ Condoms 	Supplies: <ul style="list-style-type: none"> ▪ Gloves (latex, non sterile) ▪ Soap ▪ Toilet paper ▪ Vaseline ▪ Bucket with lid ▪ Basin (45cm diameter) ▪ Mosquito net (impregnated) ▪ Talcum powder ▪ Nail cutter (small) ▪ Scissors (small, steel) ▪ Waste disposal bags ▪ Cotton wool ▪ Gauze 4x4 non sterile ▪ Bandages, crepe, 4" ▪ Mackintosh, 2 metres ▪ Jik ▪ Bed sheets ▪ 3-inch mattress ▪ Condoms ▪ Wooden spatula 	Supplies: <ul style="list-style-type: none"> ▪ Gloves (latex, non sterile) ▪ Soap ▪ Toilet paper ▪ Vaseline ▪ Talcum powder ▪ Waste disposal bags ▪ Cotton wool ▪ Gauze ▪ Bandages ▪ Jik ▪ Condoms
Medications: <ul style="list-style-type: none"> ▪ Aspirin/paracetamol ▪ Anti-malaria tabs (Fansidar) ▪ Alberdazol ▪ Multi-vitamins ▪ Piriton ▪ Iron tablets 	Medications: <ul style="list-style-type: none"> ▪ Paracetamol ▪ Alberdazol ▪ Oral rehydration salts (ORS) ▪ Multi-vitamins ▪ Tetracycline skin ointment (3%) ▪ Gentamicine eye drops ▪ Calamine lotion ▪ Savlon (chloramide forte) ▪ Dettol cream ▪ Nystatin oral drops (24 ml) ▪ SP - Fansidar ▪ Iron tablets ▪ Piriton (pm - generic) ▪ Antihistamine tube 	Medications: <ul style="list-style-type: none"> ▪ Paracetamol ▪ Alberdazol ▪ Oral rehydration salts (ORS) ▪ Multi-vitamins ▪ Tetracycline skin ointment (3%) ▪ Gentamicine eye drops ▪ Calamine lotion ▪ Savlon (chloramide forte) ▪ Dettol cream ▪ Nystatin oral drops (24 ml) ▪ SP - Fansidar ▪ Iron tablets ▪ Piriton (pm - generic)
Reference materials: <ul style="list-style-type: none"> ▪ Handbook ▪ Reference materials ▪ Portable flip chart ▪ Register/Diary ▪ Notebook ▪ Pencil/ballpoint pen ▪ Carrying bag/basket 		

difficulty in eating can be very distressing for the sick person, making them feel helpless and ineffective. The loss of weight can cause much fear. All the foods the family is familiar with can be combined to meet the nutritional requirements of the PLWHA and hence allay the fears and answer their many questions. Several factors may influence nutrition. These include:

- Cultural beliefs, taboos, and practices relating to foods
- Economic status of the family and community
- Natural climatic changes like drought and floods
- General conditions of the PLWHA
- Poverty

The foods (see box and Figure 10.2) should be:

- Familiar — What the family uses daily
- Affordable
- Available
- Accessible

10.4.2 Components of a Balanced Diet

Foods can be divided into three basic categories, with each playing its important role in nutrition. The basic food groups are:

- **Body building:** Includes animal and vegetable proteins such as meat, fish, milk, chicken, eggs, beans of all types, soya, groundnuts, green grams, cow peas, *dengu*.
- **Energy giving:** Includes starchy foods like potatoes, yams, cassava, bananas, sugar,

wheat, rice and maize meal, bread, *chapati*, pasta, as well as all fats and vegetable oils.

- **Protective:** Includes foods that contribute a variety of essential nutrients, such as oranges, pineapples, papaw, mangoes and other fruits, as well as carrots, *sukuma wiki*, spinach, tomatoes, all local green leafy vegetables.

In addition, water and minerals like iron and calcium are essential to good nutrition. Water is necessary for bodily functions and to prevent dehydration. Minerals are necessary elements of blood, bone, teeth, and body processes. Examples of foods that are rich in iron are fish, meat, dark green leafy vegetables, etc. Calcium is derived from milk, groundnuts, eggs. Other important minerals like potassium, selenium, zinc, and magnesium are vital for survival.

Note: In most cases, people with HIV/AIDS need food supplements.

10.4.3 Common Nutrition Problems

The most common problems associated with poor nutrition are:

- Severe weight loss as a result of poor appetite leading to failure to meet dietary requirements. This can be overcome by encouraging small frequent feeds.
- Anaemia due to poor dietary intake or lack of iron in the diet or as a result of infections such as malaria or hookworm or other parasite infestations that destroy red blood cells.

- Skin conditions due to lack of vitamins in the diet, e.g., scurvy and pellagra.
- Failure to thrive, or maintain a reasonably good level of health.

10.4.4 Common Feeding Problems

During some illnesses PLWHAs may have extra difficulty eating, or may need to eat different types of food.

During Diarrhoea

- Eat soft, mashed foods that are easy to chew and swallow.
- Eat small meals, five or more times a day.
- Drink a lot to prevent dehydration (water, tea, *uji*, juice, home-made rehydration solution).

Oral Thrush

- Eat soft, mashed foods.
- Drink lemon water or suck on a lemon.
- Avoid sugary foods and milk.

Sore Mouth

- Avoid spicy and *pili-pili* foods.
- Avoid foods requiring a lot of chewing.
- Avoid very hot food, but try cold foods to see if they will numb the mouth.

➡ Seek help when:

- The PLWHA is not able to eat enough to maintain strength.

FOOD GROUPS			
Body-Building Foods (Proteins)	Protective Foods		Energy-Giving Foods (Starches)
	Greens/Vegetables	Fruits	
<ul style="list-style-type: none"> • Beef, goat meat, lamb, chicken, pork • Fish • Eggs • White ants (<i>tsiswa</i>) • Groundnuts • Milk, <i>maziwa lala</i> • Green grams • Beans (<i>marahagwe</i>) • Peas (cow, garden, and pigeon peas) • Sim-sim (sesame) • Lentils, green grams (<i>dengu</i>) 	<ul style="list-style-type: none"> • Cabbages • Carrots • Tomatoes • Cassava leaves • Pumpkin leaves • Eggplant (<i>biringanya</i>) • Bamboo shoots • Cauliflower • Cucumber • <i>Sukuma wiki</i> (kale) • <i>Mchichi</i> (<i>terere</i>, <i>Tsimboka</i>) • <i>Mrenda</i> (<i>mutere</i>) 	<ul style="list-style-type: none"> • Pineapples • Mangoes • Oranges • Pawpaws (papaya) • Ripe bananas • Lemons • Jack fruit • Passion fruit • Watermelons • Gooseberries • Guavas • Avocados 	<ul style="list-style-type: none"> • Maize meal (<i>ugali</i>) • Rice • <i>Matoke</i> • Cassava • Bread • Potatoes • Sorghum • <i>Chapati</i> • Millet • Yams (<i>nduma</i>) • Plantain • Pasta (spaghetti, noodles)

Figure 10.2: Main classes of foods

Vitamins or protective foods



Energy foods

Proteins or body building foods

10.5 Caring for a Child with HIV Infection or AIDS

HIV-positive children need the same nursing care as HIV-positive adults, and the same loving attention as any non infected child. Their caregivers should strive to:

- Feed the child well with a balanced diet.
- Maintain good personal and food hygiene.
- Have the children immunized as required.
- Ensure that the child is given love at home or wherever care is being provided.
- Make sure the child gets early treatment for infections.
- Treat the child as normally as possible and allow the child go to school except when there is an outbreak of infection in the school. Let the child spend time playing with others.
- Apply all the other general and specific nursing care procedures according to the presenting opportunistic infection and the general condition of the child.

10.6 Nursing Management of Common AIDS Conditions in the Home

The common conditions that require nursing attention are fever, diarrhoea, skin problems, wounds, and mouth and throat problems.

10.6.1 Fever

Fever may indicate one of many different illnesses. It makes a PLWHA very

uncomfortable and can be dangerous especially in small children. Fever may cause loss of body fluids. It may also lead to delirium and convulsions, which can cause brain damage.

Fever may be associated with any of the following conditions:

- AIDS-related opportunistic infections such as pneumonia and tuberculosis
- Diseases like malaria, measles, meningitis
- Infective diarrhoea
- HIV infection itself

What to do home:

- Check whether the PLWHA has a fever, by either using a thermometer if available or putting the back of your one hand on the patient's forehead and the back of the other hand on your own forehead to compare the two.
- Try to lower fever by:
 - ▶ Removing any of the patient's clothing and blankets that are not necessary and exposing the patient to a fresh air breeze.
 - ▶ Cooling the skin by bathing the patient or by putting cloths soaked in warm water on the chest, forehead, and armpits.
 - ▶ Giving medicines that help reduce fever like aspirin, paracetamol, or Calpol.
- Give plenty of fluids water, juice, soup to replace the fluid that is being lost through sweating, to prevent dehydration.

Figure 10.3: Checking temperature at home



➤ Seek help when:

- The temperature persists in spite of all your efforts.

10.6.2 Diarrhoea

Diarrhoea is a common problem in persons with HIV/AIDS. A person has diarrhoea if:

- Their stools are frequent (3 or more in a day) and loose and watery.
- The stools contain blood or mucous (bloody diarrhoea signifies dysentery).

Greenish offensive diarrhoea is always infective. Diarrhoea is sometimes accompanied by abdominal pains and vomiting.

How to Prevent Diarrhoea

- Use clean boiled water for cooking and drinking.
- Wash and dry fruits before eating them.
- Eat clean freshly prepared food. Clean food before cooking, and cook food properly.
- Protect cooked food from being contaminated by covering it to avoid flies.
- Reheat pre-heated foods thoroughly at a high temperature and then allow to cool to the right temperature to avoid mouth sores.
- Maintain good personal hygiene by washing hands and drying them if possible:
 - ▶ After using the toilet.
 - ▶ After helping a sick person to use the toilet.
 - ▶ After cleaning soiled children or sick people. Note that more protection is required here, especially the use of gloves or other protective material.
 - ▶ Before preparing food or drink for the family.

- ▶ Before eating.
- ▶ After any procedure on the sick person: bed bath, wound cleaning, changing bedding.

Dangers of Diarrhoea

- Dehydration
- Malnutrition

How to Treat Diarrhoea

- Give more fluids than usual, especially what the PLWHA finds favourable: unsweetened juices, *uji*, soup, rice water, oral rehydration solution.
- In children, if child is breastfeeding, continue to feed the child to avoid malnutrition. If the mother is HIV infected adhere to the current instructions on feeding such a child.
- In case of vomiting or loss of appetite, feed the PLWHA frequent small amounts of balanced diet that is easily digested.
- After the diarrhoea stops, give the PLWHA an extra meal each day for 2 weeks to help regain the lost weight.
- Prevent dehydration by early recognition and treatment.

How to Recognize Dehydration at Home

A patient with dehydration will present with the following signs and symptoms:

- Feeling very thirsty with a dry mouth
- Feeling irritable or lethargic
- Loss of skin elasticity: when pinched the skin goes back very slowly
- In children there will be sunken eyes and fontanel
- Lack of tears despite attempts to cry

What to do at home:

- Correct dehydration by giving plenty of fluids after every loose motion passed. Give *uji*, soup, tea, rice water, or oral rehydration solution.
- Prevent dehydration by referring patient to hospital if diarrhoea persists.

➤ Danger signs of dehydration

- The tongue is dry,
- The eyes are sunken, and
- Skin goes back slowly when pinched.
- The person may be extremely thirsty and may seem irritable or very tired.

10.6.3 Skin Problems

What to do at home:

- Wash the PLWHA's clothing with water and soap, rinse well, and hang to dry in the sun. (See Figure 10.4.)
- Clean the skin frequently with water and soap, rinse well, and keep it dry.
- Avoid scratching with fingers. Protect children from scratching by putting mittens or socks on their hands.
- Keep the nails short.
- Prevent itching of the skin by putting cool water or cool wet cloths on the skin, applying any lotions provided in the hospital, and protecting the skin from heat.

10.6.4 Treatment of Wounds

Open wounds may become infected if not managed properly. This can cause fever or may lead to swelling of the lymph nodes.

Treating Open, Uninfected Wounds

- Use polythene bags (or gloves if available). Wash hands before and after the procedure.
- Wash affected area with clean water, previously boiled with a little salt added to it: 1 teaspoon of salt to 1 litre of boiled water.
- Cover the wound with clean cloth or bandage if necessary, or leave open after cleaning, according to health worker's advice.
- Use gentian violet to help keep the area dry and aid healing.
- Use hydrogen peroxide to remove dead tissue.
- If the wound is on the legs or feet, raise the affected area with a pillow if in bed or a stool while sitting.
- Encourage walking exercises but discourage standing for long periods.
- Follow proper infection prevention procedures.

Figure 10.4: Cleaning the PLWHA's clothes



Cleaning Infected Wounds

- Use polythene bags (or gloves if available) and wash hands before and after the procedure.
- Clean the wound from the centre outward.
- Cover the wound with a piece of clean cloth.
- If the wound is dry, leave it exposed as it heals faster.
- Avoid tight dressing.
- Always use clean dressing.
- Change the dressing once a day.
- For dressings that are re-used, rinse thoroughly in cold water and pour the rinse water into the latrine. Soak dressings in bleach solution or boil. Wash with water and soap, rinse well, and hang in the sun.
- Dispose of soiled dressings that are not re-used by burning or throwing into the pit latrine.
- Protect the PLWHA from getting tetanus by taking them for TT vaccination.

10.6.5 Pressure Sores

These are sores caused by the breakdown of the skin due to pressure. They appear on patients who are very ill and unable to turn in bed. Pressure sores may form on any part of the body where there is bone prominence, e.g., buttocks, back, hips, elbows, feet, ankles.

Prevent pressure sores by:

- Getting the PLWHA out of bed as much as possible.
- Turning the PLWHA every 2 hours.
- Attending to pressure areas by massaging areas of prominent bones with soap and water.
- Using soft bed sheets and changing the bedding whenever the bed is wet.
- Straightening the bedding often.
- Putting cushions under the body to keep the bony parts from rubbing together.
- Holding a bedridden child on someone's lap as often as possible.

If pressure sores develop in spite of these precautions, treat as in Section 10.6.4.

Seek help when:

- The wound is infected or does not respond to treatment and you cannot manage.

10.6.6 Mouth and Throat Problems

Problems of the mouth and throat are common in HIV-positive persons. Sometimes the problem progresses to the point where swallowing becomes painful. This may prevent the PLWHA from eating properly.

What to do at home:

- Provide the PLWHA with good nutritious food and give vitamin supplements.
- Rinse the mouth frequently with warm salty water (1/2 teaspoon of salt in a cup of water) or use a mouthwash, particularly after meals.
- Advise to eat soft foods avoid spicy foods that irritate the mouth.
- Use a straw for drinking liquids and soups.
- Encourage cold foods, which help make the mouth numb.

Oral Thrush

Oral thrush is a fungal infection that causes small white patches on the mouth and tongue. The patches look like milk curds. Oral thrush is quite common in PLWHAs.

What to do at home:

- Gently clean the tongue and gums with a soft toothbrush 3 or 4 times a day.
- Rinse mouth with salt water or lemon water.
- Encourage PLWHA to suck a lemon. This helps in slowing down the growth of the fungus.
- Apply gentian violet twice a day.
- Give anti-fungal oral gel, as prescribed by the doctor.

Dental Problems

It is important to clean the teeth thoroughly to prevent tooth decay. People with AIDS suffer from inflammation of the gums, tooth abscesses, and infection.

To help prevent dental problems:

- Take the person for dental check-up regularly.
- Help the person to brush the teeth, paying attention to the area between the teeth using a piece of strong thread (dental floss).

- If the PLWHA does not have a toothbrush, tie a small piece of towel around a stick and use it to clean the teeth (Figure 10.5).
- Make a tooth cleaning powder to substitute for toothpaste, if necessary, by mixing salt and bicarbonate of soda (baking soda) or ashes in equal amounts. Wet the toothbrush before putting it into the prepared powder.

Figure 10.5: Home-made tooth brush



10.7 Helping with Elimination (Toilet) Needs

People who are HIV positive will at one time or another need assistance with their toilet needs. This is an area that is commonly ignored and yet can be a major source of distress. Helping with elimination needs includes paying attention to the following areas:

- Training the person on good personal hygiene, e.g., washing hands after using the toilet.
- Regularly changing soiled bed linen if the patient has no control of bladder and bowel movements.
- Using waterproof materials to protect the mattress and the under sheet from soiling.
- Taking care when handling the soiled linen by handling the areas not contaminated, for example by using polythene paper bags or a big leaf to hold soiled linen if gloves are not available. Explain to the PLWHA why this protection is needed, as some people may see it as a sign of rejection.

- Rinsing out in water the infected material, e.g., stool, blood, pus.
- Decontaminating the soiled linen appropriately.
- Burning non re-usable materials or throwing them into a pit latrine.
- If PLWHA is not able to go to toilet, improvising a commode by using a plastic container (e.g., for cooking fat) put inside a bigger bucket to make it comfortable for the PLWHA to use (see Figure 10.6).
- Improvising a bedpan by cutting an opening in the side of a plastic 20-litre container (Figure 10.6).

NOTE: Always remember to wash your hands with soap and water after attending the patient.

10.8 Physical Therapy

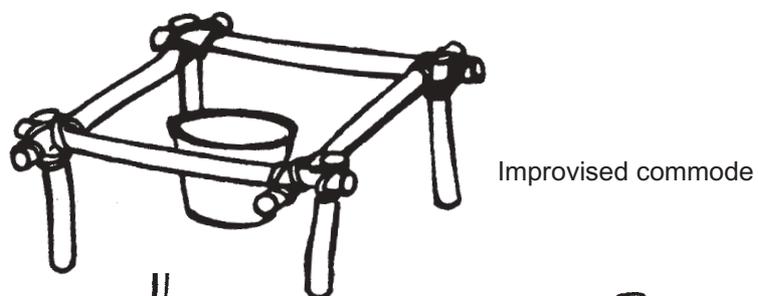
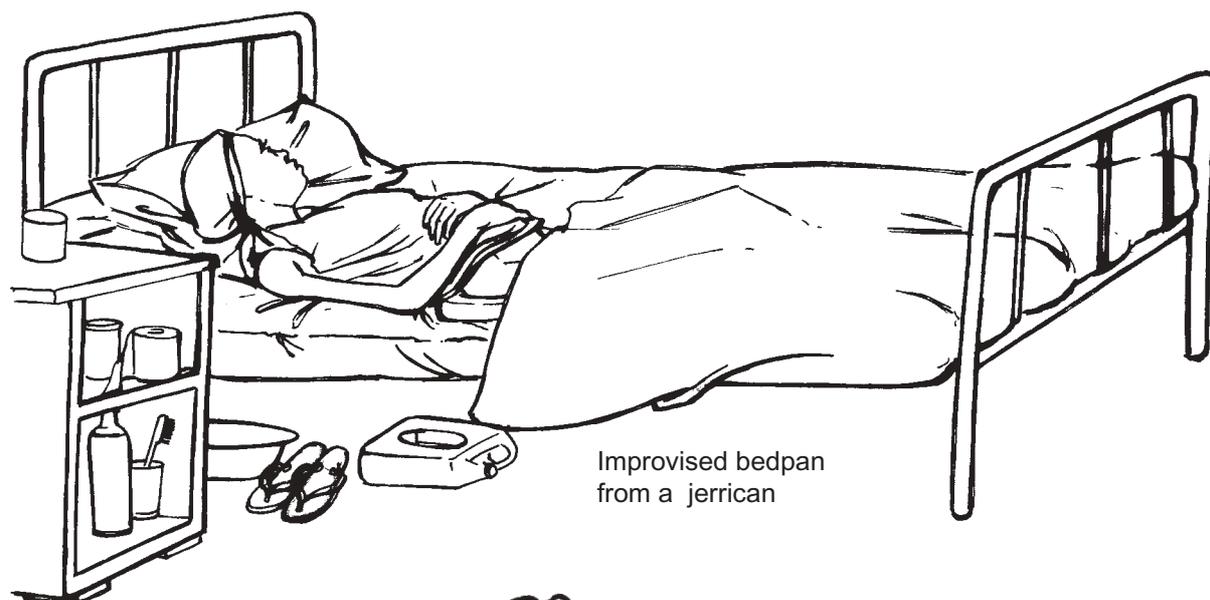
People who are in bed because of AIDS have difficulty moving their arms and legs enough to keep their muscles strong and their joints flexible. Many PLWHAs become sicker, wasted, and frustrated if they are not helped to exercise their bodies and limbs. Physical therapy helps ensure that bedridden PLWHAs get enough exercise to maintain muscle tone and flexibility. It also helps bring a feeling of being useful. Physical therapy can be done both for PLWHAs who are still capable of lifting themselves and for those who are no longer capable.

Physical therapy includes exercise or massage that helps to:

- Improve blood circulation and prevent blood clots in the veins
- Improve digestion
- Prevent stiffness of joints
- Prevent muscle wasting
- Prevent secondary infection, e.g., inhalation pneumonia from lack of exercise
- Relax the PLWHA

When an arm or leg is kept bent for a long time, some of the muscles become shorter and the limb cannot fully straighten, or short muscles may hold the joint straight so that it cannot bend. This is called a *contracture*. Sometimes contractures cause pain. If the person has had

Figure 10.6: Home-made improvised bedpans and commode



contractures for many months, it will be difficult to completely straighten the joints. But simple exercises and massage will prevent the contractures from getting worse and can make the joints a little less stiff and keep the muscles strong. A number of these simple exercises are pictured in the *Home Care Handbook*.

10.9 Infection Prevention

Infection prevention in home-based care for people with HIV/AIDS has four primary aims:

- Preventing self-infection
- Preventing PLWHA-to-caregiver infection
- Preventing caregiver-to-PLWHA infection
- Preventing PLWHA-to-sexual partner(s) infection

10.9.1 Self-Infection

In this mode of infection, the PLWHA gets infection from one part of the body to another, e.g., wounds, faeco-oral infections through improper hand washing after toilet, etc.

10.9.2 PLWHA-to-Caregiver Infection

This can be a very distressing situation the caregiver is infected with either the HIV virus or other infections in the process of caring for the PLWHA. It can occur as a result of:

- Not using gloves or other available plastic waterproof material while handling soiled linen, or blood and other body fluids.
- Attending an HIV-positive person while having open uncovered cuts, wounds, or abrasions.
- Acquiring chest infections such as tuberculosis while caring for the PLWHA.
- Splashing blood in the eyes while attending childbirth by an HIV-positive mother.

10.9.3 Caregiver-to-PLWHA Infection

The PLWHA has a lowered immunity as a result of the HIV infection and is therefore prone to infections. If the caregiver is sick with any common infection, it is safer to have another care provider take care for the PLWHA during the period of the illness. Common infectious diseases include the following:

- Common cold or flu
- Diarrhoeal diseases
- Skin conditions such as scabies
- Typhoid

- Chest infections like bronchitis, pneumonia, and tuberculosis
- Fungal infections, especially those affecting the skin

10.9.4 PLWHA-to-Sexual Partner(s) Infection

Being HIV-positive does not mean the person is no longer capable and in need of sexual satisfaction. In the early stages of HIV infection, the person has minimal or no signs of the disease and is therefore as attractive as before. The infected person still has sexual feelings and thus is capable of passing the infection sexually to any sexual partner(s). This form of infection can be prevented by:

- Educating the infected person on the infection, including mode of spread and all known preventive measures.
- Stressing total abstinence (primary or secondary) as the primary preventive measure.
- Urging a PLWHA who is not able to abstain to have only one sexual partner with whom they **must** use condoms to prevent re-infection and spread of the disease.

10.9.5 General Measures

There are other general infection prevention measures that the care provider both in health facilities and at home should try to adhere to. These include the following:

Hand Washing

- Washing hands before and after handling the PLWHA or infected material.
- Washing hands after removing the gloves because they could have gotten pierced or torn in the process of use.
- Washing hands before preparing or serving food.

Using Gloves or Other Plastic Materials

- Wearing gloves or other locally available plastic papers while handling linen soiled with body secretions such as blood, faecal matter, vomitus, and pus and when handling soiled instruments and dressing materials.
- If in a hospital setting, always using a separate pair of gloves on each patient to avoid cross contamination. Use of disposable gloves is appropriate but where resources are limited, autoclaving of reusable rubber gloves should be emphasized.

Maintaining General and Personal Hygiene

- Bathing daily and washing hands frequently.
- Regularly airing PLWHA's linen to ensure a clean and fresh environment.
- Keeping all skin sores or wounds covered with a bandage or clean cloth.
- Ensuring that things used in the care of the PLWHA are kept away from children.

Keeping Food Safe

- Storing food covered or in fly-proof cupboard.
- Drying utensils out in the sun.
- Using clean boiled water for drinking.
- Washing and drying all fruits and raw vegetables before eating.
- Always washing your hands before and after preparing food.

Disposing of Waste Properly

- Burning
- Burying
- Emptying into pit latrine

Decontamination procedures

1. Protect hands with gloves
2. Rinse soiled items in cold water; pour water into the latrine.
3. Put soiled items into a large pot of water with some soap or detergent as though you were going to wash them. Pound vigorously with a heavy stick.
4. Boil for ten minutes. Stir with the stick.
5. Rinse items thoroughly and place in the sun to dry.

Figure 10.7: Maintaining general and personal hygiene

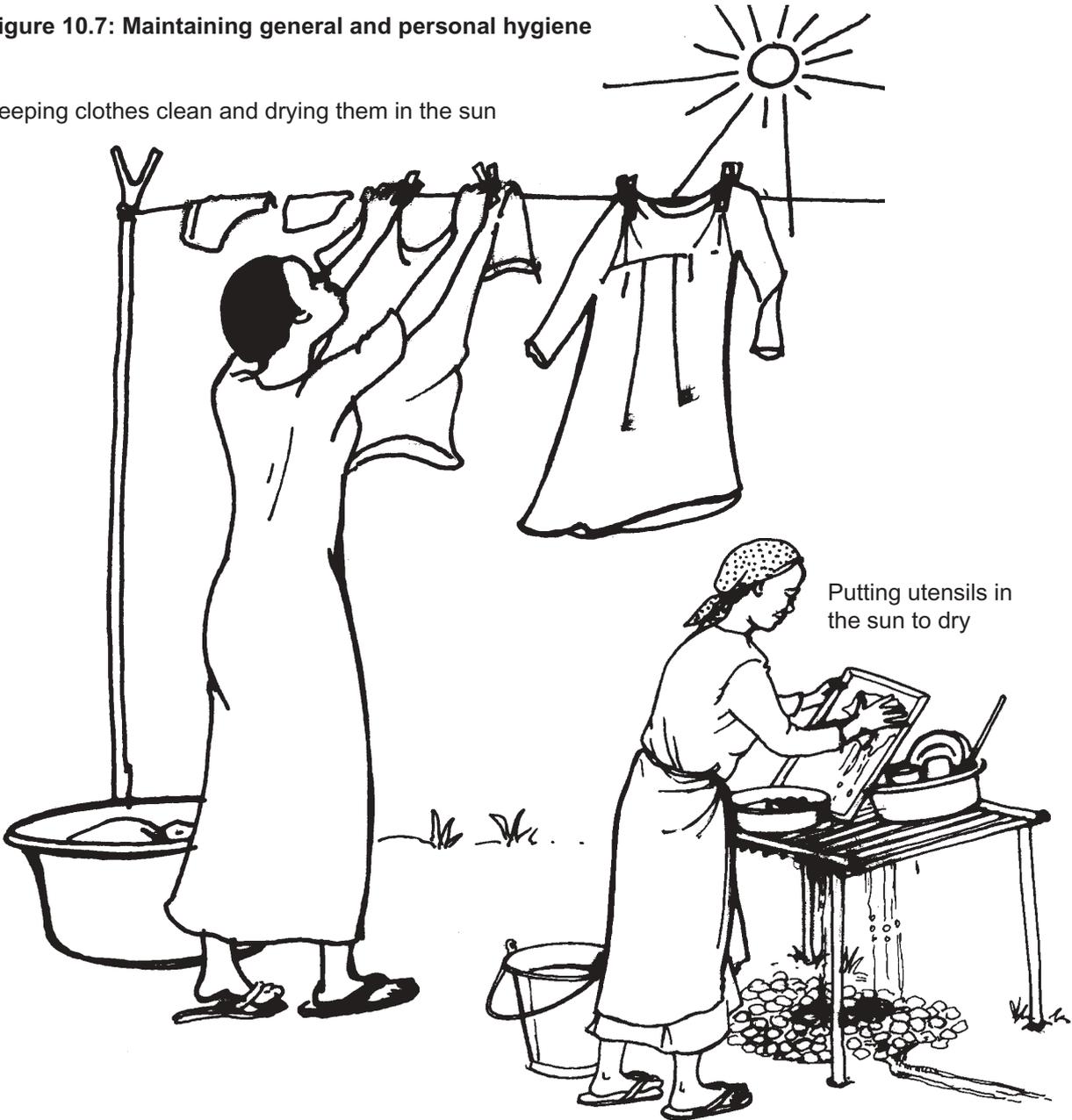


Washing raw vegetables and fruits before eating

Keeping yourself clean

Figure 10.7: Maintaining general and personal hygiene

Keeping clothes clean and drying them in the sun



Putting utensils in the sun to dry

Boiling drinking water



Keeping food covered



11

COUNSELLING AND PSYCHO-SPIRITUAL CARE

People with HIV/AIDS experience a variety of social support needs, psychological distresses, and spiritual yearnings. These needs are felt most strongly during the initial period of the disease when the HIV-positive results are received and in the later phase when the illness progresses and opportunistic infections occur.

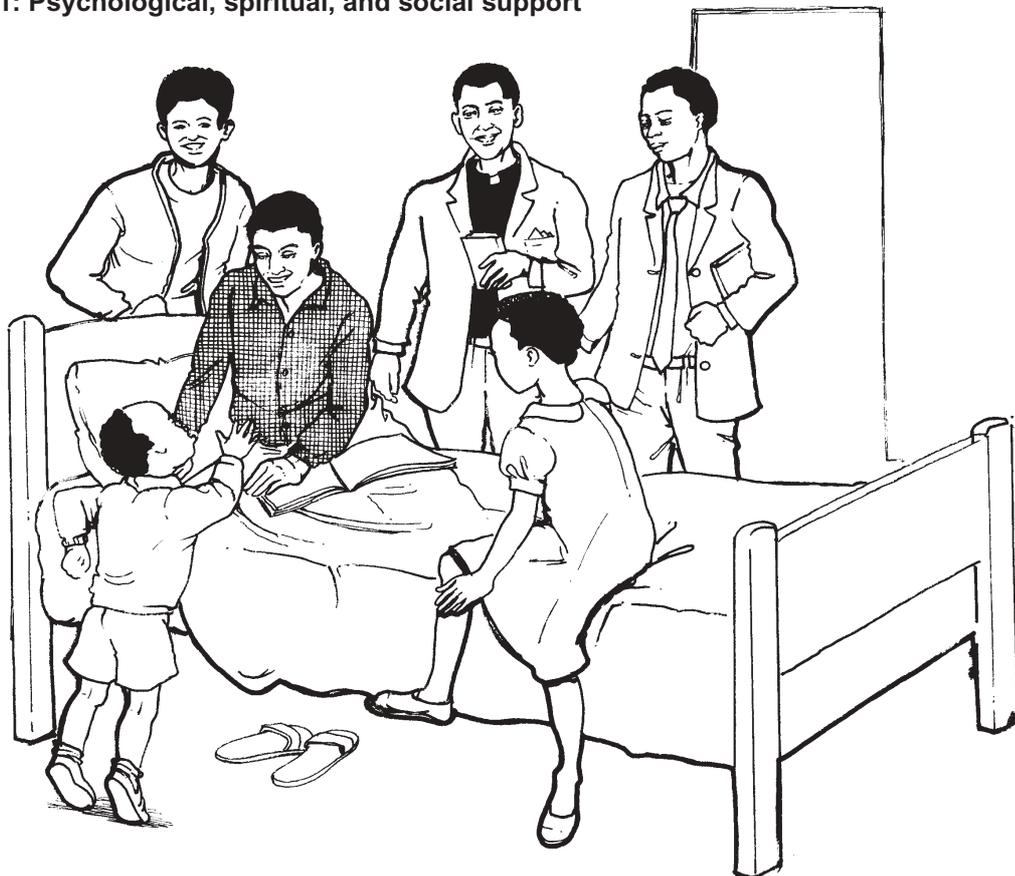
As described earlier, the HIV-positive person and family members may require a great deal of this type of support. Reduced income or unemployment comes as a major obstacle to emotional and spiritual well-being, as the HIV-positive person may be either denied employment as a result of the disease or unable to work or generate income during periods of severe illness. Family members may also be so taken up by caring for the person that they miss

work or school frequently or do not have time to attend to income-generating activities regularly. Unreasoned discrimination isolates the PLWHA and family from any community activities. Some neighbours may even avoid any social interaction with the family because of their HIV status.

To help counter these negative experiences and feelings, and promote positive living, several areas will need attention:

- Spiritual support/Pastoral care
- Social support
- Psychological support/Counselling
- Behaviour change counselling

Figure 11.1: Psychological, spiritual, and social support



11.1 Spiritual/Pastoral Care and Support

While providing spiritual/pastoral care, spiritual leaders should avoid introducing their own values and faith as opposed to the PLWHA's beliefs, but instead enhance the PLWHA's spiritual growth. This plays a great part in encouraging the PLWHA to have a positive view of life and to forgive others and self for any misconceptions and blames.

The aims of offering spiritual/pastoral care services to PLWHAs and their families are:

- To strengthen the spiritual, physical, mental, and social well-being of the PLWHA.
- To enable the PLWHA to face life with confidence and the assurance that their God, however perceived, unconditionally loves and accepts them.
- To facilitate the opportunity for the PLWHA to receive necessary sacraments.
- To remind the PLWHA of the mortality of our bodies that is, everyone will one day be subject to death.
- To reconcile with the past, present, and future.
- To enable the family to cope, to fulfil the obligation to the PLWHA, and to come to terms with their own loss.
- To help the community to avoid condemnation of the infected and affected and hence be challenged to help when needs arise.

With appropriate spiritual/pastoral support, it is expected that the PLWHA will:

- Accept forgiveness by others
- Forgive others
- Have reassurance that God accepts them

11.1.1 Issues in Giving Spiritual Support

Spiritual caregivers should not impose their faith on the PLWHA. They should also consider the following points:

- PLWHA's religious affiliation.
- The age group, gender, marital status, and culture of the PLWHA.
- Preparation of the family and the PLWHA before the support is given.
- The need for sensitizing the community on the importance of spiritual support to help them take the initiative to visit the PLWHA individually or in groups and, once the

support group or the individual has visited, to explore possibilities of targeting the individual for spiritual follow up.

11.1.2 Who Can Offer Spiritual/Pastoral Care

Spiritual/pastoral care and support can be offered by any of the following people:

- Appointed religious or spiritual leaders.
- Appointed lay leaders.
- Any other mature follower of the same faith of the infected and affected member who is present at the time of need.
- A spiritual leader or a pastor who is the choice of the PLWHA and/or the family members.

In effect, anyone can listen to a person's fears and concerns about spiritual matters if they have good counselling and communications skills. The key is being respectful and non-judgemental.

Figure 11.2: Who should give spiritual/pastoral care



11.1.3 When Spiritual/Pastoral Care Is Necessary in HBC

- On a day-to-day basis.
- When one needs hope and assurance.
- When one is isolated and faced with the possibility of death, or the death of a loved one.
- When one is discriminated against and stigmatized because of being infected with HIV.
- And sometimes when all hope is gone and everything else has faded, and the Almighty God remains the only hope.

11.2 Social Support

PLWHAs need company and association without stigma or discrimination. Recreation and

exercise back up social support, which can be achieved through participation in community activities. PLWHAs have the right to belong to clubs and other groups, and need to be considered as people of value and with rights to be respected.

Involvement in social activities they can manage is important to PLWHAs so that they are not cut off from activities they enjoy, e.g., political rallies, church/mosque/temple gatherings. Other needs of PLWHAs include:

- Love and acceptance from all around.
- Source of income/employment/income-generating activities.
- Confidentiality regarding HIV status by all who know about it.
- Security of person and property.
- Respect and help with the activities of daily living.
- Care of orphans and children in need, including any necessary legal interventions, especially regarding property inheritance.

11.3 Counselling/Psychological Support

In addition to involvement in day-to-day community activities without discrimination or isolation, HIV-positive people and their family members may also need professional psychological support through counselling.

Counselling is a helping relationship that assists people to understand and deal with their problems, and to communicate better with those around them. In HIV/AIDS counselling the counsellor focuses on the person rather than the disease. Counselling does not mean giving advice or taking over the client's problems. It does mean encouraging the client to discover present feelings, behaviour, and emotions and thereafter to identify solutions to the problems.

With the HIV/AIDS scourge, most counsellors focus more on the pre- and post-test counselling. However, counselling should not just end at the test but continue thereafter depending on the nature of the test results. Let us first look at pre- and post-test counselling.

11.3.1 Pre-Test Counselling

Within the context of home-based care, a number of clients will likely require pre- and post-test counselling. In most cases these will be the spouse of an HIV-positive client or a care

provider who might be worried and wants to know about their HIV status. Other relatives who are not directly involved with the PLWHA's care may want to know their status after learning more about the disease. While counselling these people, the counsellor will need to:

- Make sure the client understands the basic facts about HIV infection and AIDS.
- Assist the client to understand what the test really means and what the results mean, whether positive or negative, including the window period when results are negative in spite of existing infection.
- Prepare the client to receive the results, both positive and negative.
- Ensure that the client has trust in the counsellor, who should in turn ensure confidentiality of all the information obtained from the client.
- Explore potential support from loved ones, family, and friends and inform the client of all available support centres and groups in the event the results are positive.
- Explore what the client might do if the test is positive, the possible ways of coping with such a result, whom to tell, and what to tell.
- After exploring all of these issues, assist the client to make an informed decision whether to take the HIV test or not.

11.3.2 Post-Test Counselling

Patients or clients who have undergone pre-test counselling for an HIV antibody test will require post-test counselling whether the test results are negative or positive. Either way, the counsellor will need to give a detailed explanation of what the test results mean.

For HIV-Negative Results

If the test result is negative, the counsellor should:

- Remind the client about the window period, especially if there are possible risks of previous exposure to the infection, e.g., an HIV-positive sexual partner. This should also include the possibilities of re-testing after a specified period of time.
- Review the basic facts on HIV that were covered during the pre-test counselling.
- Stress the importance of avoiding risky behaviour that exposes the client to HIV infection.

For HIV-Positive Results

After an HIV-positive test result, the health worker should:

- Ensure that the client understands the meaning of a positive test result and is aware of the possibilities and dangers of spreading the infection to future sexual partners.
- Discuss how the client feels about the test and about being infected.
- Discuss plans the client has to deal with the immediate future.
- Discuss any support services available and refer the client, if desired, to available community services or support groups.
- Establish a relationship for future counselling and schedule appointments.
- Encourage client to bring partner(s) for counselling and subsequent testing.
- Stress the importance of abstinence or condom use to avoid future re-infection and further transmission of the disease.
- For HIV-positive women, explain the possible outcome of pregnancy so that they can make informed decisions about having children.
- Assist the client to work out possible follow-up plan for care both at home and in the health facilities.
- Discuss how to stay healthy, particularly including the importance of good nutrition, moderate exercise, adequate rest, and prompt treatment of opportunistic infections.

11.3.3 Other Counselling Needs

Apart from pre- and post-test counselling, there are other areas of focus the counsellor will need to look into. These include the following situations:

- Preventive counselling for those who are sexually active and therefore exposed to the risk of getting HIV infected.
- Positive living counselling for people who are found to be HIV infected. This will include encouragement and motivation to live positively and continue with daily activities, as well as provision of a sense of hope, acceptance, love, and support.
- Individual supportive counselling for family members of PLWHAs to enable them to cope with the psychological, emotional, and economic impact of the disease.
- Family counselling for families who have to take care of an HIV-positive relative. Family members in such a situation will need a lot of information on the infection, expected outcomes, and what to do at different stages of the disease.

- Bereavement counselling for the PLWHA and the family, who may be suffering a variety of losses and grieving in anticipation of the impending death. Children may need special attention because they may not be able to articulate their fears.

11.3.4 Who Can Offer HIV/AIDS Counselling

HIV/AIDS counselling can be offered by any of the following:

- The professional counsellor who is trained in basic counselling skills or HIV/AIDS counselling, like pre- and post-test counselling. These will include counsellors, psychiatrists, psychologists, social workers, nurses, etc.
- Religious leaders who are trained in pastoral counselling.
- Health workers who have been exposed to the HIV/AIDS counselling orientation programme and are preparing the client/patient for referral to a qualified counsellor.

11.3.5 The Qualities of a Good Counsellor

A good counsellor is able to put the person at ease and draw out any problems or concerns. The good counsellor is also adept at getting the person to consider alternative ways of dealing with the problems and choosing the most appropriate for action. Two things are critical: projecting a caring attitude and avoiding judgement. The tools of the trade for counsellors are listening, responding, understanding and communicating, and keeping confidences.

Active Listening

Every client has a story to tell and the way a counsellor responds will greatly depend on whether they have been actively listening to the story. Active listening involves carefully noticing and attending to both verbal and non verbal messages. It is important for the counsellor to check whether responses are being influenced by own thoughts and feelings. While listening, the counsellor should pay special attention to two areas:

- The content of the story: that is, listening to the story as the client tells it.
- The process of the story: This involves listening to the feelings, concerns, and worries that the client might or might not verbalize. These may be in form of body language or tone of voice that may be contradicting the content of the story being told.

Listening therefore involves:

- Knowing what to listen for.
- Looking for themes of the story and sore notes that may need challenging.
- Recalling and pointing out expressions.
- Reflecting on what is being said.
- Resisting any distractions.
- Encouraging the client to tell the story.

The counsellor's facial expressions and whole body language play a big part in encouraging or discouraging the client to keep talking. Provided they are not overdone, the use of encouraging phrases like okay, yes, eehh, mmnh, etc., can be encouraging to the client, who will know the counsellor is listening throughout the discussion.

Empathic Responding

This is an intellectual process that involves understanding correctly another person's emotional state and point of view. Empathy can also refer to the process of getting inside the world of the other person and experiencing the world as the person does. Examples of such responses are:

I understand how distressed you feel (emotional state) because your husband won't even talk about having another child (point of view).

I understand how exited you feel (emotional state) because your daughter is graduating after six years of hard work at the university (point of view).

It is even possible to have examples that are related to HIV/AIDS like, *I understand how distressed you feel because your husband thinks you are the one who infected him.*

Understanding and Communicating

Although many people feel empathy and understand the other person's feelings, the truth is that very few know how to put it into words so as to communicate such understanding to the person. On the other hand, it would be a mistake to say nothing, otherwise the client might think that all they have been saying does not merit response or is not worth hearing.

Communicating the understanding helps the client to feel understood and therefore encouraged to continue with the session. Since clients express feelings in a number of different ways, the counsellor can communicate an understanding of feelings in a variety of ways such as:

Figure 11.3: Good counselling with acceptance and understanding



- By single words: You feel good. You are depressed. You feel trapped. You are angry.
- By different kinds of phrases: You feel left out. You are really steaming. You are on top of the world.
- By citing the behaviour that is implied: You feel like hugging him. Now that it is over, you feel like celebrating.

Maintaining Confidentiality

The diagnosis of a client is not a community issue, therefore the few people privileged to know the HIV status of the PLWHA should not discuss or share the information with others without the prior permission and information of the client. Those privileged to know this confidential information will include the caregivers, the spouse of the PLWHA, and, if the PLWHA is not married, the parents. The PLWHA is at liberty to inform anyone else who needs to know.

It is important for caregivers, spouses, and parents to be aware of the condition they are handling in order to avoid cross infection among them and to facilitate proper care and acceptance of the PLWHA. This shared confidentiality also alleviates fears and suspicion among the immediate family members.

The counsellor's role will therefore be to prepare the PLWHA well enough to be able to communicate the diagnosis to the relevant people with ease. The other role will be to prepare the family members for the news of the HIV status of the client.

11.4 Behaviour Change Support

There are two aspects to behaviour change counselling:

- To encourage persons who have tested *HIV-negative* to adopt behaviours and lifestyle patterns that may be less risky than those practised before the test.
- To encourage persons who have tested *HIV-positive* to adopt behaviours and lifestyle patterns that enhance their own health status and that prevent further transmission of HIV.

Counsellors need to be aware that whether the results are negative or positive, behaviour change may present a troubling dilemma to persons who are married or in union. Taking steps to change behaviour in this case means more than simply an individual decision; the reactions of the spouse or partner must also be considered. Ideally, couples should be tested and counselled together to help them adjust to any changes that may be necessary in their life.



The ABC of safer sex

- A - Abstain!
- B - Be faithful to a single partner whose only partner is you!
- C - Condomize! Use a condom every time
- D - Don't take chances!

11.4.1 For HIV-Negative Persons

People often seek out HIV testing because they are worried that they may have at some point for some reason contracted the virus. The cause of the worry may be their own behaviour or the known or suspected behaviour of a spouse or partner. A negative test result is like a second chance for such worried folks: They find out they are clean and they want to stay that way. Behaviour change counselling takes advantage of that window of opportunity to support HIV-negative persons in their choices of a healthier, safer lifestyle.

For people who are concerned about their own risky behaviour, the idea is to reinforce the message that they can maintain their negative status by avoiding behaviours that expose them to the risk of HIV infection. They should be encouraged to take the A-B-C precautions: **A**bstaining from sex, **B**eing faithful to a single

faithful partner, and using **C**ondoms for each and every sexual act. Known drug users should also be advised not to share needles.

The situation is more problematic for people who are worried about the behaviour of a spouse or partner. Such a situation is especially difficult for women, who often have no power in sexual negotiations and could not refuse sex or suddenly insist on the use of condoms. Encourage the person to be as assertive as possible in insisting that the spouse or partner go for counselling and testing.

Regardless of the source of the original worry, HIV-negative persons should also be encouraged to seek prompt treatment for any symptom of any sexually-transmitted infection.

11.4.2 For HIV-Positive Persons

For the person whose test results are positive, the immediate damage has of course already been done. The idea of behaviour change counselling in this case is to prevent further transmission of the disease and to focus on behaviour choices that support positive living. The A-B-C precautions remain important for this group as well. The use of condoms not only helps prevent the further transmission of the disease, it also reduces their own chance of re-infection, which builds up the amount of the virus in the system.

Married women who test positive may find that their husbands react violently to the results of the test. This may be true even if the husband also tests positive. Careful counselling is in order here to ensure that couples fully understand their situation and their options.

Sexual behaviour is only one area that may need to be examined and supported for change. HIV-positive persons may also need help with adjusting their attitudes toward nutrition, exercise, and other aspects of any normal healthy lifestyle for some people giving up the daily *pombe* and *nyama choma* feast may be as difficult as changing sexual behaviour. Eating a well balanced diet, exercising regularly, reducing alcohol intake, and stopping the use of tobacco and other recreational drugs can add years of healthy living to the HIV-positive person's life. Proper rest, stress reduction, and prompt treatment of any infections that arise are also important to maintaining good health.



12

PALLIATIVE AND TERMINAL CARE

Before the advent of the HIV/AIDS epidemic there was a reasonably clear distinction between palliative and terminal care. Cancer patients, for example, typically remain in a fairly steady state before the disease takes its toll and renders the patient bedridden and completely dependent. AIDS has changed that to some extent; because of their lowered immune capacity AIDS patients may move back and forth between needing palliative and terminal care as they battle opportunistic infections, any one of which could be the last. Between episodes of infection, until the disease finally progresses to the terminal stage, the PLWHA may be quite able to carry on with a reasonably normal life.

It is therefore necessary to take a broader view of palliative and terminal care. For the purposes of these guidelines, palliative care may be defined as care intended to keep the person with HIV/AIDS as healthy as possible as long as possible. Terminal care, on the other hand, is the care given to a completely bedridden and dependent patient pending death.

12.1 Palliative Care

Palliative care generally refers to the care of people whose disease does not respond to curative treatment. Palliative care eases symptoms and keeps the patient as comfortable as possible. From that perspective, virtually all of the various elements of care described in these guidelines can be considered palliative.

12.1.1 Goals of Palliative Care

HIV infection brings with it a wide array of minor and major health problems and conditions, and susceptibility to potentially fatal infections. Unlike most other terminal diseases, however, it also carries a level of stigmatization that leaves infected persons feeling alienated and discriminated against. Often these are not just feelings, they are the facts of life for persons with HIV/AIDS, as families and communities do in fact reject them. Thus people infected with HIV experience a multitude of physical ailments

compounded by psychological, emotional, and spiritual problems.

To meet those multiple needs, if we define palliative care, as above, as the care that is provided to keep the PLWHA as healthy as possible as long as possible, then the goals of palliative care are self-evident:

- Manage the common symptoms that occur as a result of the infection.
- Help the PLWHA cope with the stigma and emotional trauma of the infection.
- Permit the PLWHA to take responsibility for the course of care.
- Assist the PLWHA and the family to prepare for the death, psychologically, spiritually, and physically (e.g., writing a will).
- Avoid any discriminatory or judgmental attitude.

This last may be the most difficult goal for caregivers to achieve because it challenges their own deep-seated views and emotional reactions.

12.1.2 Palliative Care Needs and Activities

The needs and activities of palliative care are those presented in earlier sections of the guidelines:

- Clinical care, with special emphasis on prompt treatment of all opportunistic infections
- Nursing care, with special emphasis on proper nutrition
- Counselling and psycho-spiritual care
- Social support
- Training family members to provide care and help manage particular problems

12.2 Terminal Care

A patient is referred to as being in the terminal stage of a disease when the infection or illness has progressed beyond what medicine can cure. This is therefore a period in which, despite all

the treatment given, the patient does not respond. The period lasts as long as the patient is alive. Terminal care neither hastens nor postpones death. Dying occurs in its own time as the major organs of a person stop functioning the brain, heart, and lungs.

In all illnesses referred to as terminal, as in HIV/AIDS or different types of cancer, the care given is intensive and very involving since the patient totally or partially depends on care providers for all daily living needs. In many cases the patient may be on life support machines. During this period all care providers in both health institutions and the home need to take precautions to avoid burnout syndrome. Burnout occurs when caregivers become exhausted and tired. It can be relieved through regular group meetings, social visits by members of the community, and even alternating the tasks of care in shifts.

12.2.1 Goals of Terminal Care

Terminal care continues palliative care. Its main goal is to prepare the patient and the family members for the impending death and to help the patient die with dignity. To achieve this goal, the health worker or family care provider should aim at:

- Enhancing the quality of life of the patient.
- Relieving pain and other distressing symptoms.
- Providing practical emotional support for the patient and the family members.
- Helping patient and family members to organize their lives and orient them to the forthcoming death. This can include assistance with writing or verbalizing wills.
- Facilitating a comfortable and dignified death.
- Ensuring bereavement support to the family after the death.

12.2.2 Terminal Care Needs and Activities

The needs of terminally ill patients should never be considered less than they were in the early stages of the illness. Needs include spiritual/pastoral care, psychological and emotional support, and physical care including clinical and nursing care. The following activities will help ensure that all these needs are met.

Giving Comfort

The need for basic comfort remains particularly important. Meeting this need entails:

- Extending physiotherapy by encouraging deep breathing or giving back rubs and body massage.
- Using relaxation techniques, e.g., watching television, movies, or games, or engaging in social discussions.
- Providing or arranging for counselling and spiritual support if desired.
- Providing physical contact by touching, holding hands, and keeping the patient company. This ensures psychological and emotional support to the patient and family.
- Encouraging communication with the family members and community. It is important to avoid talking in whispers in an attempt to keep your conversations out of reach of the patient; this can cause suspicion and lead to mistrust.

Maintaining Patient Independence

As long as the person is conscious and feeling, they need to retain their sense of independence and personal dignity. Caregivers can help with this by:

- Accepting the PLWHA's own decisions about daily activities, e.g., refusal to eat, staying in bed, or even not wanting to talk.
- Respecting PLWHA's requests, e.g., to be allowed to die at home, who should be permitted to visit, etc.
- Giving the PLWHA support by allowing them to talk about death and express their feelings about it. This helps them realize that their concerns are heard.
- Enhancing the PLWHA's self-esteem by reflecting on life achievements and accomplishments.
- Helping the PLWHA plan with family members and friends or orphan programmes for the future of their children. This helps ease their worries over their children.
- Discouraging over-dependence by the PLWHA and family members by making sure that all they have to do for the PLWHA is clear to them and they can handle it by themselves.

Providing Clinical Care

Clinical help for the terminally ill focuses on:

- Minimizing pain and controlling terminal delirium.
- Counselling the PLWHA and family caregiver on drug compliance.

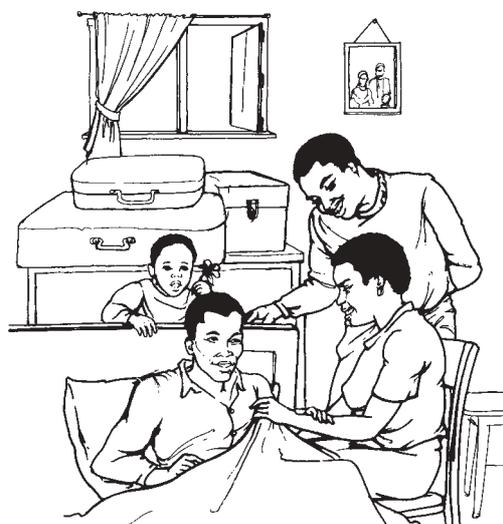
- Reducing respiratory problems like shortness of breath and the risk of aspiration.
- Reducing and/or controlling the risk of infections.
- Dealing with sleep problems, if necessary by use of specific medications, e.g., diazepam.

Providing Nursing Care

Nursing care for the terminally ill should focus on helping the patient by:

- Relieving regular pains and aches through either painkillers or massage.
- Maintaining personal hygiene through daily bed bath, oral hygiene, and supervision of feeding.
- Preventing pressure sores by changing soiled linen and turning the patient regularly, i.e., every 2 hours.
- Minimizing risk of skin breakdown such as pressure sores.
- Being available for the patient for physical comfort.
- Preventing the cracking of mucus membranes by use of Vaseline.

Figure 12.1: Nursing within home setting



Preparing for Death

Helping the PLWHA prepare for death includes:

- Acknowledging the truth of the situation and being able to talk about the fact that the PLWHA is dying.
- Relieving the fear of pain as the PLWHA nears death by describing to them what may happen, e.g., that they might lapse into unconsciousness, or experience difficulty in breathing. Reassure them that any pain will be dealt with as it comes.

- Assisting the PLWHA in deciding what they would like done after death, e.g., funeral arrangements. This should be discussed with family members and representatives of their religion.

12.3 Networking in the Provision of Palliative and Terminal Care

Taking care of a terminally ill person calls for the use of many resources in form of materials and people. To ensure this, care providers at all levels should endeavour to establish a functional networking system:

- With the nearest hospice or health facility for supply of drugs and dressings, as well as transport support when the PLWHA may need to be taken to the health facility.
- With the legal offices for the preparation of a will and security of property for those being left behind.
- With spiritual leaders to ensure adequate spiritual support, including for the family extending after the death.
- With relatives to ensure smooth preparations for both the care and the burial.
- With the children's department if preparing for facility care for children.
- With the administration for the provision of the death certificate in the event the death occurs at home. The administration may also help in transporting the body if notified earlier.
- With local CBOs/NGOs for social and material support.

12.4 Care after Death

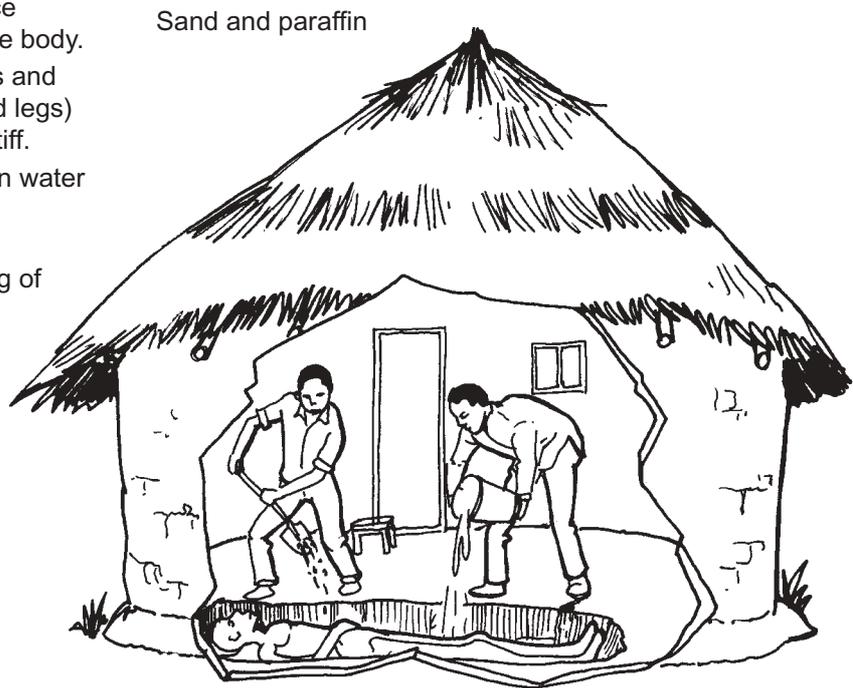
Once the patient has died the body should be treated with respect. Infection prevention procedures should be followed when handling or treating the body during the first 24 hours after death. However, family members, friends, and relatives should be told that after that period, no special precautions need to be taken during the funeral such as wrapping the body with polythene papers or disinfecting it. The care provider should comfort those who need comforting without getting in their way. The care provider should also try to avoid breaking unexpected bad news by telephone, but instead use person-to-person communication.

12.4.1 The Last Offices

This is the care given to the body immediately after death. The procedure involves the following tasks:

- Using protective material (e.g., gloves) when handling the body fluids, e.g., diarrhoea and blood. Strict measures of infection control are of paramount importance especially when cleaning the body.
- Closing the mouth and eyes and aligning the limbs (arms and legs) before the body becomes stiff.
- Washing the body with clean water and soap.
- Closing all the body orifices (openings) to prevent oozing of body fluids.
- Covering any open wounds with elastoplast or bandage or clean cloths.
- Disposing of remaining medications such as narcotics by burning, flushing in toilet, or putting in pit latrine.
- Clearing and removing any other equipment, using universal precautions of infection control and sterilization.

Figure 12.2: Traditional ways of preserving bodies

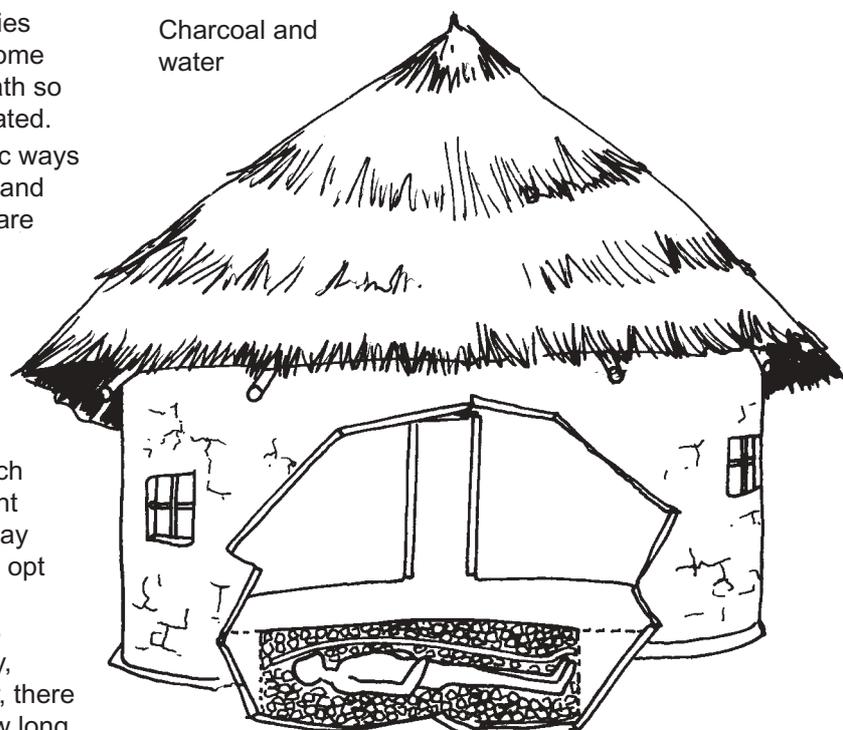


Once the body is tended to, the following steps should be taken:

- Notifying health care agencies who have been providing home care about the person's death so that services can be terminated.
- Discussing different hygienic ways of traditional body handling and preservation for those who are unable to access mortuary services.

12.4.2 Some Traditional Methods of Body Preservation

These are different ways in which bodies are preserved by different communities. Several factors may make families and communities opt for these traditional methods of preserving bodies. The reasons include distance to the mortuary, economic factors, etc. However, there is no reliable information on how long these methods can properly preserve a body.



12.5 Follow-up Services for Family Members Left Behind

An AIDS death leaves a lot of destruction in its wake. The process is long and debilitating and often exhausts family resources. Family caregivers are usually exhausted, too, in the other sense of the word, both physically and spiritually.

And the reality is that the stigma attached to AIDS means that in the months of terminal care the household may never have any visitors except the community health worker and other home care team members. An important bond develops between the family and the community health worker. The bond is particularly important for children, who may be losing a parent and sense of security, and who see the health worker as their only friend.

This situation has both positive and negative aspects. The health care team can be enriched spiritually by the services they render and the poignant acknowledgement of the importance of the services. On the other hand, the level of dependence that can develop is beyond the capacity to sustain for a home care team that has many such client families. There is need for health workers to strike a personal emotional balance between doing the best you can in such a situation and letting the situation reach the point where separation will cause even further devastation.

At a professional level, the job of the health worker is to try to mobilize sufficient community resources and support to ensure that the needs

of children especially are met. Here is where the effort to get communities involved can have big dividends. Ideally, effective community mobilization will go a long way toward enlightening community members and reducing stigma, so that eventually the problem of the isolation of AIDS families will be reduced.

Until that time, however, the community health worker and other home care team members will remain the only source of stability for AIDS bereaved families. The team members will be called upon to help the survivors. Among the actions that may be required are:

- Arranging for the children and other family members to receive bereavement counselling and spiritual support.
- Working with local organizations to provide foster care for the children.
- Seeking legal aid so that the spouse's and children's rights to inheritance are protected.
- Arranging bursaries to cover school fees.
- Linking older children and adult family members with programmes to support income-generating activities.
- Enlisting members of the extended family to support young children with food, shelter, and a loving environment.
- Taking other measures to ensure that the children are not lost.

Kenya already has nearly a million AIDS orphans. They need all the help the nation can provide, and it is part of the home care team's responsibility to try to mobilize that assistance.

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GLOSSARY

Abstinence - Avoiding sexual activity altogether

AIDS - Acquired immune deficiency syndrome, a progressive, ultimately fatal condition (syndrome) that reduces the body's ability to fight certain infections. Caused by infection with human immunodeficiency virus (HIV).

Analgesics - Medicines for pain

Antacids - Medicines for pain in the lower chest and upper abdomen caused by too much acid in the stomach

Antibiotics - Medicines for treating infections caused by bacteria

Antidiarrhoeics - Medicines for diarrhoea

Antitussives - Medicines for cough

Asymptomatic - Not having any symptoms, even though infected with a disease

Bacteria - Micro-organisms; some are helpful to body functions, but many cause diseases

Concept - An idea

Condom - A rubber sheath worn on an erect penis during sexual intercourse to prevent pregnancy and sexually transmitted diseases

Community health worker - A trained person, often a volunteer, who works within a community to teach people about health practices, provides some simple treatments, and refers sick people to clinics/medical centres for other necessary treatment

Contamination - The process of introducing harmful substances, such as germs

Contracture - Condition that occurs when a joint is not moved for some time, causing the muscles to tighten and preventing the limb from straightening fully

Counselling - Communication between two people in which one person has a problem and the other is trying to help solve the problem

Decontamination - The process of removing or destroying harmful substances such as germs

Diagnosis - A doctor's or medical practitioner's conclusion about what a sick person is actually suffering from

Draw sheet - A bed sheet, usually used with a waterproof pad, that is placed on the bed of an incontinent patient to protect the other bedding

Drug administration - The manner in which medicines are given to the sick

Environmental hygiene - Keeping the surroundings, houses, compound, etc., clean

General hygiene - Keeping the body and surroundings fresh and clean

Home-based care - Services given at home to people who are ill. Services to people with HIV/AIDS focus on clinical care, nursing care, psycho-spiritual care, and social support

Immune system - The part of the body's structure and function that fights against infections

Infection - Invasion and multiplication in the body of disease-causing germs

Integrated - In this context, combining services to prevent/manage sexually transmitted infections (including HIV) with services for family planning and mother/child health care

Linen - Sheets, blankets, pillowcases, quilts, and other bedding

Massage - Treatment by rubbing/kneading parts of the body to improve circulation, muscle tone

Mode of transmission - The way a disease spreads from one person to another

Mouthwash - A solution to freshen the mouth

Nutrition - Food, feeding; providing a balanced diet

Opportunistic conditions - Infections and diseases that take advantage of HIV-weakened immune system

Oral rehydration salts - Medicines given to people having diarrhoea and/or vomiting to replace the lost water and salts

Physical therapy - Treatment through physical means such as exercises, massage, etc.

Prescription - A written order by a doctor or health worker indicating the name(s) of medicine(s) a specific sick person should take and how they should be taken

Procedure - The specific way something is done

Referral - Sending sick person from the home or community to a health facility (hospital, health centre, dispensary) or other care service, or from the health facility to the community

Sedatives - Medicines given to people having problems with getting to sleep

Semen - Fluid containing sperms that is produced by men during sexual intercourse

Sexually transmitted infections/diseases - The term given to a group of diseases affecting both men and women and generally transmitted during sexual activity

Signs - What the health worker finds when examining a sick person

Soiled linen - Bedding having sick person's faeces, urine, pus, blood, etc.

Spatula - A wooden or metal instrument used for examining the throat

Symptoms - The aches, pains, or other problems a sick person describes to a health worker

Unscreened blood - Blood that has not been tested for HIV

Virus - The smallest disease-causing organism

Vitamins - Substances found in food that are essential for the proper functioning of the body

White blood cells - The part of the blood that guards the body against disease-causing organisms

Zero grazing - Restricting your sexual activity to one sexual partner whose only partner is you

RECOMMENDED HOME-BASED CARE SUPPLIES AND MEDICATIONS

Community volunteer kit	Patient primary kit	Patient re-supply kit
<i>Supplies:</i>	<i>Supplies:</i>	<i>Supplies:</i>
<i>Quantity:</i>	<i>Quantity:</i>	<i>Quantity:</i>
Gloves (latex, non sterile)	Gloves (latex, non sterile)	Gloves (latex, non sterile)
100	100	100
Bar soap	Soap	Soap
1 bar	1	1
Toilet paper	Toilet paper	Toilet paper
2 rolls	2 rolls	2 rolls
Scissors (small)	Vaseline	Vaseline
1	1 (250g)	5x100g
Razor blades	Bucket with lid	Talcum powder
25	1 (25 ltr)	5x100g
Waste disposal bags	Basin (45cm diameter)	Waste disposal bags
100	1	5 pkts 100
Jik	Mosquito net (impregnated)	Cotton wool
750ml	1 single size	1x100g
Surgical spirit	Talcum powder	Gauze
750ml	1 (100g)	50
Plastic apron	Nail cutter (small)	Bandages
1	1	5 doz
Mackintosh (2 metres)	Scissors (small, steel)	Jik
1	1	5x250ml
Condoms	Waste disposal bags	Condoms
100	100	5x100
	Cotton wool	
	Gauze 4x4 non sterile	Medications:
Medications:	Bandages, crepe, 4"	100g, 2 rolls
Aspirin/paracetamol	Mackintosh, 2 metres	1 pkt 100
100	Jik	Paracetamol
100	Bed sheets	Alberdazol
24 tabs	3-inch mattress	12
50 tabs	Condoms	1
100	Wooden spatula	Oral rehydration salts (ORS)
		250ml
		Multi-vitamins
		300
		Tetracycline skin ointment (3%)
		3 tubes
		Gentamicine eye drops
		3 bottles
		Calamine lotion
		250ml
		Savlon (chloramide forte)
		500ml
		Dettol cream
		Nystatin oral drops (24 ml)
		20g
		SP - Fansidar
		5 bottles
		Iron tablets
		5x24 tabs
		Piriton (pm - generic)
		100
		Carrying bag/basket
		100
		Handbook
		1
		Portable flip chart
		1
		Register/Diary
		1
		Notebook
		1
		Pencil/ballpoint pen
		1
		Carrying bag/basket
		1
		Tetracycline skin ointment (3%)
		3 tubes
		Gentamicine eye drops
		2 bottles 5ml
		Calamine lotion
		Savlon (chloramide forte)
		250ml
		Dettol cream
		500ml
		Nystatin oral drops (24 ml)
		20g
		SP - Fansidar
		1 bottle 24ml
		Iron tablets
		24 tabs
		Piriton (pm - generic)
		100
		Antihistamine tube
		100

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