Under the office of the President

NATIONAL HIV HOME BASED CARE TRAINING MANUAL

APRIL 2016

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Training Manual

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Acknowledgments

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Foreword

The multi-sectoral response to HIV and AIDS and STI has been guided by the National HIV and AIDS, STI Policy. In line with efforts to continue and sustain the progress of the multi-sectoral response in the country, the Ghana AIDS Commission (GAC) in collaboration with key partners and stakeholders have developed four National HIV & AIDS Strategic Plans spanning from 2001 to date with the current Plan being the National HIV and AIDS Strategic Plan 2016-2020 (NSP 2016-2020) to direct the implementation for the national HIV and AIDS response.

Many organisations and communities are now expanding into new programmatic areas, including home-based care for Persons Living with HIV (PLHIV).

Community Home-Based Care (CHBC) interventions in Ghana are at a nascent stage and a national strategy and guidelines are critical to guide its implementation. In Ghana, Community Home-Based Care (CHBC) is being implemented mostly by Civil Society Organizations along with Ghana Health Service staff, the two are mandated to carry out home visits to clients. Unfortunately, CHBC activities are carried out in a policy vacuum, without established mechanisms for coordination and no standardized training of service providers.

The Ghana AIDS Commission in collaboration with development partners and stakeholders developed a country-specific CHBC policy and guidelines targeting policy makers, administrators and those who develop and operate CHBC programme for harmonized CHBC service delivery.

In line with the existence of the CHBC policy and guidelines, this CHBC Training manual has been developed and it is expected that this document will assist in having direct HBC service providers who will be well equipped to implement harmonized HBC services. It will also enable those who manage and operate the programmes to share information and feedback, thus guiding a well-coordinated and standardized CHBC programme across the country

Dr. Angela El-Adas
Director General, GAC

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AIDS	-	Acquired Immune Deficiency Syndrome
ANC	-	Antenatal Care
ART	-	Antiretroviral Treatment
ARVs	-	Antiretroviral Drugs
CBHC	-	Community-Based Health Care
CBHW	-	Community -Based Health Worker
CBOs	-	Community Based Organization
CHBC	-	Community Home Based Care
CHPS	-	Community Health Planning and Services
CSOs	-	Civil Society Organizations
CSS	-	Community Systems Strengthening
DICs	-	Drop-In-Centers
DOTS	-	Directly Observed Treatment Short-Course
DSW	-	Department of Social Welfare
e-MTCT	-	Elimination of Mother-to-Child Transmission of HIV
FBOs	-	Faith Based Organizations
FSWs	-	Female Sex Workers
GAC	-	Ghana AIDS Commission
GCNH	-	Ghana Coalition of NGOs in Health
GF	-	Global Fund
GFATM	-	Global Fund to Fight AIDS, Tuberculosis, and Malaria
GHS	-	Ghana Health Services
GNTBVN	-	Ghana National TB Voice Network
HCWs	-	Health Care Workers
HEI	-	HIV Exposed Infant
HFFG	-	Hope for Future Generations
HIV	-	Human Immunodeficiency Virus
HTS	-	HIV Testing Services
IEC	-	Information, Education and Communication

IHCC - International Heath Care Centre
M&E - Monitoring and Evaluation
NACP - National AIDS and STI Control Program
NAP+ Ghana - Network of People Living with HIV Ghana
NGOs - Non-Governmental Organizations
NTP - National TB Control Program
OICI - Opportunities Industrialization Center International
OIs - Opportunistic Infections
OVC - Orphans and Vulnerable Children
PE - Peer Educators
PLHIV - Persons Living with HIV
PMTCT - Prevention of Mother to Child Transmission of HIV
PwD - Persons with Disabilities
RH - Reproductive Health
STBP-Gh - Stop TB Partnership Ghana
STIs - Sexually Transmitted Infections
TB - Tuberculosis
TSUs - Technical Support Units
WAAF - West Africa AIDS Foundation
WHO - World Health Organization
YPLHIV - Young People Living with HIV

1.1 Introduction

This document provides a comprehensive and practical knowledge as well as solutions for community home based care for PLHIV and also provide knowledge on opportunistic infections and how to treat and managed them. It is prepared for all home based care service providers irrespective of their literacy rate and gender. It is a trainer's manual with illustrative examples and communication strategy to assist the trainer to effectively equip the caregiver with the requisite knowledge and skill.

1.1.1 Contextual Overview

Ghana is committed to ensuring that the National HIV response has in place all relevant policies and programs that promotes the provision of the entire spectrum of HIV services and care. However, in Ghana, not until 2012, Community Home Based Care (CHBC) seemed to have been neglected. Unlike other countries with CHBC programs guided by National Policies, CHBC in Ghana remained fragmented, being implemented mostly by Civil Society Organizations (CSOs) along with some Ghana Health Service (GHS) staff mandated to carry out home visits to clients, in a policy vacuum, without established mechanisms for coordination and no standardized training of service providers.

The quest to examine this issue critically led to the development of the first ever National CHBC Policy and Guideline in 2012 intended to provide direction and back activities carried out by the few implementers as well as encourage other partners' to actively get involve in Home Based Care (HBC). The CHBC policy outlines a number of core elements that must be considered in ensuring sustainable and effective HIV CHBC. They are:

- Provision of basic physical and nursing care
- Continuum of care – which includes accessibility, referrals, care and support services for the infected and affected
- Staffing
- Nutritional support for People Living with HIV and AIDS
- Communication and preventive care – education and involvement of mass media
- Supplies and equipment
- Finance and sustainability
- Monitoring and Evaluation

Initial overview of HBC in the country however revealed inadequate understanding of the concept as well as the required players and skills for HBC for HIV and TB clients. This was confirmed by a "rapid/needs assessment' of the situation, carried out by the West Africa AIDS Foundation (WAAF) on behalf of the GAC. These findings, together with a National Community Home Based Care Policy and Guideline and a National Strategic Plan (NSP 2016 - 2020) that fully support home based care provision, have substantiated the need for developing a National HIV CHBC Training Manual. The CHBC Training manual is to be used to train a variety of service providers, to learn concepts and skills so as to provide high-quality and appropriate support, within a continuum of care for persons infected and affected by HIV and AIDS as well as TB.

1.1.2 Purpose of the Training

This manual has been designed to provide training to staff of community health care facilities to enable them in turn, train home based care givers - who may be relatives or other household members, community volunteers or any other individual who takes care of People Living with HIV and AIDS (PLHIV) in the home setting. The manual is also suitable for training other community health workers interested in training relatives or friends of PLHIV at the community or home level. The training will enable trainees to have the requisite knowledge and skills to perform specified tasks of community home based care to support the overall care of PLHIV.

The training requires five (5) days of classroom time including practical training. It has been developed such that it is very participatory. Trainees are engaged through discussions, role-plays and active practicing of various procedures. Upon satisfactory completion, the trainee is certified as a competent home-based care facilitator and or service provider.

1.1.3 Why the training manual?

PLHIV need access to support and care services to ensure quality of life. For many, hospital care at some point becomes neither necessary nor desirable, and so home based care is an important alternative. Especially considering the increasing numbers of defaulting cases as well as the aim to reach testing and treatment goals recommended by the World Health Organization, it is becoming increasingly evident that not only will people continue to advocate more for services to be available closer to them at the community level, but also, for all forms of care for PLHIV to be delivered with high quality. The need for home and community care for PLHIV has already gained international recognition and is likely to continue and become stronger than before.

In Ghana, just as in other parts of the world, the number of known PLHIV continue to increase through efforts such as "know your status" campaigns. Moreover, through integration of PMTCT into regular ANC services, more women are finding out about their HIV status. It is clear that the need for continuity of care is therefore also increasing. In addition, the devastating socioeconomic consequences on PLHIV and their families, inadequate resources and the limitations of health facility care all lead to inadequacies in health care delivery that leave many without access to optimum health care. The need, therefore to complement facility level care with comprehensive systems of home and community care for PLHIV, to improve quality of life, especially in resource-constrained settings, is extremely important.

Recognizing the need for alternative care to complement facility level care is not new in Ghana. In fact the National AIDS Control Program has taken the lead in providing training to PLHIV who desire to volunteer their time and effort to take care of other PLHIV. These PLHIV who care for their colleagues are commonly referred to as Models of Hope. A Model of Hope is a PLHIV Peer Educator who is on ART and is prepared to assist in a health facility and/or in the community to help peers live positively and adhere to ART. They are to assist the ART care provider as well as other support staff involved in the care of the client to provide the maximum possible care to the client.

Nevertheless, Ghana HIV programmatic data continues to reveal that the work of Models of Hopes far exceeds what many of them can handle. In addition to their work at the facility level, Models of Hope are required to work at the community level. This therefore places very heavy loads on the Models of Hope and sometimes preventing them from effectively engaging in home based care.

A survey by WAAF revealed that many persons who are currently involved in some form of home based care seem to think home based care is equivalent to palliative care. However, when asked what they felt should be added as part of a home based care program, many listed items such as: *ARV adherence, provision of basic needs in the home, following up on defaulters, taking care of terminally ill persons etc*. Therefore, to broaden understanding, provide the needed skills, standardize and enable monitoring of these components of HBC, a comprehensive manual needs to be developed in order to guide the actions and inactions of home based caregivers.

1.1.4 Development of the Training Manual

Like many other training modules, the design of this one draws on the input from an array of stakeholders. The module layout was put together by the WAAF team based on best practices and examples from a number of existing training modules and manuals such as training manual by the International Training and Education Center on HIV (I-TECH), Models of Hope Training Manual - NACP 2013, National Community Home Based Care Policy and Guidelines- GAC 2012, Training Home Based Care Givers to Take Care of PLHIV- STD/AIDS Program of Uganda and Ghana National Community Health Worker Training Manual by World Vision Ghana.

Stakeholders subsequently made input into the layout and also gave suggestions for the content, which was used to develop the framework of the manual. The manual has been developed in such a way that it provides facilitators with the information, specific activities, and materials needed to effectively plan and deliver a hands-on training programme. It also encourages participatory learning and provides hands-on identification of case scenarios, problem solving experiences and exercises.

It is expected that this manual will respond to the needs of PLHIV, TB clients and stakeholders mainly at the community level across Ghana as well as other related organizations. As the area of PLHIV-related HBC is envisioned to evolve, it is expected that the modules will also evolve. We look forward to receiving inputs and improvements from its users.

1.1.5 Organisation of the Training Manual

The manual is divided into the following sections:

- Part I: Provides background information, methods to be used as well as tips for the trainer.
- Part II: Provides an outline and breakdown of sessions.
- Part III: Presents specific session workshops, each covering a different area/topic of HBC and a sample course schedule.

1.1.6 Training Goals and Objectives

The goals of this training are:

1. To develop/refresh the knowledge and skills of community-based service providers in home-based care and the transfer of basic "nursing" care skills to "primary" caregivers and to people living with HIV and or AIDS to enable them take care of themselves.

2. To improve the quality of life for PLHIV by establishing a link between hospital/health professionals and the “primary" caregivers at home.

It is envisaged that by the end of the training, trainees will, amongst others, be able to:

1. Enhance their knowledge on basic facts of HIV and AIDS.
2. Enhance their knowledge on basic facts of TB and its relation with HIV and AIDS
3. Enhance their understanding of the problems PLHIV and those infected with TB face in general
4. Describe the process of mobilizing the community to provide support for home based care activities for PLHIV and TB clients
5. Explain the concept of home based care and the activities undertaken in home based care.
6. Explain the concept of home based care training to caregivers who provide care services for people living with HIV, AIDS and TB.
7. Demonstrate skills necessary to transfer "nursing" care skills to home based caregivers and PLHIV in the classroom and in the field.
8. Evaluate the course.

1.1.7 How to use the Manual

The training may be presented in its entirety or as individual sessions, depending on the needs of the intended audience and the time available.

The contents and format of the manual enables it to be used alone or together with other reference materials on HIV and CHBC.

1.1.8 Tips for the Trainer and Methods Used

The instruction methods for this training have been kept simple to best accommodate trainees to follow the course easily.

Training sessions should begin with what trainees already know and think, and should address the issues they are concerned about. This is best achieved using methods that encourage people to communicate with each other. Communication is a two way process, which is, sharing information, ideas, feelings and knowledge. It means that people in the exchange are speaking as well as actively listening.

Trainers often say that they find it easier to do most of the talking because they feel they do not have the skills and confidence to try other methods. This technique does not give trainees the opportunity to find ways to solve problems.

During the training sessions, the trainees will also have the opportunity to practice the techniques being demonstrated during the training, as this is a more effective way of learning than simply listening or seeing, as shown below.

Trainees retain information through;
20% of what they **hear**
30% of what they **see**
50% of what they **see and hear**
70% of what they **see, hear and say**
90% of what they **see, hear, say and do**

- ➔ **To transfer the information/knowledge within this manual, trainers should make use of both visual materials and participation methods, to increase access to the provided information.**

In your role as a trainer, avoid being judgemental and forcing your opinions on trainees - **listen,** and only give advice when asked. Choose your words carefully. Think about:

- Being direct and clear, while not offending trainees;
- Using words that are acceptable to describe sexual practices, male and female genitals, and your ability to talk freely about sex;

- Using words which do not offend people who have HIV and AIDS, TB and their families;
- Using expressions that do not stigmatize or blame people; for example, use "person living with HIV or AIDS" and not "victim."
- Assessing what trainees already know. This is important so that time is not spent telling trainees what they already know as this will necessarily not be relevant to them. Therefore, It is important to find out about:
  - Trainees' concerns, fears and anxieties;
  - What they know about subjects and the misunderstandings that exist;
  - What they think can and cannot be changed through education;
  - The factors that influence that person's behaviour

Tips and Materials

1. During the training session:

- **use the KISS rule**: **K**eep **I**t **S**hort and **S**imple, avoiding complicated language;
- stress that **everyone's opinion is valuable**, and make clear that the only rules are that one person speaks at a time, that they stick to the topic, and that no one is obliged to talk;
- **Talk honestly about behaviour change** options. For example: if trainees are reluctant to talk about sex, start off with other forms of behaviour change they may feel more comfortable with, such as drinking or smoking less;
- **Repeat the information without boring trainees.** Ask them to summarize what you have said;
- **use visual aids**, and make sure these aids can be seen clearly;
- **Break the main group into smaller subgroups** to discuss issues, and then ask trainees to summarize their discussions in the main group.

➔ **Listen to and note down what trainees say. Don't become involved in the discussion, except to guide it by reminding the trainees of the questions, for example. Ensure that everyone has a chance to speak. Encourage trainees who are quiet, but avoid putting pressure on them.**

Training Materials

The following materials will be needed to conduct this course:

- Laptop or desktop computer with Microsoft PowerPoint presentation
- Blackboard and chalk or white board and markers
- Flip chart
- Any other material(s) the trainer thinks would be useful

Additional materials specific to each session are listed at the beginning of that session's description.

Training Evaluation

In addition to getting a general overview from trainees about their thoughts on the training, it is also important to get their feedback on each of the individual training sessions immediately after the sessions are conducted. In doing this, the trainer can be sure that the training is meeting everyone's needs. The trainers can use the information from the feedback to make changes and improve the next training session.

At the end of each training session or discussion:

- Ask each person for their final comments;
- Summarize what trainees have said, without giving your own opinion, unless you are directly asked;
- Ask trainees what their ideas are for developing any suggestions that came out of the training session.

*** The Home-based Care Training Evaluation Form, at the back of this manual is to be used at the end of the entire training**.

1.1.9 Outline and Breakdown of Sessions

Throughout this training manual you will find Activity Plans intended to lead you, the facilitator, through the day of training. The plans have been selected to provide a logical progression through the material so that participants can build on their knowledge and effectively understand each activity. The facilitator may notice that the estimated time allotted and expectations of how activities proceed vary from group to group. Use the plans as a starting point, but keep in mind how an individual group may respond and what their needs might indicate.

The plans are divided up into 15 sessions that include the HBC organizational structure. Each session has a communication strategy and a monitoring and evaluation framework. The sessions represent related groupings of knowledge or skills that should be approached together. The sessions minimize the amount of presentation by the facilitator, but rather focus on participatory activities that may involve group discussion, movement, and interaction between participants. Be mindful of the space, safety and mobility concerns of participants as you the facilitator chooses and arranges the setup space for the meeting/ training sessions.

Throughout the activities, you will see important information for each session. The information will provide you with notes about **timing, aim, learning objectives, session activities and preparations/materials for each session.** Timing for each session may vary so check for appropriate planning of breaks. Pay close attention to what may need to be prepared ahead of each session or between activities to make activities flow smoothly during the day. At the end of each session you will also find **key points** that relate to that specific topic as well as **reference material(s)** for the trainer.

1.1.10 Sessions in the Manual

There are 15 HBC specific sessions in this manual that are organized as follows:

Session	Title	Contents
1A	Introduction to the course	Overview of course contents
1B	The concept of HBC and Support	Understanding the important elements and the concept of HBC
2	Skills in Training CHBC Givers	Identifying the skills required to complete a training course for Training HBC providers
3	Facts about HIV,AIDS and TB	Basic Facts on HIV, AIDS and TB
4	Problems Faced by People Living with HIV and AIDS and how to resolve them	Psychological and Social problems faced by PLHIV
5A	Living Positively with HIV and AIDS	How PLHIV can live long and healthy lives
5B	Prevention of Infections in the Home	Good hygiene and prevention methods aimed at maintaining the spread of HIV and other infections among family members and non-infected persons

5C	Nutrition and Food Safety	Importance of nutrition in managing HIV and AIDS (includes a sample menu that is country-specific)
6	Mobilizing the community for Home Based Care	Importance of mobilizing the community for HIV HBC
7	Management of HIV and AIDS Signs & Symptoms at Home	Common signs, symptoms and complications associated with HIV infection and how to manage them at home
8	Demonstration of Home-Nursing Procedures	Practical skills needed to care for a person who has HIV infection that can be managed in the home setting
9	Conditions that Need Special Attention: TB and STI's, Malaria, PMTCT	Symptoms and precautions for tuberculosis, sexually transmitted infections, malaria, conditions commonly found in those who are HIV-positive as well as Prevention of Mother to Child Transmission of HIV
10	Women, HIV and AIDS	Special considerations for women living with HIV infection
11	Men, HIV and AIDS	Special considerations for Men living with HIV infection
12	Children, Adolescents, the Aged and HIV and AIDS	Special considerations for children that are infected and affected by HIV
13	Care of the Dying and the Dead	Considerations and precautions to be taken when caring for someone during the final stages of HIV-related illness as well as after their death
14	HBC- project Organizational Structure	Basic information about the organizational structure of HIV HBC including a communication strategy and an M&E Framework
15	Care of the Caregiver	Stress Management for those who take care of PLHIV

1.1.11 Sample Five-Day Home-Based Care Training Workshop

	Day One	Day Two	Day Three	Day Four	Day Five
Morning Session A	1.Introduction to the Course 2. Concept of HBC and Support	5B. Prevention of infections in the Home	7. Management of HIV and AIDS Symptoms at Home continued	10. Women and HIV	14. HBC Organizational structure
Break – 15 minutes					
Morning Session B	3. Facts about HIV, AIDS and TB	5C. Nutrition and Food Safety	8.Demonstration of Home Nursing Procedures	11. Men and HIV	15. Care of the Care giver
Lunch – 1 Hour					
Afternoon Session A	4. Problems faced by PLHIV and how to resolve them	6. Mobilizing the Community for HBC	8. Home Nursing (cont'd)	12. Children, Adolescents, the Aged and HIV and AIDS	
Break – 15 minutes					
Afternoon Session B	5A. Living positively with HIV and AIDS	7.Management of HIV signs and Symptoms	9. Conditions that need special attention	13. Care of the Dying and the Dead	

Session 1A: Introduction to the Course

Time: One hour - (60 minutes)

Aim: To introduce trainees to the course and to one another.

Learning Objectives

By the end of the session, trainees will:

- Be able to describe the course goals and objectives
- Compare the course objectives with their own expectations
- Be able to agree on their role in meeting the objectives.
- Test their knowledge on HBC

Table 1.1: Communication Strategy; Introduction to the Course

Session One: Course Introduction, Concept of HBC and Support				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Introduction to Training Course • Reasons for providing HBC • Advantages of HBC • Components of HBC and safety precautions • Linking PLHIV to support services	• Caregivers	• Trainer-Led Discussions • Lecture • Group Presentations	• Flip Charts • Markers • Laptops • Projectors • Manual	• 60 Minutes

Table 1.2: Session Activities; Introduction to the Course

Activity	Time (minutes)	Content	Materials	Pictures
1	15	Icebreaker Exercise	Folded slips of paper with pictures of different flowers, colours, animals	Yes
2	30	Group Work	Flip Charts, Markers, Goals and Objectives handout	
3	15	Pre Test	Pre Test Questionnaires	

Handout Materials

The following materials for this session are included at the end of this chapter:

- Pre Test Questionnaire
- Course Goals and Objectives

Activity 1: Icebreaker Exercise (15 minutes)

Topic: Warming up and getting to know the trainees

Instructions: Since this is the first session, the trainees need to get to know each other. To warm them up you can use an icebreaker exercise that will introduce them to each other.

1. Be ready with folded slips of paper with pictures of different flowers, colours, animals, etc. (1 per trainee). Make them so that there is a set of two (2) identical slips for each picture (i.e. 2 with a flower, 2 with a cat, etc).
2. Introduce yourself as the trainer and introduce your colleague trainer(s) if you are more than one and then tell them that they will be playing a game.
3. Ask each of them to pick up 1 folded slip of paper.
4. Ask each trainee to find the other person in the audience who has the same picture on their slip of paper.
5. Ask them to find out as much information as they can about each other in the given time (2 minutes), e.g. favourite food, colour, animal, but also what they do in relation to HIV services

6. After the given time, ask them to introduce their partner to the group based on the information they have collected.

This exercise should make the trainees feel more comfortable with each other and as a group. To make the sessions lively and meaningful, the trainees should also understand the importance of taking part in discussions, asking questions, and learning from each other's experiences. Once you are satisfied that everyone has had a chance to speak, continue with the session.

Note: the trainer is free to use any other method of introduction of trainees

Activity 2: Group Discussion / Presentation (30 minutes)

Topic: Introduction to the course

Instructions: Encourage comments and discussion among trainees regarding the following questions:

- What they have heard about the training
- What their expectations are
- Explain the objective of the training
- Comparison of their expectations with the objectives of the training
- How they can reach the objectives of the training

➔ Share what the course will focus on (refer to Course Goals and Objectives handout)

➔ Inform them that they will do a Pre Test now and the Post Test after the entire training

Activity 3: Pre Test – Individual Written Activity and Group Review (15 minutes)

Topic: Pre Test

Instructions:

- Explain to the trainees that you want to find out how much they already know about HBC. Let them know they will take a pre-test now and a post-test at the end of the training.
- Distribute copies of the Pre Test to all trainees and ask them to fill in the answers to the questions.

- Tell them not to worry if they don't know the answers.
- Spend a few minutes reviewing the Pre Test as a group, having each trainee grade his or her own paper as you read the correct answers out loud. Based on the results and feedback, adjust and emphasize course content as needed.

Home Based Care for People Living With HIV and AIDS

Course Goals and Objectives

The goals of this course are:

- To develop the skills of community-based service providers in home based care delivery and the transfer of nursing care skills to "primary" caregivers and to people living with HIV and AIDS (PLHIV) to enable them to take care of themselves.
- To improve the quality of life for PLHIV by establishing a link between hospital/health professionals and the untrained "primary" caregivers at home.

HBC Pre- Test Questionnaire

The questions below are multiple choices. Please read the questions carefully and tick **one** answer for each question you think is correct.

1. What is Home Based Care?

    - Care given in the home for the elderly and bed ridden patients
    - Any form of care given to people at home
    - It is care in the home for people who do live near a hospital

2. Who is a caregiver of Home Based Care?

    - A trained nurse or doctor only
    - Anyone trained in Home Based Care
    - A community health worker only

3. Which of the following is a social problem faced by PLHIV?

- PLHIV are stigmatized in the community
- PLHIV receive better health care
- PLHIV tend to be more included in community activities

4. Which of the following can be a factor for a PLHIV to live positively?

- Denying other than acknowledging their status
- Having a positive attitude
- Taking medication when they feel very sick

5. How can HIV transmission be prevented in the home?

- Don’t share sharp objects or anything that can cut or come into contact with blood like toothbrush, razors, etc
- Don’t use the same toilet facilities
- Splash hands with water after dealing with sick person

6. Why is good nutrition important for PLHIV?

- PLHIV put on weight more quickly and have to reduce the fat in their diet
- A well balanced diet provides the body with energy and nutrients to help fight infections and keep it healthy
- Good nutrition reduces the risk of transmission of HIV

7. Which symptom could be managed at home? As in providing first aid before seeking help from a professional

- Mild Dehydration
- Nausea and vomiting
- Having seizure

8. Tuberculosis (TB) is a co infection of HIV whereby home based-care is not enough and health care should be sought. Which is the one symptom to look out for?

- Increase of appetite and gaining weight
- Feeling cold during the night
- Pain in the upper back or chest

9. What is one key component that can reduce HIV transmission from mother to child?

- Make sure the baby drinks and eats different foods in the first 12 months of life
- HIV positive women should take Antiretroviral drugs before, during and after pregnancy
- HIV positive women should feed the baby with both the bottle and breast milk.

10. What is the most crucial role a HIV positive male can carry out to reduce the risk of HIV transmission?

- Use a condom with all sexual partners
- Only have unprotected sex with their wife
- Having unprotected sex with all partners

Session 1B: The Concept of Home-Based Care and Support

Time: Two and a half hours (150 minutes)

Aim: The aim of this session is to help participants better understand the concept of HBC.

Learning objectives:
By the end of the session, the trainees will:

- Discuss the concept of home-based care.
- Explain the reasons for home-based care services.
- Discuss the levels and key players in home-based care services for PLHIV.
- Describe the advantages of HBC to PLHIV, family, community, and the health care system
- Describe the safety precautions needed in providing HBC.
- Discuss the components of home-based care.

- Identify the roles and responsibilities of a community-based health care worker in home-based care.
- Display a caring attitude toward PLHIV when carrying out home-based care activities
- Demonstrate ability to provide home-based care services
- Process of linking PLHIV to support services

Table 1.3: Session Activities; Concept of Home-Based Care and Support

Activity	Time (minutes)	Content	Materials	Pictures
1	120	Lecture, presentation and discussion of HBC	White board and markers	Yes
2	30	Building a "reference card" of support linkages	Index cards and pens	

Handout Materials

The material for this session is included at the end of this chapter

- Introduction to the Concept of Home-Based Care for People Living with HIV/AIDS

Activity 1 (120 minutes):

Begin the session interactively:

- Ask trainees to share their experiences of having seen or nursed someone at home with HIV or AIDS
- Ask 2 to 3 trainees to give their definition of HBC for PLHIV and reasons why PLHIV may specifically require HBC
- Ask trainees to discuss at what levels HIV and AIDs patients can be cared for. (For example, home, community, health care centre etc.)

Give an explanation on the *levels of care* for PLHIV and the *type of treatment* given.

- Guide a brief, open discussion on specific challenges PLHIV face with regards to access to and continuation of care. Also, have the group identify some specific challenges care providers for PLHIV face, especially those involved in HBC.
- Use this discussion and the group's ideas as a lead-in to giving a talk about the importance of having a caring attitude towards PLHIV, while ensuring that the caregiver is emotionally and physically safe (refer to section on safety in handout). It is important to identify the status of the caregiver because of the challenges faced by PLHIV and care giving itself. Identifying this will ensure a strong network of support for both the caregiver and PLHIV. Use this concept to frame the next topic below regarding key players.

Ask trainees to identify key *players* in the care of HIV and AIDS patients. Allow them to ask questions throughout.

- Keep a list of key players on the whiteboard and explain that these are the primary caregivers who will be trained. Discuss the reasons why they need to be trained.

- Explain to trainees that facility and institution -based support teams are key players in providing HBC to PLHIV.
  - Discuss how these support teams would link with community-based facilitators. Discuss the possible ways of linkage, including training.
  - Identify and explain other HIV and AIDS support organizations HBC facilitators need to link with. Keep track of the list on the whiteboard.
  - Have the trainees generate names of locals in HBC services, e.g., organizations involved in care of PLHIV.

As a group, think together about:

1. Elements of a job or tasks to be done by describing what needs to be done considering the meaning of HBC
2. Once the group has finished this work, look out for ideas generated when the group works together to come out with the points and thinking about the role of and duties of CBHW and HBC givers in HBC
3. Look out for differences and missing items

Ask questions and offer clarity.

Activity 2 (30 minutes)

Topic: Let the trainees get to know the resources and support organizations CHBC facilitators and / or service providers can link up with.

Instructions

Hand out 1 index card per trainee and have them title them “Reference Card for CHBC Support Linkages.” Explain that they can hold onto this card for their own use and use it as an unofficial ‘contact card’ or reminder of resources at their disposal as a support network for care.

On the front side of the cue card, in any format the trainees feel is best for them, have them list official health care providers, HIV support organizations or other local resources involved in the care of PLHIV. They can look at the lists on the board from Activity 1 as a reminder. On the back of the card, have them list ways or reasons HBC providers can think of in reaching out to these organizations.

Introduction to the Concept of Home-Based Care for People Living with HIV and AIDS

What is home-based care?

Home-based care for people living with HIV and AIDS consists of selected services that are provided at home. The services are in the areas of:

- Nursing care (personal and general hygiene)
- Nutrition
- Advice and promotion of positive safe sexual behaviour
- Support (e.g., counselling, links with other services)
- Treatment of AIDS-related conditions
- Physical therapy

HBC also includes services such as adherence to ART, defaulter tracing and re-enrolling into care.

Rationale for HBC

With the growing numbers of people infected or affected by HIV and AIDS many things have come to the attention of individuals and nations:

- Sick people with AIDS are discharged from hospitals where there are trained professionals and are sent home where they are often cared for by untrained relatives with no professional back up support.
- These caregivers at home are most often women with no training in nursing the sick or in protecting themselves or other family members from infections arising from handling infected material (e.g., body fluids).
- PLHIV and AIDS patients need continuity of quality care to prolong their lives and reduce suffering.
- There are limitations on hospital care, including limited resources, that affect the care that can be given to PLHIV

- There are increasing numbers of defaulters and loss to follow up cases

All these concerns mean that PLHIV most often do not get the right complement of or appropriate care they need. Home-based care has been noted to be the way to ensure that quality care can be continuously provided for PLHIV outside the health unit level.

The purpose of providing home-based care to PLHIV is to:

- Prevent problems before they arise
- Manage existing problems
- Enable people to know when to get help

Advantages of HBC

The importance of home based care cannot be overlooked. It looks at the socioeconomic, psychosocial, and medical wellbeing of the client /patient, the family, the community and the health care system.

For the Client - PLHIV

Home-based care has many advantages to the person with HIV and AIDS. These range from the comfort of familiar surroundings to a sense of belonging to the family.

- Familiar environment: A patient who is nursed in a familiar environment usually suffers less stress and anxiety than one who is far from home in a strange hospital or clinic. This makes the illness more bearable. The home environment also allows the PLHIV to continue participating in family matters. This would not be the case if the person were hospitalized in an institution far away from home.

For the Family

- Good basic care can be given successfully at home. It is usually less expensive for families to care for PLHIV at home than in hospital. For example, there are no hospital bills, transport to and from hospital, etc. Moreover, nursing PLHIV at home helps bring family members together and makes it easier to coordinate family activities. Information and education on HIV and AIDS will help family members to better understand and accept the PLHIV condition.

For the Community

- Training in home based care helps community members become more aware of HIV & AIDS. It also helps to address myths and mistaken beliefs about the disease and encourages people to take steps to prevent infection. Taking care of PLHIV at home reduces the community's cost of reaching PLHIV and encourages community participation in the care of this person. Home-based care also helps maintain community cohesiveness in responding to the needs of community members. A well-organized HBC can help reduce community based stigma and discrimination towards those infected and affected by HIV.

For the Health Care System

- The essence of HBC is that it does not require the creation of extra services where none exist. Sometimes hospital care is simply not possible. Home-based care also helps to ease the demand on the resource-limited health care system. Home based-care can mean that hospitals will be less crowded, so that doctors, nurses and other hospital staff can continue to give quality care to those who urgently need to be in hospital.

The major components of home based care services given to PLHIV

This section briefly describes the services given at home in the areas of nursing care, nutrition, sexual behaviour, support, management of AIDS-related conditions and physical therapy.

1. Nursing Care (including Personal and General Hygiene)

Good personal hygiene (keeping the body clean) and clean surroundings help prevent infections and the spread of diseases. A person with AIDS who does not maintain cleanliness is more likely to be infected by various diseases.

Services in this area that are provided to PLHIV include:

- Personal hygiene (e.g. body care)
- Housekeeping (e.g. handling contaminated utensils and bedding)
- Environmental hygiene (e.g. cleaning the compound)

2. Nutrition

Good nutrition is essential for good health. A person needs to eat different kinds of food to build and maintain the body. Good nutrition also helps the body's defence system fight infections and diseases by increasing white blood cells in the body.

Nutrition services are services provided to PLHIV in terms of preparation and service of food from the three food groups, such as energy giving foods (E.g. yam, cassava, potatoes, rice etc.), protective foods (E.g. fruits and Vegetables) and body building foods which include meat, milk, eggs, nuts, fish among others). The purpose is to ensure a proper and well balanced diet is appetizing.

3. Advice and Promotion of Positive Sexual Behaviour

These are services provided to PLHIV in terms of:

- Information and education on STIs, HIV and AIDS
- Information and education on safer sex
- Provision of condoms in order to promote responsible/safer sexual behaviour and prevent the spread of HIV and AIDS and other STIs where penetrative sex is practiced
- Information on Family Planning and reproductive health issues.

4. Support

Support services are services in the areas of social, spiritual, emotional/psychological, and material support.

PLHIV can often suffer from anxiety, anger, guilt, or distorted imagination. They therefore need a lot of assurance that they are accepted by others including family members. If PLHIV are able to move about, caregivers should be encouraged to include them in day-to-day activities – for example, eating while socializing with the rest of the members of the family. This improves their mental status and brings a sense of belongingness.

Spiritual support is also important. Due to the feelings noted above, PLHIV should be encouraged to trust in the Supreme Being (God / Allah) as a source of rest for the mind. Forgiveness and reconciliation replace anger and guilt. Caregivers can invite a religious person to introduce the knowledge of God/Allah to the client as the client wishes. This is not mandatory. Emotional and psychological support is also important as HIV can cause emotional as well as physical and psychosocial pains. Some of these include:

- Shock, fear, denial
- Acceptance, withdrawal, depression, suicidal tendencies.
- Sickness
- Anger, despair, sadness

Caregivers need to identify the specific needs of each PLHIV. Counsel them, listen to them, be patient with them, and provide them with basic needs, emotional and psychological support.

5. Management of AIDS-Related Conditions

These are services given to PLHIV and AIDS clients in terms of:

- Home traditional treatment, e.g., care of wounds and sores, drug administration, and control of ailments such as diarrhoea
- Referral for medical treatment for: diagnosis, prescription and supply of drugs

6. Physical therapy

Physical therapy services include physical exercises and massage for the person with HIV and/or AIDS to help blood circulation, improve digestion, ease stiffness of joints, and prevent any secondary infections. They also help relieve stress by helping the patient relax.

What safety precautions are needed in providing HBC?

For the safety of both the patients and themselves, home-based caregivers must follow certain precautions.

1. Protection for PLHIV

PLHIV need protection from other infections because:

- HIV gradually destroys the body's immune system.

- PLHIV especially those who have advanced to the AIDS stage may have decreased or no immunity to infections that caregivers may be carrying.
- Even relatively mild infections, such as a cold, may cause PLHIV and especially AIDS patients to become very ill.

2. Protection for Care Provider

Caregivers need to protect themselves because:

- The HIV is spread through contact with some specific body fluids from PLHIV.
- The PLHIV may also have active tuberculosis.

3. Types of Protection Required

Infection and cross-infection can be prevented by:

- Observing good personal hygiene habits.
- Keeping living space of PLHIV clean.
- Avoiding exposing PLHIV to persons with other contagious diseases. E.g. TB etc.
- Wearing gloves or other protective hand coverings to prevent contact with wounds/ body fluids such as blood.
- Covering broken skin, sores, or cuts with waterproof dressing such as Elastoplast.
- Strictly following procedures for decontaminating equipment, utensils, soiled bedding, etc.
- Screening and treating PLHIV and caregiver for tuberculosis.
- Screening other family members for HIV.

What are the jobs and tasks of CHBC service providers?

- HBC service providers will perform the following specific jobs and tasks for PLHIV.
- Mobilizing the community for HIV and AIDS education sessions.
- Providing first aid to clients/patients

- Linking PLHIV to other support organizations.
- Transferring knowledge and skills to the family members/caregivers.
- Conducting home visits and group discussions.
- Assisting families and individual PLHIV to plan the future.

The task of the CHBC service provider categorized for the different disciplines is as follows;

1. **For PLHIV**

- Establishes linkages with institutions dealing with PLHIV (to identify those needing HBC), including health institutions.
- Provide HBC services.
- Provide information and education on STI, HIV and AIDS and family planning.
- Referral/linking PLHIV with specialized care/support services: social groups, counselling, health centres.
- Follow up on the PLHIV to ensure services are appropriate and adequate

2. **For the Caregiver**

- Training
- Supervision
- Assistance in establishing linkages with institutions serving PLHIV----hospitals, counselling services, and social groups.

Process of linking PLHIV to support services

It is important that PLHIV and their families are assisted in identifying support that is needed. Once this is done, groups/agencies/individuals that can provide support needs to be identified. The PLHIV should be informed about the existence of the agencies/ individuals and the services they offer. The identified groups/individuals should be introduced to the PLHIV and their homes. PLHIV should be assisted in evaluating the groups/individuals who provide support. Allow PLHIV to choose the agency/individuals to meet their own needs. Assist in ensuring the necessary help is received, either via home visits or other means. Finally, follow up to ensure coordination of services.

Session 2: Skills in Training Community Home Based Care Givers

Time: Two hours **- (**120 minutes)

Aim: The aim of this session is to enable trainees to understand the process of training Home Based Caregivers so they can take care of PLHIV.

Learning Objectives

By the end of the session, trainees will be able to:

- Appreciate the concept of training home-based care service providers and PLHIV and the role of CHBC service providers in skills transfer to primary caregivers and PLHIV.
- Identify primary caregivers and PLHIV to be trained during home visits.
- Explain the principles of learning and teaching non-literate adults.
- Demonstrate ability to transfer skills to primary caregivers using the content in the curriculum.
- Use appropriate evaluation techniques to assess the learning process during and after the lesson

Table 2.1: Communication Strategy; Skills in Training Community Home Based Care Givers

Session Two: Skills in Training Community Home based Care Givers				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Identifying Primary Caregivers • Principles of Learning and Teaching Non-Literate Adults • Transferring Skills to Primary Caregivers • Understanding the Role of CHBW	• Caregivers	• Trainer-Led Discussions • Role Play	• Flip Charts • Markers	• 120 Minutes

Table 2.2: Session Activities

Activity	Time (minutes)	Content	Materials	Pictures
1	120	Discussion, Demonstration/Role Play Summary		

Activity

Introduction: 45 min

Introduce the session by explaining that trainees will use role-plays to demonstrate how they will prepare topics to teach HBC service providers. Explain that these role-plays are very important, because the trainees have an important job in transferring skills to primary caregivers of PLHIV. As a review, ask trainees to identify possible types or situations of primary caregivers they might encounter during home visits.

Role-plays can be difficult or feel strange. Acknowledge this, but explain to the trainees that it is important to start thinking about real challenges they might face when they visit these caregivers and that they should use the role-plays to practice communication techniques. Explain that by the end of the session, each trainee should be comfortable, competent and confident in being able to prepare a lesson and present it.

Inform trainees that they will select a topic of their choice, focusing on empathy/compassion, Confidentiality/Discretion, special cases (e.g. teaching sign language). From there, they will:

- Identify materials needed and prepare to deliver their session.
- Prepare sample review questions to assess the learning of their simulated HBC providers or plan any other methods to evaluate how well their information has been absorbed.

Allow trainees ample time to prepare themselves for practice sessions.

Demonstrations/ Role Plays: 1 hour 15 min

1. Divide trainees into 2 teams. Have trainees present a session using their prepared lesson.
2. Facilitators and colleagues will act as observers whilst other trainees act as HBC providers being trained. Encourage the trainees role-playing as HBC providers to ask questions and make it challenging and realistic as possible for the trainees presenting the lesson.
3. Give guidelines for observers and then share feedback with each trainee after each role play session, starting with self-assessment by the trainee themselves, the role-played HBC provider, trainee observers and finally the trainer.
4. Summarize the observation points and ask trainees to share:
    a. What was easy?
    b. What was difficult?
    c. What attitudes were displayed?
5. Clarify the difficulties and find out what important points they have learned from the micro-teaching and what they need to do to improve the skills.
6. Summarize and conclude the session.

Note: Due to time constraints, not all trainees might be able to take part in the role-play. Ensure they are actively engaged through their other duties as observers whilst others are demonstrating.

Session 3: Facts about HIV, AIDS and TB

Time: One hour and forty minutes- (100 minutes)

Aim: This session should enable trainees to acquire accurate information about HIV, AIDS and TB

Learning Objectives

By the end of the session, trainees will:

- Have a good idea about the prevalence and impact of HIV and AIDS globally and nationally
- Examine common beliefs, values and opinions, myths and misconceptions.
- Describe HIV infection, transmission, progression to AIDS, signs and symptoms.
- Understand the relationship between HIV infection and STIs
- Identify ways to prevent the spread of HIV
- Understand the relation between HIV and TB and TB/HIV co-infection

Table 3.1: Communication Strategy; Facts about HIV, AIDS and TB

Session Three: Facts About HIV/AIDS				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• HIV Prevalence and Impact • Common Beliefs, Values, and Feelings about HIV and AIDS and PLHIV/AIDS • HIV and AIDS Infection, Transmission, Progression, Signs and Symptoms	• Caregivers	• Mini-Presentations • Trainer-Led Discussions • Group Discussions	• Flip Charts • Markers • Laptops • Projectors • Manual/Hand Out • Power Points • Fact Sheets	• 100 Minutes

• Relationship between HIV Infection, AIDS and STDs • Preventing Spread of HIV and AIDS				

Table 3.2: Session Activities; Facts about HIV, AIDS and TB

Activity	Time (minutes)	Content	Materials	Pictures
1	60	Group Discussion on Basic facts about HIV	Flip charts, markers	
2	40	Mini presentations on HIV and AIDS as well as TB Topics		

Handout Materials: The following materials for this session are included at the end of this chapter:

- Global and Ghanaian HIV and AIDS & TB most current statistics
- Common Community Beliefs and Feelings about HIV and AIDS and People with AIDS & TB Questions/Statements for Values Clarification Exercise

Activity 1: Group Discussion

Topic: Basic Facts about HIV

Instructions:

- Begin a discussion by making the following statement: “What do you know about the current situation of HIV & TB, both globally and in Ghana?”
- Present Statistics available in Ghana

- Ask Trainees to discuss briefly how they see the overall impact of HIV in their communities
- Divide group into smaller subgroups of about 5 and ask them to discuss the following:
    - Common community beliefs and feelings about HIV and AIDS and PLHIV and those infected with TB
    - Ask the groups to discuss each point, noting whether they agree or disagree and why.

Have them discuss this for about 15 minutes and then report back to the main group by making short presentations.

Tip: Tell the trainees that in this session they will have the opportunity to explore and clarify their own beliefs, values, and feelings about living with HIV and AIDS and /or TB/HIV. Invite them to be as honest as possible and that each and everyone's views will be respected. You can use the list of common community beliefs and feelings about PLHIV to facilitate this session.

Activity 2: Mini Presentations on TB, HIV and AIDS topics

Topic: HIV infection, transmission, progression and signs and symptoms

Instructions:

- Using the same groups from Activity 1, assign each subgroup a topic: infection, transmission, signs/symptoms, relation with OIs or prevention
- Once the subgroups have discussed the main points and information around their topic, have them present the information to the whole group. They are welcome to use a flip chart or whiteboard if they would like.
- Add points of clarification, correction or emphasis and encourage questions throughout the mini presentations. Also encourage trainees to participate in adding points their colleagues may have missed

Common Community Beliefs and Feelings about HIV, AIDS and PLHIV

- People with AIDS are to blame themselves for getting infected.
- Health workers should be able to refuse any care service(s) for a patient with AIDS.
- People with AIDS should have the same rights as all other patients.
- HIV is just a punishment for immoral behaviour.
- All health workers should be tested for HIV and removed from practice if found to be positive.
- Health workers should have no fears at all about caring for people with HIV or AIDS.
- People with HIV who continue to have sex should be put in prison.
- People with AIDS should be allowed to continue to work
- AIDS is mainly a problem of people with immoral behaviour.
- People with HIV infection should be isolated to prevent further transmission.
- I would feel uncomfortable inviting someone with HIV infection into my house.
- Sex workers are largely responsible for spreading HIV.
- AIDS patients should be cared for in hospitals and not in the community.
- Is it possible for you to be HIV positive now? - If yes, how do you think you got it? - If not, why not?
- Is it possible for your spouse to be HIV positive now? - If yes how would he/she have contracted it? - If you think not, why not?
- If you found out this afternoon that you were HIV positive, whom would you tell?
- If you found out this afternoon that you were HIV positive whom would you not want to find out about it?
- Having TB is a sign that someone in the family must also be infected with HIV.
- Especially if the person also has HIV, there is no cure for TB.

Statistics on HIV & AIDS and TB

In 2015, the estimated number of PLHIVs in the world was 36.7 million, with 70% living in sub-Saharan Africa (WHO, 2016). 1.1 million AIDS related deaths were recorded in 2015 with Tuberculosis accounting for a third of it (UNAIDS, 2015). Other global statistics, according to WHO (2016) and UNAIDS (2015) are summarized below;

- Only 54% of people living with HIV know their status
- 46% of adults living with HIV were accessing ART in 2015
- 49% of all children living with HIV were accessing treatment in 2015
- 77% of pregnant women living with HIV had access to ART for PMTCT in 2015.
- There are 6.5 million PLHIVs in Western and Central Africa with only 28% accessing ART.

According to GAC (n.d., p.10), the HIV prevalence is 1.47 with a representative population of 250,232 in Ghana. New Infections and deaths were 11,356 and 9,248 respectively. 14% (1,295) of this total number of deaths were amongst children with 409 of this being infants (1-4 years of age). 2% of adults aged 15-49 are HIV Positive according to GDHS (2014). The 2015 HSS Survey also ranks Greater Accra Region as the highest in terms of HIV Regional Prevalence (NACP, 2016)

HIV and AIDS and TB: The Basics

What is HIV?

- Human immunodeficiency virus (HIV) attacks the immune system, which is the body's defence against pathogens and disease.
- If untreated, HIV becomes AIDS (Acquired Immunodeficiency Syndrome), which is fatal.
- There is no cure for HIV. Once you have HIV, you have it for life.
- Because it compromises the immune system, HIV leaves the body at high risk for opportunistic infections (OIs), sexually transmitted infections (STIs) and tuberculosis (TB)

How is HIV transmitted?

- HIV is transmitted through contact with the following bodily fluids:
    - Blood
    - Semen, pre-seminal fluids, vaginal fluids, rectal fluids
    - Breast milk
- Common modes of transmission include:
    - Unprotected sex
    - Sharing of sharp objects; razors, needles etc
    - Mother to child (during pregnancy, labour or breastfeeding)

How can HIV be prevented?

- Abstinence, or delayed onset of sex
- Being faithful to one's partner
- By reducing number of sexual partners
- Consistent and correct condom use
- Do not share toothbrushes and sharp objects (eg. Blades, needles)
- **PMTCT**: prevention of mother-to-child transmission. HIV-positive mothers can receive treatment to protect their children from being infected with HIV.

Symptoms, Testing and Treatment

- Symptoms may be flu-like (e.g. fever, headache, rash, nausea)
- However, the only way to know your HIV status is to get tested
- Although there is no cure, HIV can be treated with antiretroviral therapy (ART) so that PLHIV can live a healthy life

What is TB?

- TB is a bacterial disease that is spread through the air from one person to another
- People can be infected with the TB bacteria but not show symptoms. In such cases, we say they have latent TB.
- When TB disease manifests, symptoms include a long lasting cough , chest pain, coughing up blood, weakness, fatigue, appetite loss, weight loss, chills, fever or night sweats

- Although TB is found mostly in the lungs, the bacteria can infect other organs of the body. When this happens we say the infected person has Extra Pulmonary TB which means TB outside of the lungs.

How can TB be prevented

TB can be prevented by practicing universal precautions.

- Do not stand directly in front of someone who is coughing
- Educate people who are coughing to cover their mouths when coughing either with the inner part of their arms/elbow or with a handkerchief.
- Educate people who cough not to spit phlegm around but rather, dispose it in a safer way (eg. in a container)
- Educate people who are coughing not to self-medicate but rather seek medical check-up at the health facility
- Avoid being in very crowded areas that are not well ventilated

Symptoms, testing and treatment

- Cough is the common symptom of TB. Sometimes the cough can go with blood stained phlegm.
- The symptoms of TB could be different depending on which part of the body it affects. For this reason, it is better to seek medical attention if there is any swelling on any part of your body or any sever pains being felt in your back or bones.
- TB of the lungs is usually diagnosed by identifying the TB bacteria in one's phlegm. This is done using the microscope.
- In recent times, there are more sophisticated tests available for TB. One of these sensitive test is the Gene X pert which looks for TB DNA.
- Sometimes, the TB bacteria cannot be found in the phlegm so the client will be required to do a Chest X-ray.
- For those with TB outside the lungs, small pieces of these organs which we call biopsies are taken by the doctor and sent to a special laboratory to identify the TB bacteria.
- TB can be cured with TB medicines: the usual course of treatment is a combination of medicines that are taken for a period of 6 months but sometimes longer

- It is very important that the client takes the TB medicines correctly as prescribed by the prescriber.
- If TB medicines are not taken correctly, the bacteria may not be sensitive and immune to the medicines and what we call resistance builds up. This means that even if the person decides to take the medicines again, they will not be able to kill the bacteria. We say the person now has Drug Resistance TB. If this happens to more than one of the TB medicines, we say the person has Multiple Drug Resistance TB or MDR-TB.
- MDR-TB is a very serious condition and many people die as a result of this because it is very difficult to treat.

HIV and Tuberculosis (TB)

- TB and HIV co-infection is common and dangerous. Each disease makes the other worse and progress faster in the body.
- TB and HIV co-infection is more common among PLHIV who are not on treatment or who are not taking their ARVs well. This is because due to the high viral load of HIV, the immune system of the person continues to be weak and is not able to protect the person from TB bacteria which are common in the air and which the person might be breathing in.
- TB is the leading cause of death for PLHIV. Therefore it is important to screen all PLHIV for TB as much as we can and to encourage PLHIV to be on ART and to take their ARVs correctly.

Session 4: Problems Faced by PLHIV and How to Resolve Them

Time: 1 hours (60 minutes)

Aim: This session will discuss various problems faced by PLHIV in various stages of their infection

Learning objectives

At the end of this session, trainees will be able to:

- Explain the problems faced by PLHIV and how they can be helped
- Explain the social and economic problems faced by PLHIV
- Discuss spiritual dimensions of HIV and AIDS and explain the importance of spiritual support

Table 4.1: Communication Strategy; Problems Faced by PLHIVs and How to Resolve Them

Session Four: Enhance Understanding of the Problems PLHIVs Face in General				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Psychological and Social Challenges Faced by People Living with HIV/AIDS • Finding Solutions to Identified Challenges	• Caregivers	• Presentations • Group Activities • Role Play	• Power Point • Handouts • Poster Paper • Flip Charts • Markers	• 60 Minutes

Table 4.2: Session Activities; Problems Faced by PLHIVs and How to Resolve Them

Activity	Time (minutes)	Content	Materials	Pictures
1	30	Game: Find a thief who robs the happiness of a person with HIV	Poster paper, flip over and markers	
2	20 10	Role-Play Summary	Chairs	

Handout Materials: The following material for this session is included at the end of this chapter:

- Psychological and social problems faced by people living with HIV and AIDS

Key points

- When a person tests positive for HIV infection, he or she will go through a chain of emotions
- Hope can help each person to fight HIV and AIDS and to live positively and longer
- Support groups offer emotional, physical, and medical help to people infected with HIV
- Follow-up counselling/adherence counselling can help an HIV-positive person to understand, cope with, and accept their HIV-positive status
- HIV-positive people have the same basic rights as other people
- A basic responsibility of a person living with HIV is to preserve human life by not deliberately infecting others
- Maintaining confidentiality is important
- Stigma is mainly due to a lack of education which affects people's understanding of the disease

- Spiritual support is very important, especially when a person knows he or she is approaching death

Note to the trainer:

There are two activities in this session. One is a group discussion and the other is a role-play. The trainer should encourage the groups to identify the psychosocial problems faced by PLHIV and find solutions. These activities may take up to 80% of the time meant for the whole session.

ACTIVITY 1: "Find the Thief" Game (30 Minutes)

Topic: Emotional and social impact of HIV

Aim:

The purpose of this game is to understand that HIV itself doesn't cause emotional and social problems. The group has to identify the damage caused by the thief who robs happiness from the affected persons.

Instructions:

Begin a discussion by making the following statement: "Isn't it a myth that the virus causes emotional disturbance? It is our 'fear' about disease, pain, suffering, and death that causes problems. The fear about social stigma and discrimination and some negative experiences also cause these problems. This 'thief' causes a lot of damage to the self and body. We shouldn't let this happen. Who is the thief and what is the damage? We have to find the thieves and put them behind bars. So we are going to play police."

1. Create groups of 4 to 6 persons; have them sit in circles.
2. Spread out a large piece of poster paper in the middle of each group.
3. Ask one person from each group to be the leader.
4. Have the leaders draw a thief in the middle of the paper.
5. Instruct the other group members to write or draw the various problems (psychological, social, and economic) faced by PLHIV around the figure of the thief.
6. After people are done listing to the problems, each member of the group should share one experience that he or she has had in the past relating to one of the problems.

7. The group should discuss, plan, and find strategies to “arrest” (stop the damage from) the “thief.”
8. Once everyone is finished, each group’s poster should be stuck on the wall for everyone to see.
9. Toward the end, ask each group leader to summarise their discussion in 3 to 5 minutes in front of the entire group.

ACTIVITY 2: Role-play (20 minutes)

Title: “We shall overcome”

Aim:
This is a one-to-one counselling role-play. This helps the trainees listen to the other person, discuss their problems, and arrive at a solution to overcome these problems. People may discuss real or imaginary problems depending on what they are comfortable with – it is only important that they gain practice in listening and responding to the concerns of another.

Instructions:

1. Ask trainees to divide into groups of 2, with one person playing the client and the other the counsellor for 10 minutes.
2. After 10 minutes, the roles should be reversed.
3. Toward the end, the trainees will come together and 5 volunteers will share their experiences with the entire group.
4. The trainer will then ask the group questions about the responsibilities of a person living with HIV and AIDS. This is also a good time to tell them about support groups and local organisations that help people living with HIV and AIDS and hand out any information available.

Note: Counselling role-play can be intimidating, and deals with very serious topics. If time permits, it may be helpful to have the trainer and co-trainer (or a volunteer trainee) do a short demonstration to help break the ice.

The trainees can make up their own examples and situations for the role-play. Below are listed a few suggestions or starting points:

- “My family is not accepting of my HIV status and some refuse to eat with me”
- “I’m scared my HIV infection will become AIDS and I am afraid to die”
- “I feel like I can’t live a normal life anymore”
- “I don’t want people to find out my HIV status or else they will discriminate against me. I have to lie to my friends.”

Variations:
The trainees may go out and sit under a tree or walk while discussing. Instead of groups of 2, there can be 3 in each group. One person can be the observer and that person will narrate his or her observations about the counselling and discussion.

Points to be covered during group discussion:

- Importance of support groups
- Income-generating activities and other social support services
- Confidentiality
- Importance of adherence to ART
- The responsibilities of a person living with HIV and or AIDS

Summary (10 minutes)
The trainer will wind up the discussion by summarising the session.

Handout Material

Psychological and Social Challenges Faced by People Living with HIV and AIDS

A positive diagnosis of HIV can lead many to negative psychological effects. Here are some of the examples and ways to manage the psychological stress of diagnosis.

Table 4.3: Psychosocial Challenges and How to Resolve Them

Emotion	What can be done?
SHOCK: The person might be shocked to learn he or she has HIV and feel confused.	It is good for people to be with someone they trust.
DENIAL: The person might not want to believe that she or he has HIV or AIDS.	Community health workers and/or Models of Hope can help them to understand how they might have become infected and what having HIV or AIDS means.
ANGER: They might be angry with themselves (feeling guilty) or with the person they think gave them the infection (blaming others) or even blame God.	Talking to someone they trust can help them to overcome this feeling and accept their situation. Anger can also be directed at the caregivers, which should not be taken personally. Help the HIV-positive person to talk about his or her anger, guilt, and shame.
FEAR: People with HIV or AIDS fear many things: Pain, losing their job, other people knowing that they are infected, rejection, leaving their children, the future of their family, being a burden on their family, infecting other family members, and death.	These fears lessen when they talk to someone who understands them.
SELF DISCRIMINATION: People with HIV can sometimes have self-stigma or internalized stigma. They have negative	It is good to help PLHIVs by making them join a support group where they can learn and share experiences with other PLHIV

feelings about themselves and are very afraid of possible negative reaction from family, friends and community. They therefore continue to keep their status to themselves and do not even feel comfortable accessing help and medical care.	It is also good to help PLHIV change beliefs they may have had before their own diagnosis, for instance that HIV is acquired only through sex and therefore anyone who has it is promiscuous.
LONELINESS: A person with AIDS might often feel lonely, as if they have no one in the world that can offer them comfort or support.	Families and communities must understand that people with HIV and AIDS need companionship. Infected people can often find others with HIV and AIDS and provide companionship and support for one another.
SELF-CONSCIOUSNESS: People with HIV or AIDS might think everyone is looking at them or talking about them even though this is not the case.	They should be encouraged to stay active in the community. Help them to understand that as long as they take preventive measures, they will not spread the infection to their loved ones.
DEPRESSION: If someone finds out that they have HIV or AIDS, they may feel that there is no good reason for living. Depression can make someone weak in both mind and body and is a debilitating illness that can be fatal if left untreated.	Encourage them to continue with their normal routine as well as to put on nice clothes, visit friends, keep busy with things that matter, do something that helps others, and to think about their children and friends, who still need them. Encourage an HIV/AIDS patient to seek counselling and mental care. (see below)
ACCEPTANCE: After some time, people with HIV or AIDS will usually begin to accept their situation. This helps them to feel better. Such persons will feel more peaceful, and will begin to think about the best ways to live.	

What more can a caregiver offer?

Hope: it is important to have hope. Hope lifts spirits and gives strength to face each situation. Hope can help each person to fight HIV and AIDS, to live positively, and longer. You can help someone with HIV or AIDS have hope about many things. For example, hope can come from thoughts like:

- They will live a long time
- Their baby will be healthy
- Each sickness will be treated as it comes
- They are loved and accepted for who they are
- They will look and feel healthy and be able to go about their normal duties if they adhere to ART
- Scientists may find a cure

Remember, even if a person has hope today, it is still possible for them to feel angry or depressed tomorrow. This is normal. Even people without HIV or AIDS go up and down emotionally every day. The important thing is to try to instil feelings of hope again and again!

(Follow-up) Counselling

Counselling aims to enable a person to cope better with stress, find realistic ways to solve problems and make informed decisions. A counsellor's role is to listen and ask questions, and to provide relevant information, practical suggestions and emotional support. Counselling is not about giving advice or telling people what they should do. Follow-up counselling can help an HIV-positive person to understand, cope with, and accept their HIV-positive status. HIV infection affects all dimensions of a person's life: physical, psychological, social, spiritual and (often) financial. Good counselling should always consider both the physical and mental well-being of a person.

Counselling should also inform people about the facts of HIV infection. Correct information helps to dispel myths about HIV and AIDS. Support is crucial to the success of any medical treatment. It is important that the person understands why and how illnesses related to HIV should be treated. The person should also be informed about the locally available treatment and care and how they can be accessed. People who have HIV, or people who are in contact with someone with HIV, are often afraid that the negative feelings described above will become too strong. These feelings cannot, and should not, be avoided. They are normal reactions to a crisis. Family, friends, neighbours, health-care workers, or anyone who cares can help another person cope with these feelings by listening and talking to the person about their feelings.

Support Groups

Support groups consist of people who may be HIV-infected themselves, as well as social workers, counsellors, and health-care workers. People from the community who are interested in lending support to HIV-infected people may also be part of the group. The purpose of forming such support groups is to lend emotional, physical, and medical help to people infected with HIV. If people with HIV infection join such support groups, they will find comfort as well as help in dealing with their day-to-day problems. This will also give them emotional and social security. Facing a problem together is much easier than dealing with it alone.

Rights and Responsibilities of PLHIV

Human rights, broadly speaking, concern the relationship between individuals and the Government. International human rights laws define what governments can, cannot, and should do, to or for us. For example, governments should not torture people, imprison them arbitrarily or invade their privacy. Governments should, however, ensure that all people in a society have shelter, food, medical care and basic education. The right to the highest attainable standard of physical and mental health appears in one form or another in most of the rights as written in the *Universal Declaration of Human Rights.*

Acknowledging and promoting that these basic human rights extend to all people is critical to protecting the rights and dignity of those infected and affected by HIV/AIDS - and to decreasing the vulnerability of individuals everywhere. HIV-positive people have, for example, like all human beings have the following basic rights:

- To be treated with respect at all times
- To have access to appropriate health care

- To have confidentiality regarding their condition by all who know about it (within limits pertaining to the safety of their sexual partners, family members, and caregivers).
- To have a source of income / income-generating activity
- To own, inherit, and bequeath property
- To be free to worship according to their faith, which should be respected by the caregivers
- To participate in community activities and school

Basic Responsibilities of PLHIV:

- To preserve human life by not deliberately infecting others
- To inform their sexual partners of their HIV status
- To take steps while able to provide for their families' future

Confidentiality

Maintaining confidentiality means not telling other people outside the care team, either accidentally or deliberately, any (personal) information about a patient and/or client. Examples of confidential information in the situation of a person with HIV, which especially may not be disclosed:

- That the sick person has HIV
- The medications he/she is taking or the treatments they are receiving
- How the person contracted HIV
- Whether the person is homosexual
- Whether the person uses drugs

Why is confidentiality so important?

Confidentiality is important for two main reasons:

- It insures the dignity of the sick person. When someone's most personal information is kept confidential, they feel less vulnerable.

- The promise of confidentiality generates a feeling of trust between the patient and caregiver. The patient feels they can reveal personal information and rely on their caregiver to keep it confidential. When information about a person with HIV is accidentally or deliberately released, it can cause a great deal of harm, with both emotional and practical consequences.
- In addition to the despair of losing control of their private information, the person may:
    - Be rejected by family, friends and community
    - Lose their job or may not be hired for a job
    - Not receive the support and good health-care that are needed

Social Problems faced by PLHIV

Stigma and Discrimination

"HIV and AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities, or society. It is characterised by rejection, denial, and discrediting, disregarding, underrating, and social distance. It frequently leads to discrimination and violation of human rights." (HDN 2001, p.7)

In simple terms, stigma means shame or disgrace to a person, usually because of a contagious disease he or she has contracted or because of shameful behaviour. This often results in people from the community keeping away from the sick person or stigmatizing the person. Discrimination is the unfavourable or unfair treatment of a stigmatised person or class of persons in comparison to others.

Certain diseases are particularly disfavoured in society, so people suffering from such diseases often face discriminated. HIV and AIDS is one of such diseases.

Factors that contribute to HIV and AIDS-related stigma:

- Lack of education and understanding of the disease, for example, HIV and AIDS are always fatal.
- Myths and fears about how HIV is transmitted: shaking hands, hugging, drinking from the same container, and mosquito bites.

- The disease's association with behaviours (such as men who have sex with men and persons who inject drug-use) that may already be stigmatised in many societies.
- Self-discrimination: There are cases where HIV-infected people discriminate against or punish themselves even when accepted by others. They are not comfortable mingling with people who are not infected with HIV.
- Religious or moral beliefs that lead some people to believe that having HIV and AIDS is the result of moral faults (such as promiscuity or "deviant sex") that deserves to be punished.

Form of HIV-related stigma and discrimination and solutions:

Stigma and Employment

While HIV is not transmitted in the majority of workplace settings, the supposed risk of transmission has been used as a reason by numerous employers to terminate or refuse employment. There is also evidence that if PLHIV openly declare their status at work, they may experience stigmatisation and discrimination by others. People who are living with HIV or AIDS often lack knowledge of their rights in society. They need to be educated to empower them to challenge the discrimination, stigma, and denial that they face in society.

When persons infected with HIV lose their job, they can face difficult financial problems. Financial problems also arise when the infected person is a daily-wage earner and cannot attend work on a regular basis due to the various illnesses associated with HIV and AIDS. At such times, it is difficult for people to get access to medicines and nutritious food.

Reducing Stigma and Discrimination

Stigma and discrimination can deter people from getting tested to know their status (and thus perhaps unknowingly infect others) and prevent people who are infected from receiving adequate care and treatment. So, it is extremely important to work towards reducing stigma and discrimination.

The involvement of people living with HIV and AIDS in social activities as part of the community is essential for reducing stigma and discrimination. People speaking out about their HIV status is one of the first steps to be taken in tackling stigma and discrimination. This can make people realise that HIV is part of their community and not just "other people's problem."

The success of Models of Hope demonstrates the importance of this approach. The role of people who are HIV-negative should also not be underestimated. For example, an HIV-negative person who speaks out about HIV and AIDS show wider support for those who are infected and begin to change people's stigmatized views.

Spiritual Support

Loneliness, loss of control, and thoughts about impending death may give rise to an interest in spiritual matters and a search for religious support. For such people, it is important that those who share their faith visit them and give emotional support. It has to be noted that though stigmatisation may occur because of religious beliefs, HIV is sometimes even regarded as a punishment from God. It is important for all people to be able to experience and live in a positive and supportive religious environment.

Please Note:

For more on spiritual support during the stage of palliative care, refer to the session 'care of the dying and the dead'.

Session 5A: Living Positively with HIV and AIDS

Time: Two and a half hours - (150 minutes)

Aim: The aim of this session is to educate the trainees on how to support PLHIV manage HIV and lead live positively.

Learning objectives:

By the end of the session, trainees will be able to

- Demonstrate an understanding that HIV is a manageable infection.
- Describe the importance of the following aspects in the management of HIV infection:
    - Medication
    - Nutrition
    - Healthy habits
    - Positive attitude
    - Good hygiene
    - Condom use
    - Describe the basic responsibilities of a person with HIV infection
    - Understand the importance of making a will and / or sorting things out in the event that death should occur

Table 5.1: Communication Strategy; Living Positively with HIV and AIDS

Session Five: Enhanced Knowledge on Living Positively With HIV and AIDS, Nutrition and Prevention of Infections				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Factors that Help Positive Living • Prevention of	• Caregivers	• Presentations • Group Activities • Condom	• Handout • Poster Papers • Markers and	• 375 Minutes

Infections at Home • Demonstration of Condom Use • Importance of Making a Will		Demonstration • Case Studies– Kwaku's Story, Kofi's Diarrhoea, Ama's Loss of Appetite etc..	Pens • Glue • Scissors • Condoms • Model Penis	

Table 5.2: Session Activities

Activity	Time (minutes)	Content	Materials	Pictures
1	45	Group activity: Pancake Diagram – Relative importance of various factors that help positive living	Poster papers in different colours, marker pens, glue, and scissors	
2	15	Demonstration of condom use	Condoms, model of penis, pre-lubricated condoms, garbage bin, newspaper	
3	20	Case study: The Importance of Making a Will or at least sorting things out prior to death	**Handout – Kwaku's Story (The Importance of Making a Will)**	
4	70	Group discussion: Positive Living	Poster paper and markers	

The following material for this session is included at the end of this chapter:

- Kwaku's Story: The Importance of Making a Will

Box 1.1: Key Points; Living Positively With HIV

- A person with HIV infection can live a long and healthy life.
- A Person with HIV should aim at being productive to earn a living
- HIV infection is a manageable disease that can be controlled by a combination of proper medication, nutrition and hygiene.
- A person with HIV should adhere to his / her treatment
- Exercise and adequate rest are also important in managing HIV infection.
- Addictive drugs and alcohol interfere with medication and treatment.
- A person with HIV infection has every right to be sexual. A fulfilling sexual life is an essential part of our physical, mental, and spiritual heath.
- A condom should be used even if both partners are HIV-positive.
- It is the responsibility of every person with HIV infection to see that he or she does not deliberately infect others.
- A person with HIV infection should make a will and take steps, while able, to provide for the family's future.
- An HIV-positive person should keep in touch with organisations in their community for help.

Activity 1: Group Aactivity - Pancake Diagram (45 minutes)

Objectives: To emphasize the important points, PLHIV should remember to live a productive life with a positive outlook and to understand more about the community's perception of risk and the degree of importance of each item.

Instructions

1. Split the trainees into groups of 4 to 6.
2. Give each team 1 big white poster and 1 coloured poster. **The idea is to itemize the points to live productively and positively according to their risk perception.**
3. Instruct the trainees to cut the coloured paper in circles like a pancake, in various sizes according to the degree of perceived importance, e.g., if the group thinks “Exercise” is the most important point, the biggest circle will have Exercise written on it. If the next in the priority list is “Nutrition”, then a smaller circle will be cut and “Nutrition” written on it. If the next is Adherence, then the next circle will have Adherence written on it, the next being safer sex, etc (note: if people are unable to read or write, use different colour papers to show the different topics, e.g. green paper for nutrition, blue for exercise, etc)
4. Ask trainees to draw a human body in the middle of the white poster and then paste the pancakes they have made randomly around it.
5. Each group should then stick their poster on the wall for others to see it.
6. Once everyone has had a chance to look at the posters, open a discussion about why people have assigned degrees of importance to the different topics.

Activity 2: Condom Demonstration (15 minutes)

Topic: The correct way to use a condom. Before beginning the session, ask trainees why they think condom usage is important in relation to living with HIV and AIDS.

Instructions:

1. Distribute the handout with step-by-step illustrations showing the correct usage of a condom.
2. Ask the trainees if they know the meaning of “safer sex.” *When it is a mixed audience (men and women), they may be embarrassed to answer such question. In such cases, you may have to encourage trainees not to be shy, otherwise provide the answers yourself.*
3. You may then proceed to the demonstration of using a condom. This again might cause embarrassing moments, especially for the women. You can ask trainees to volunteer to demonstrate with the help of the model. If people are unwilling, you can demonstrate it

yourself. By then the trainees may have become comfortable and you can ask them to do the demonstration again.

4. Also include information about the proper usage of a lubricant and show an example of a lubricated condom.

Activity 3: Case Study (20 minutes)

Instructions:

1. Give out handout “Case Study: The Importance of Making a Will” or assisting a PLHIV sort things out prior to death
2. Present Kwaku's case to them. Ask questions such as:
    - Who do you think is responsible for Kwaku's present condition?
    - What should Kwaku’s father have done?
    - What would have happened if Kwaku’s father had thought of making a will?
    - Who can help people with HIV infection make a will?

Possible responses:

Kwaku suffered because a will had not been made. The same uncle who took away everything, looked after him, with the intention of getting the property. Or it was easier for the grandmother if she had got the rent from the room.

Support organizations are helpful in providing help in making a will. This is very important to guard your spouse and children’s rights and their future.

Keep in touch with support organizations for counseling, medical and economic support when necessary

Summary (20 minutes) - Ask the trainees if they still have questions. Once any questions have been answered, summarize the session on a whiteboard.

Activity 4: Group Discussion on Positive Living (70 minutes)

Topic: Positive Living

Instructions:

1. Divide the trainees into 2 groups.
2. Give each group a topic (see below), which will be discussed within the group and presented by one person from each group.
3. You should tell them briefly the points they should cover during the discussion. They should also be told that they can add additional discussion points when needed.

Group 1: The importance of good habits, food, exercise, and activities in leading a long and healthy life – Points to Cover:

- We should change harmful habits
- We should eat from all groups of food to remain healthy
- Exercise is necessary to both strengthen us and provide us with good sleep
- We should get enough sleep
- It is important to be busy within and outside home
- Being part of support organizations helps

Group 2: The importance of health care, hygiene, and having hope of a healthy and happy life in a person with HIV infection – Points to Cover:

- Cleanliness of the home and body is very important
- Medications should be taken at all times
- Practicing safe sex at all times
- Stress can be reduced by prayer and or meditation or by interacting with to people close to the PLHIV
- The most important thing in life is HOPE – of a long and healthy life

Order of events

Group Preparation (30 minutes)

While preparing for their presentation, the trainer offers support and guidance to individual groups. At the end of 30 minutes the groups are called back to make their presentations.

Group presentations and feedback (40 minutes – 15 minutes each)

The groups now make their presentations one at a time. The trainer will write down the main points made on the flip over/board. After each group's presentation, a feedback and discussion session will follow about the facts presented and the skills and methods used. Use the following questions:

- What was good about this session?
- What did you learn? How does it compare to what you hoped or expected to have learned?
- How can it be improved?

Kwaku's Story: The Importance of Making a Will

Who is Kwaku?

This story means to highlight the importance to being mindful of those around the HIV infected individual. In particular, this story highlights the importance of making a will.

- Kwaku is 8 years old.
- Kwaku is the only child of his parents.
- His father was an auto driver and his mother worked as a part-time maid.
- They earned enough to give Kwaku a comfortable life.
- They had a cot, a fan, and a black-and-white TV.
- Kwaku was one of the most neatly dressed children in his class.
- His father owned a one room apartment where he lived with Kwaku.

What happened to Kwaku?

- Last year his father died and six months ago his mother also died.
- Now Kwaku lives like a destitute (very poor person).
- His father's brother took away all the things from the house and gave the room for rent.
- Kwaku was sent to his grandmother, who is very old and poor and can barely take care of him.
- He has stopped attending school and walks around in dirty clothes.

Questions for discussion:

- Who do you think is responsible for what happened to Kwaku?
- What should Kwaku's father have done?
- Who can help people with HIV infection make a will?
- What would have happened if Kwaku's father had thought of making a will?

Living Positively with HIV and AIDS

Living with HIV or AIDS is not easy. There may be a lot of challenges – physical, mental, financial, and social. The family will also go through a lot of trying times. In many families, caregivers themselves may be HIV-infected.

Today, HIV infection is **no longer considered a death sentence**. It is being viewed as a chronic infection that can be controlled by a combination of proper medication, nutrition, and hygiene. This should give hope to the person with HIV and he or she should be determined to live a long and healthy life. Studies have shown that the damage caused to the body by HIV can be reversed to a great extent if people change their habits: eat nutritious food, exercise, practice good hygiene, practice safer sex, treat infections on time and adhere to ART. Such people tend to live healthier and longer lives.

Importance of vitamin supplements

Multivitamin supplementation with vitamin B complex, vitamin E and zinc delays the progression of disease among HIV-infected people. Supplementation with multivitamins also reduces complications including oral thrush, oral ulcers, and difficulty in swallowing. Nausea, vomiting, and diarrhea are also less frequent among HIV-infected people who receive multivitamins. Multivitamin supplements delay the progression of HIV to AIDS.

To lead a healthy and long life, PLHIV should adhere to the following habits:

- Remain faithful to your partner/spouse
- Always use a condom, even if your partner is already infected
- Do not smoke. Smoking is harmful to the lungs and weakens the body. Infections like tuberculosis and pneumonia can be more easily contracted or aggravated by smoking. If you can’t quit, cut down as much as possible.
- Do not drink alcohol to excess, especially hard liquor, as it will interfere with your ARVs
- Do not use illegal drugs. Seek help to stop. If you cannot stop right away, reduce intake as much as possible. Drug use interferes with ARVs and other medicines taken to treat infections

- Do not share needles and syringes
- Eat nutritious food
  - Eat as well as possible, with a mixture of staple foods, peas and beans, leafy dark-green and orange vegetables, fruits and oils, and fats. (refer to section on nutrition)
  - Eat three complete, nutritious meals every day. Avoid excessive snacking between meals. If you choose to snack, ensure they are healthy and nutritious.
  - Drink plenty of potable water – at least 8 glasses a day, especially if you are taking medicines
- Exercise
  - Exercise regularly at least half an hour every day. Forms of exercise can be walking, cycling or games like football. Choose according to your ability and choice
  - Exercise helps you to relax more and sleep better
  - Don't exercise when you are not well. Allow yourself time to recover.
- Rest
  - Have a regular sleep schedule
  - Irregular and insufficient sleep puts the body under stress and weakens your immune system
  - Sleep at least 7 to 8 hours a day
- Keep yourself occupied
  - Be involved in the daily activities of the house
  - When at home, play indoor games like cards, ''ludu'' or ''oware'' with children or family members
  - Be socially active and visit friends and relatives
  - If working outside the house, continue with your work
  - If possible, activities like poultry farming and gardening can also be enjoyed (protect hands with gloves or plastic bags and wash hands well afterwards)

- Be part of support organizations
    - Attend support group meetings
    - People with HIV make excellent counsellors, so offer your services as a counsellor
    - Keep in touch with support organizations for counselling, medical, and economic support when necessary
- Treat infections promptly
    - Follow your doctor's instructions and take the medications you are prescribed
    - Treat symptoms through normal remedies, e.g., ginger tea for colds and paracetamol for headaches (refer section on symptom management)
    - If symptoms don't go away in a day or two, consult a health worker
    - Don't go near people with a cold, flu, herpes zoster or any other infection until they are healed.
    - Family members should also get their infections treated quickly
- Maintain good personal hygiene
    - Keep windows open to let fresh air in. There are fewer germs when things are clean.
    - Have a bath everyday
    - Maintain good oral hygiene
    - Keep nails short
    - Be careful while handling body fluids, including menstrual blood (refer to section on home nursing)
    - Wash hands before eating or touching food and after using the bathroom or touching stained clothes. Frequent washing of hands is very important.
- Get regular health care check-ups
    - Take medications as prescribed and recommended by your doctor
    - See your doctor regularly

  - Seek care whenever you develop new symptoms of infection
  - Taking the vitamin supplements prescribed by the doctor regularly, will keep you from acquiring many infections.
- Handle pets carefully
  - Pets can be a source of infection, especially cats and birds.
  - Have family members care for pets, especially cleaning up of faeces.
  - Ask the health worker to advise you on handling pets.
  - Avoid stray animals.
- Cut down on stress
  - Reduce stress by prayer and or meditation.
  - Get involved in activities at home and outside the home.
  - Talk to someone you trust about the diagnosis and the illness.
  - If depression or anxiety doesn't lessen from these activities, see a doctor.

Drugs and Alcohol

Drugs and alcohol are bad for the immune system and health when used in large quantities. Drinking can create a problem with the effect of medications and damage the liver. Smoking irritates the lungs and can make lung infections like pneumonia worse. Drugs like ganger damage the immune system and give a false sense of energy, leaving the body exhausted. Any drug bought from the street vendors or any unauthorized institution may contain a mixture of other dangerous substances Which may be harmful to the PLHIV.

Under the influence of alcohol or drugs, people tend to indulge in risky behaviour. For example, alcohol and drugs may affect a person's decision-making abilities and during sexual intercourse, they may neglect the important precaution, which is the usage of a condom during sex. Thus HIV-infected people who abuse or are addicted to alcohol or drugs put themselves as well as their sexual partners in danger.

Be sure to tell the health-care provider(s) about the patient's drug or alcohol use. Without this information, they could misdiagnose their symptoms or prescribe a drug that could worsen the person's condition. The health-care provider may encourage them to quit or cut down, but this should not prevent them from seeking the medical care they need.

Problems Faced by Injection and Drug Users and People Addicted to Alcohol

A person addicted to alcohol or drugs who is also infected with HIV has more problems than other HIV-positive people. They have to tackle their addiction along with the challenges of HIV When they try to give up drugs or alcohol, they may face severe withdrawal symptoms.

Another issue to be aware of in relation to alcohol is the use of traditional medicine. Some of these medicines are often manufactured with alcohol. Therefore, they can reduce the effectiveness of other medicines and damage the liver and other organs. It is important that the health care worker/home visitor knows if a patient is using traditional medicines.

Sex and PLHIV

PLHIV have every right to engage in sex. Sex is an important part of our lives. For many, a fulfilling sexual life is an essential element of physical, mental, and spiritual health. Sex after testing HIV-positive can still feel as it used before. One piece of advice: *It still has to be safe*! Some people believe that having HIV means that it's too late for them, that safer sex is no longer relevant. But that is false! **Practicing safer sex will continue to protect your health and the health of your sexual partner.**

Even if you and your partner are both HIV-positive you have to use condoms, otherwise you can get more viral load as well as different strains of viruses from having unprotected sex. There are different types and strains of HIV, and you and your partner may not be infected with the same type. Safer sex also protects you from other STIs, which can weaken your immune system and make life more difficult. There are many reasons for having sex, from stress reduction to love. You and your spouse or partner should discuss this. HIV infection should not bring your sex life to an end.

Practicing Safe Sex to protect those around you

Safe sex is using a condom (or dams) and a lubricant during sexual intercourse. It is important to practice safe sex to prevent STIs and, or unplanned pregnancy. Other practices of safe sex involve sticking to one sexual partner (WAAC, 2010).

Correct use of a condom (WAAC, 2010)

- Check the expiry date on the condom packet.
- Open the packet but be careful not to tear the condom
- Squeeze the air out of the tip of the condom.
- Keep hold of the tip of the condom and roll it all the way down to the base of the penis.
- Use plenty of water-based lubricant on the outside of the condom. Do not use oil based lubricants such as Vaseline and massage oils as these weaken the condom and increase the risk of breakage.
- Before withdrawing, hold the base of the condom, so it doesn't slip off.
- Carefully wrap the used condom in a tissue and throw in the bin. Don't flush it down the toilet

The following tips will help prevent condoms breaking or leaking:

- If lubricant is needed, use a water-based lubricant like glycerin. Do not use a lubricant made with oil, like Vaseline.
- Store unused condoms in a cool, dark, dry place. Heat, light, and humidity can damage condoms.
- If you have a choice, choose pre-lubricated condoms that are packaged so that light does not reach them.

Note: Even if both the partners are HIV-positive, a condom should be used to avoid contracting further infections. The infections carried by one partner will easily be transmitted to the other, further weakening that partner if a condom is not used.

How to Prevent Sexual Transmission of HIV

HIV infection can be prevented by:

- Abstinence (if possible)
- Delay age of onset of sexual activity

- Avoid multiple sexual partners
- Correct, Consistent Condom use (practicing safe sex)

Abstinence may not always be possible. If this is the case, the best method is to use condoms correctly and every time, which greatly reduces the risk of HIV infection as well as other STIs through sexual intercourse.

Session 5B: Prevention of Infections in the Home

Time: 1 hour 15 minutes - (75 minutes)

***Aim*:** In this session trainees will learn HIV preventive measures to adopt to prevent themselves from HIV infection or re-infection. This session will also address personal cleanliness in the house and surrounding areas, which is very important in keeping both the patient and caregiver healthy.

Learning objectives:

By the end of the session the trainees will know:

- Who is at risk of HIV infection
- How to prevent infections in the home setting
- How to maintain good hygiene within and outside the home

Table 5.3: Session Activities; Prevention of Infections in the Home

Activity	Time (minutes)	Content	Materials	Pictures
1	30	Discussion and presentation of prevention of HIV infection	White board and markers	YES
2	45	Lecture and demonstration on prevention of HIV and other infections at home	Garbage bin, newspaper, gloves or plastic bags with no holes	YES

The following material for this session is included at the end of this chapter:

Reference Materials:

- Prevention of Infections in the Home

Box 2.1: Key points; Prevention of Infections in the Home

- Needles should not be shared; Universal Precautions should always be kept in mind when taking care of a person infected with HIV.
- Good personal and social hygiene should be maintained.
- Razors and toothbrushes should not be shared with anyone.
- HIV-infected people should never donate blood.
- In case of accidental exposure to HIV infected blood or body fluids, the health-care provider should be contacted immediately for further advice, which may include referral to the heath facility for PEP.
- Other members of the household should be advised to undergo HTC

Activity 1: Discussion of good hygiene (30 minutes)

Topic: Maintaining good hygiene

Instructions:

- If there are more than 8 trainees, divide them into 2 groups
- Each group will then discuss the topic for 15 minutes. The trainer may help start the discussion by asking questions like:
    - *What does good hygiene mean to you?*
    - *Why do you think good hygiene is so important when caring for PLHIV?*
- Once the group(s) is finished, a representative from each group will present the topic to the other group.
- The other group will point out if anything is wrong or missing and provide feedback about what has been presented.

Note: The trainer should note the points as they are presented. This can be reviewed to understand what trainees have/have not grasped.

Activity 2: Lecture and demonstration on home prevention techniques (45 minutes)

Topic: Preventing infections in the home

Instructions:

- Stress the need for the home and the family members within to maintain cleanliness.
- Encourage questions from the trainees throughout the presentation.
- Ask several questions based on the information given in the slides, such as:
  - Is it important to wash hands before preparing food?
  - Why should hands be covered with gloves/plastic bags?
  - Where and how should waste from the house be disposed of?
  - If you don't have a bathroom what should you do?
- Give out plastic bags and show them they can be used to protect the hands when throwing out the trash or doing other activities that may transmit infection. (More techniques will be covered in the session on Home Nursing Care.)

Session Summary (15 minutes)

The session can be closed by briefly reviewing the points discussed during the session. Any questions can be answered. The trainer should make it clear that he or she will be available even after the session to answer any other questions. Some of the trainees might be too shy to ask questions in front of others so it is important that you are able to answer questions in private

Prevention of Infections in the Home

Universal Precautions

We should always take precautions and practise infection control because we have no way of knowing what infections we or anyone else might be carrying. By practising **Universal Precautions**, the caregiver and the patient are both protected from infections. We should be extremely cautious with blood or any other body fluids - urine, faeces, vomit, semen, saliva, drainage from a wound (open sore, cut, surgery), vaginal secretions, menstrual blood, and bleeding after a woman gives birth. "Universal Precautions" means following specific procedures when washing hands, wearing gloves when required, cleaning various areas of the house, washing clothes, and preparing food.

Note: In addition, keep in mind that in home-based care, the home is the place where a person with HIV will be cared for and will spend most of his or her time. This means it should be a safe place where he/she will not contract infections. This can be made possible only by practicing good hygiene and following Universal Precautions.

Hand washing:

Washing our hands really well with soap and water, preferably under running water, is still the best way of preventing the spread of infection.

Hands should be washed:

- Before and after every contact with the sick person
- Before and during food preparation
- Before eating
- Before feeding another person
- Before caring for a baby
- Before and after using the toilet
- After removing gloves
- After removing mask
- After coughing into our hands or blowing our nose
- After changing nappies
- After changing soiled bed sheets and clothing
- After contact with any bodily fluids
- After working in the fields or garden

Gloves

Gloves provide a barrier for both the patient and us. Gloves should be used only once and then put in the garbage, disposed of securely. If gloves are not available, use plastic bags over the hands. Make sure there are no holes in the plastic bags.

Gloves/plastic bags should be worn for:

- Cleaning up any body fluids (vomit, faeces, urine, blood) on the sick person, the floor, the toilet or commode, bed sheets or clothing
- Bathing or giving skin care to any area that has cuts or open wounds
- Cleaning teeth or dentures
- Washing hair in case there are open areas on the scalp
- Washing the buttocks and genital area
- Changing diapers/incontinent materials
- Picking up clothes and washing the sick person's clothes (they may be soiled)
- Disinfecting with bleach

Personal hygiene

Personal hygiene is very important because it helps to minimise the spread of germs from the caregiver to the sick person and from the sick person to the caregiver. The hygiene of the caregiver and of the patient is important. Cleanliness is of great importance in preventing many kinds of infections - stomach, skin, mouth, eyes, lungs, and the whole body. Personal cleanliness (or hygiene) and public cleanliness (or sanitation) are both important. Many common stomach infections are spread from one person to another because of poor hygiene and poor sanitation. Germs and worms (or their eggs) are passed in the faeces of infected persons. These are carried from the faeces of one person to the mouth of another by dirty fingers or by contaminated food or water.

Since an HIV-positive person's ability to fight germs is decreased, living under unhygienic conditions may cause that person to fall ill more often than someone living in a healthy and hygienic environment. This, in turn may hasten the progression of the virus. Care should be taken to see that the patient and the family members keep themselves, their house, and surroundings clean. *Always use clean water for all purposes.*

Do not share toothbrushes, razors, or injection needles that come in contact with body fluids. Use clean combs and hairbrushes with ‘‘Dettol’’ or any appropriate disinfectant. If these disinfectants are not available, boiled water with neem leaves can be used.

Methods for keeping the body clean:

- Mouth and teeth cleaning should be done after meals. Use a toothbrush or neem stick to gently scrub teeth, tongue, and gums to remove food.
- Bathe daily with soap and water.
- Take special care to wash the private parts.
- Dry the skin gently with a soft towel after a bath and oil the skin with cream or vegetable oil.
- Use plastic sheets under the bed sheets to keep the bed dry.
- Fingernails and hair should be kept short.

Methods for hygiene in the home:

- Wash eating utensils, including items for babies with soap and water.
- Wash all raw fruits and vegetables with clean water.
- Keep food covered so that flies cannot land on it.
- Store boiled water in a clean container, covered with a clean lid, and use a clean ladle to take out water.
- Keep the house and surroundings clean so that no flies or mosquitoes breed.
- Cover mouth when sneezing or coughing.
- Avoid spitting. If you must spit, use a container, not the ground, and keep the container covered.

- Dispose of waste properly.
    - Put soiled things like bandages, clothes, etc. into containers or buckets lined with thick plastic bags. Tie bags.
    - Put sharp items like razors or needles in metal disposal containers.
    - Keep waste away from children and animals.
    - Bury or burn the waste away from the house.

Washing clothes

Wear unbroken gloves or plastic bags while washing the sick person's clothes. If possible, wash in warm water with regular detergent. Wash the patient's clothes and bedding frequently and dry them in the sun.

Cleaning

For general cleaning, a bleach solution of 1 part bleach (bleaching powder/bleaching solution is available at most grocery shops) to 10 parts water can be used. Bathrooms should be cleaned frequently, after any spill of urine or faeces. Kitchens should be extremely clean. Utensils also should be washed very well.

Cleaning clothing or sheets stained with any bodily fluids (menstrual blood, diarrhoea, etc.)

- Make sure that the gloves/plastic bags don't have any holes.
- Rinse off any blood or diarrhoea with water. Be particularly careful if there are large amounts of blood, such as after childbirth. If possible, the bloodstained clothes should be soaked in bleach solution -one capful in half a bucket of water for 20 minutes. Wash in soapy water, and then hang to dry in the sun.
- Separate soiled items from other household laundry.

When there are no bathrooms:

In places where there are no latrines, people tend to defecate in the open. In such cases, people should use places far away from houses and the faeces should be covered with mud. When a person is too ill to go out, an old bucket with no holes can be kept inside the room and used as a commode. It should always be covered and the contents thrown away as soon as possible.

Disposal of sharps and needles:

Whenever sharp instruments or needles are used on a sick person, they should be placed into a sharp container which should be sent for incineration when full.

Additional precautions to prevent HIV transmission in the home

There are some additional items not included under the Universal Precautions that will help to prevent acquiring the virus from HIV-infected people in the home:

- Keep wounds covered. Both caregivers and people with HIV should cover any open wounds they have on their hands or elsewhere. Cover open wounds with a bandage or cloth.
- Caregivers who have cuts, wounds, sores on their hands, or even badly cracked skin, should wear gloves when giving any persona care or doing any washing.
- Ensure all household members undergo HIV testing twice a year.
- Be especially careful to follow Universal Precautions above when handling or cleaning up any bodily fluids.

Session 5C: Nutrition and Food Safety

Time: Two hours - (120 minutes)

Aim: This session will teach trainees the importance of nutritious food in managing HIV infection. It will also add on the importance of personal hygiene.

Learning Objectives:

By the end of the session trainees will be able to:

- Demonstrate understanding and importance of nutrition in managing HIV infection
- Identify the various groups of food necessary for a balanced diet
- Suggest a simple and healthy menu for a PLHIV
- Coax a person with a low appetite to eat
- Know how to manage PLHIV with symptoms in terms of their feeding
- Describe safer cooking methods
- Describe the importance of personal hygiene

Table 5.4: Session Activities; Nutrition and Food Safety

Activity	Time (Minutes)	Content	Materials	Pictures
1	120	Case studies and demonstrations: the importance of a balanced diet, personal and environmental hygiene, and loss of appetite	Flip over/ white board and markers Trainees Handout on *Nutrition and Food Safety* Handout manual *' Positive living and healthy eating'* Handouts of case studies; Kofi's diarrhoea Healthy food for Adwoa and her children Ama's loss of appetite	

Hand out Materials

The following material for this session is included at the end of this chapter:

- Nutrition and Food Safety Case Studies
- Case Studies (Kofi's diarrhoea, Healthy food for Adwoa and her children, Ama's loss of appetite)

Reference Materials: Available at end of the session

Box 3.1: Key Points; Nutrition and Food Safety

- Good nutrition plays an important role in slowing the progression of HIV.
- Medication is always less effective in people with poor nutritional diets.
- A balanced diet should consist of food from the three main groups: Body-Building Foods, Energy-Giving Foods, and Health-Giving Foods.
- Healthy foods are not expensive.
- Loss of appetite and difficulty in eating is common in people with HIV/AIDS.
- People with HIV infection get sick more often from food-borne illnesses – raw food, poorly cooked food, and contaminated food.
- The person who is cooking should take care of her/his personal cleanliness.

Activity 1: Small group discussion and presentations (1 hour 15 minutes)

Topic: Food safety, balanced diet, loss of appetite, and difficulty in eating.

Instructions:

1. Small-group discussion (20 minutes)

- Divide trainees into 3 groups.
- Give out trainee handout - Case studies
    - Ask each group to choose 1 of the 3 case studies for discussion. Instruct them to discuss and answer the questions given for their case on the handout.

- For each case study, use the information given below to guide trainees on how to address each question.

2. Group presentation and feedback (40 minutes)

At the end of 20 minutes, a representative from each group will present the case. Presentations will also be done in front of the class. **Each group will be given 10 minutes for the presentation.**

The trainer will write down the main points made on the flip over/white board. After each group's presentation, a feedback and discussion session will follow about the facts presented and the skills and methods used. Use the following questions:

- What was good?
- What did you learn from the presentation?
- What are your suggestions?

Three main topics will be covered in this session: cleanliness in the home; types of foods and balanced diet; and loss of appetite and difficulty in eating.

Note: Use pictures from any manual on Positive Living and Healthy Eating to explain these topics in brief to all the trainees. This will give them a clearer picture of how to address the problems in each case study.

Case Studies

1. *'Kofi's diarrhoea'*

You visit Kofi, who is HIV-infected, in his house. He says he has been suffering from persistent diarrhoea for weeks now and although he has been to the hospital on various occasions, all the medicines he has been given and which he has taken do not seem to work. He wonders why the medicines cannot treat the diarrhoea. He tells you that his wife is so busy, taking care of the children, earning some money for the family, looking after Kofi when he is ill and taking care of the house. His wife is looking exhausted. As you decide to sit down and survey Kofi's surrounding, you see food lying uncovered in the kitchen, no trace of pure water sachets, flies are buzzing all over the house and Kofi and his family are dressed in dirty outfits . You can guess the reasons for Kofi's diarrhoea.

What advice will you give Kofi and his wife regarding personal and food hygiene and how are you going to discuss this with them?

Possible questions:

- Do you know one of the reasons for diarrhoea is contaminated food?
- Do you know another reason for diarrhoea is unhygienic conditions?
- Do you have an idea of the cause of your wife's exhaustion and is it possible to improve her health condition?

Points to be covered:

- Keeping the house and surroundings free of flies
- Food safety
- Water safety
- Safe cooking
- Storage of food
- Storage of water
- Personal Hygiene

Types of food and a balanced diet

In this part, several examples of healthy foods are given. This session contains a list of ingredients and a week's menu; ask the trainees first what they think is healthy food, ask them for ideas. At the end of the session, the week menu can be given out as a sample handout. We recommend **the Ghanaian manual on healthy eating by Cindy Noordermeer,** since this gives examples of products used and available in Ghana.

- Show the trainees pictures of different kinds of fruits, vegetables, cereals, meat, and fish. Ask them what foods are healthy and unhealthy for people who are ill. A lot of people in Ghana have misconceptions about food. Chances are that you will get varied answers on that. The trainer should note the answers.

2. *'Healthy food for Adwoa and her children'*

You visit Adwoa, a single mother, in her house. Today you are going to counsel her about proper nutrition. The first thing she says to you when you sit down, is that healthy foods are so expensive these days, and that she hasn't got enough money for that, since she is a single mother from the day her husband died.

Note: It is your task to explain to her that healthy food doesn't have to be expensive, to give her examples on what sort of foods are healthy and give her some recipes/ideas on what to cook. How can you educate her about non-expensive healthy foods?

Points to be covered:

- Food groups
- Low-cost healthy foods
- Preparation of fufu/kenkey/banku etc.
- Balanced diet
- Sample menu

A rough calculation of the cost of a simple meal can be made to convince the person that healthy food need not be expensive.

Loss of appetite and difficulty in eating

Tell the trainees that PLHIV can have oral problems that make it difficult for them to eat. Medications also cause loss of appetite. Ask the trainees if they have encountered such problems in their homes. Remedies for a sore mouth are given in the next session about managing symptoms/opportunistic infections.

3. '*Appetite for Ama'*

You visit Ama, a 16-year-old girl, living with her mother. She has been suffering from lack of appetite for weeks now. She has visited the hospital and has been provided with medicines which she takes. However, advice from the hospital was that she should make an effort to eat. She tells you that she just doesn't feel like eating. Her sore mouth makes it difficult to eat even the very little amount that her mother forces her to eat. Eating becomes a struggle between herself and her mother around three times a day, which costs both of them a lot of energy. Her mother is worried about Ama, because she is losing weight -- and looking more and more tired and depressed.

What advice will you give mother and daughter and how are you going to discuss the issue with them?

Possible questions:

- What food does Ama like?
- What are the foods you give her?
- How many times do you give her food?

Points to be covered:

- Give foods liked by the person
- Small, frequent meals should be given
- Mashed food can be given
- Lots of water should be given

Summary (15 minutes)

The trainer will summarise the session. After this, questions should be encouraged and answered either by other trainees or the trainer.

Nutrition and Food Safety

Good nutrition plays an important role in slowing the progression of HIV and keeping an HIV-positive person healthier for a longer period of time. A well-balanced diet provides energy and nutrients to help the body fight infections. Good nutrition also helps to give a sense of well-being and strength. The same foods that are good for you when you are healthy are good for you when you are sick.

A sick person has an even greater need for food than a healthy person. People should be encouraged to think about the foods that will help make them healthy, rather than worry about foods that are not considered to be good for them. HIV disease and many of the associated diseases cause stomach problems, which make it impossible for the body to absorb the nutrients from food. As a result, the patient loses weight even though they are eating. **Medication is always less effective in people with poor nutritional diets.**

A balanced meal should consist of food from each of the groups below:

Healthy Foods

A healthy diet can be compared with a solid built house; a poorly built house will let through rain and wind and mosquitoes. A solid built house protects you from the elements, noise, mosquitoes, etc. To build a house, you need several materials. The different food groups as described below, can be seen as the different materials; **workers who built the house (energy-giving foods), building blocks of which the house is made, (the body building foods), and mosquito nets in the windows as protection against the flies and mosquitoes (the health-giving or protective foods)** *(By Cindy Noordermeer.).*

Energy-giving foods ('workers')

- Rice, wheat, brown bread, maize, potatoes, yam/cocoyam, tapioca, cassava, kenkey, plantains/banana, sugar, animal fats, and vegetable oils, shea abutter.

Health-giving/protective foods ('mosquito net')

- All vegetables and fruits, especially dark-green leafy vegetables and orange-coloured vegetables and fruits like; Carrots, avocado, tomato, "nkontomire", pineapple, pawpaw, mango, oranges, spinach, pumpkin.

Body-building foods ('building blocks')

- Beans, soya, groundnuts, peas, eggs, meat, fish, and milk.

Here are some suggestions for getting more vitamins, minerals, and proteins at low cost:

- **Liver, heart, and kidney are especially high in protein**, vitamins, and iron (for anaemia) and are often cheaper than other meats.
- **Eggs are one of the cheapest** and best forms of animal protein. They can be cooked and given to babies and adults alike.
- **Eggshells that are boiled, washed well, finely ground and mixed with food** can provide needed calcium for pregnant women who develop sore, loose, teeth or muscle cramps.
- **Cook vegetables, rice, and other foods in small amounts of water**. Do not overcook. Be sure to drink the leftover water or use it for soups or in other foods (e.g., gravies).
- **Beans and legumes** (various types of grams, kidney beans, etc.) are a cheap source of protein. If allowed to sprout before cooking and eating, they are higher in vitamins. Baby food can be made from beans by cooking them well, peeling off their skins, and mashing them.
- **Dark-green leafy vegetables have some iron, a lot of vitamin A, and some protein**. The leaves of sweet potatoes, drumsticks, yam, beans, and pumpkins are very nutritious.

More suggestions for getting vitamins and good nutrition:

- Small, bony fish are also cheaper than meat, especially the dried varieties.
- Chicken is a good, fairly cheap form of animal protein – especially if the family raises its own chickens.
- Cooking in iron pots when cooking beans, greens, and other foods adds iron to the food.
- More iron will be available if you also add tomatoes.

A healthy menu for the day includes;

- Breakfast
- Snack

- Lunch
- Snack
- Supper
- Snack
- Around 8 glasses of water. However, more is encouraged

Note: Avoid unhealthy snacks, drinking and smoking, as they all have a negative influence on the absorption of nutrients by the body. Eat fruit with every meal, drink plenty of water. See examples of a healthy week's meals in the chart below.

Table 5.5: A Sample Healthy Week Menu

Day	Breakfast	Lunch	Supper
Sunday	• Sifted corn porridge ("mpampa")	•"Kokonte" and groundnut soup	• Kenkey and garden egg stew
Monday	• Rice water with milk and sugar	•"Ampesi" and nkontomire stew and fish	• Banku with okro soup
Tuesday	• Bread with eggs, tea with milk and sugar	•"Mpotompoto" (yam or cocoyam)	• Rice and palaver sauce
Wednesday	• Rice and beans ("waakye") with shito	• Kenkey and palm nut soup	• "Akple"(it is soft like baku but prepared with only corn flour) with green leaves/okra soup
Thursday	• Oats with milk and sugar	• "Fufu" with light soup and meat	• Tuo zaafi with green leaves (groundnuts added)
Friday	•Millet porridge with milk and sugar and "koose"	• Fried yam/plantain with bean stew	• Rice with tomato stew and egg
Saturday	• Tom brown porridge with sugar and bread	•"Kaklo/tatale" (fried plantain) with beans	• Banku and okra soup
Sunday	• 'Tuubaani" or steamed beans with gravy	• Fufu with neri and dried okra soup	• Jollof rice and boiled vegetables

Source: Noordermeer, 1995

Table 5.6: Snacks from the Different Food Groups

Energy giving foods	Body building foods	Protective foods
• Boiled, roasted or fried plantain, yam, cocoyam, cassava, sweet potato • Roasted or boiled corn or popcorn • Maasa (fried fermented millet cakes) • Sugar cane • Coconut • Bread with groundnut paste or margarine, meat pie, cream crackers or biscuits	• Boiled, roasted or fresh groundnuts • Tiger nuts or cashew nuts • Boiled egg • Fried fish • Koose • Roasted bambara beans	• All kinds of fruits (well washed): banana, pawpaw, mango, orange, tangerine, pineapple, apple, guava, avocado and other local fruits • Raw vegetables (well washed): fresh tomato, cucumber, carrot etc.

Source: Noordermeer, 1995

Table 5.7: List of Ingredients Available in Ghana

Different Vegetables with Green Leaves	Other Vegetables	Wheat, Rice	Nuts
• Alefu • Cocoyam Leaves • Cassava Leaves • Baobab Leaves • Pumpkin Leaves • Garden Egg Leaves • Sweet Potato Leaves • Beans Leaves • Blue Berry Leaves • Pepper Leaves • Agushi Leaves • Onion Leaves • Local Cucumber Leaves • Konchiri • Bere • Ayoyo • Salompla • Voga • Jon Boro • Anu kuon • Spinach • Baobab Fruit and Seed	• Okra (dried or fresh) • Tomatoes (dried or fresh) • Onions (red onion and spring onion) • Garden eggs • Cabbage • Carrot • Cucumber • Pumpkin • Yam • Sweet Potato • Cassava • Cocoyam • Kokonte	• Millet • Guinea Corn • Maize • Rice • Wheat • Beans • White, Brown, and Yellow Beans. • Bambara Beans • Soya Beans	• Shea nut butter

Source: Noordermeer, 1995

Table 5.8: A Recipe to Try at Home

Recipe	Ingredient	Preparation
• "Ampesi" with "Alefu" stew (For Two people)	• **2 pieces** of garlic • **1 piece** of ginger of 1cm length • **1 sweet green** or 1 red pepper • **1 (red)** onion • **2 fresh tomatoes** or 1 big spoon of tomato sauce • **2 full hands of**; cassava leaves/alefu leaves/pumpkin leaves/pepper leaves (or other leaves available) • **2 full teaspoon** of agushie or nirhi or sunflower seeds or almonds • **I big spoon** of shea nut butter or red palm oil • **Salt**, according to the taste	• Cut the garlic, ginger and pepper in very small pieces • Cut the onion and tomatoes in bigger pieces • Wash the used leaves and cut them • Mash the seeds and pits. Heat the oil or butter and bake the garlic, ginger, onions and spices for 2 minutes • Add the tomatoes and leaves and salt • Stir the ingredients and add a little water • Add the seeds and pits and let it cool for 5 minutes, while stirring • Serve with rice/potato/yam/cassava

Source: Noordermeer, 1995

Reference Material

Food Safety and Hygiene

People with HIV infection get sick more often from food-borne illnesses than other people. Most of these diseases are caught directly from an infected person, or from raw and poorly cooked food, or food contaminated by insects, and food that has been handled by someone who has not practised good hand washing.

Guidelines for Safer Cooking

- Keep the home free from faeces.
- Use a latrine and keep it clean and free from flies.
- Keep the surroundings clean.
- Wash clothes, bedding, and surfaces that might have been contaminated with faeces and urine with hot water and soap.

Personal Hygiene

- Always wash hands with clean water and soap or ashes before, during, and after preparing food, eating, serving others, and after visiting the toilet.
- Cover all wounds to prevent contamination of food during preparation and handling.
- Use safe, clean water from protected sources. If the water is not from a protected source, it should be boiled for 20 minutes or filtered.

Hygiene in the Kitchen

- Keep all food preparation surfaces clean. Use clean dishes and utensils to store, prepare, serve, and eat food.
- Wash vegetables and fruit with clean water.
- Cover food to keep flies and dust away.
- Keep rubbish in a covered bin and empty regularly or put it in a compost pit, covering it with soil after each disposal.

Cooking and Storage of Food

- Store fresh food in a cool place or refrigerator.
- Do not store raw food, especially meat, close to cooked food.
- Avoid storing leftovers unless they can be kept in a cool place or refrigerator. Always reheat them at a high temperature.
- Cover and store food in containers away from insects.
- Throw away any food that has gone bad.
- Cook food thoroughly, but do not overcook vegetables.
- Serve food immediately after cooking.

Storage of drinking water

- Keep drinking water in a covered container that is cleaned daily with hot water.
- Do not dip hands or cups into the container.
- The best container is one with a tap.

Note: However careful one is, food-borne infections may happen. If you get diarrhoea, take available fluids to prevent dehydration. However, see a health worker without delay, if you feel very ill with vomiting and pain.

Session 6: Mobilizing the Community for HBC Services

Time: 2 hours 30 min - (150 minutes)

Aim*:* The aim of this session is to educate trainees on how to take on the responsibility of initiating and sustaining their own health care by using locally available resources. It also aims at getting the community's full participation and involvement in decision making for the planning, organizing, implementing, monitoring, and evaluating of these services.

Objectives:

- Discuss the importance of mobilizing the community for HBC services.
- Identify community resource persons/groups to work with in order to promote HBC activities for PLHIV.
- Discuss the roles of key community resource persons/groups in promoting HBC activities.
- Discuss the role of community home-based care facilitator in initiating home-based care services for PLHIV.
- Explain the process of initiating home-based care activities for PLHIV.
- Disclosure in mobilizing the community

Table 6.1: Communication Strategy; Mobilizing the Community for HBC Services

Session Six: Mobilizing the Community to Provide Support for Home-Based Care Activities for PLHIVs				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• The Concept of Home-Based Care and Support • Initiating HBC for PLHIVs • Terminologies in, and Importance of Community Mobilisation • Roles of Identified Key Community Resource Persons	• Caregivers	• Presentations • Trainer-Led Discussions • Group Discussions	• Power Points • Projectors • Posters • Flip Charts • Markers	• 150 Minutes

Table 6.2: Session Activities; Mobilizing the Community for HBC Services

Activity	**Time (minutes)**	**Content**	**Materials**	**Pictures**
1	150	Group Discussion	Flip Chart, markers	

Handout Materials:

The following material for this session is included at the end of this chapter:

- Community Mobilization for Home Based Care Services for PLHIV

Activity 1

Start a group discussion by asking trainees what they remember about the goal of CHBC approach

- Ask what they recall is the meaning of HBC. Then ask them to give the meaning of community, mobilization
- Ask why is it important to mobilize the community for HBC services
- Ask trainees to list the key persons/groups that the HBC health facilitator will work with to promote HBC
- List groups and organizations involved in HIV program in their communities
- What are their roles in HBC services
- How can the community be mobilized for HBC services
- What do we need to do to introduce HBC into our communities
- Ask trainees to explain the stages used when entering a community to introduce a program
- Lead a discussion to clarify the steps

Community Mobilization for Home Based Care Services for PLHIV

Community mobilisation is a form of empowerment whereby community members, stakeholders and, or groups plan, implement and evaluate own initiated activities in a participatory and sustainable manner to improve their health and other conditions (Storti, 2007, p.5). It implies the use of locally available resources and the community's full participation and involvement in decision making for the planning, organizing, implementing, monitoring, and evaluating of these services.

Community participation means to have community members be aware, actively involved and supportive of home based or other methods of care for PLHIV in their community.

Purposes/importance of mobilizing the community:

- To gear the community into participatory action
- To create awareness of the problem of PLHIV and the care needed
- To identify the problems and seek means of solving the problems together
- To gather information
- To establish a relationship with the community

Key stakeholders for HBC Activities who can Influence the Introduction of HBC Services:

- Local Council officials
- Religious leaders
- Organized groups, e.g., women, youth, religious
- Related community health workers
- Traditional healers
- School teachers

Ways of Mobilizing the Community for HBC Services:

- Meetings with key persons, existing committees, and community groups
- Home visits to talk to individuals and groups
- Announcements through mosques, churches, schools
- Group community talks

Steps to Take to Initiate HBC Service:

- Orient local leaders to the program
- Hold meetings with all leadership levels,
- Include influential leaders and organizations/groups that can participate and provide support to the HBC services

Session 7: Management of Signs and Symptoms of HIV and AIDS at Home

Time: Four to Five hours (240 - 300 minutes)

Aim: This session will teach the trainees to identify the signs & symptoms of various infections associated with HIV and AIDS and how to treat them at home. Trainees will also be taught how to recognize symptoms that need referrals to a health professional

Learning Objectives

By the end of the session, the trainees will be able to:

- Identify symptoms of the various infections associated with HIV and AIDS
- Treat these symptoms at home
- Know when home treatment is not enough and when the person should be taken to a doctor/health-care provider

Table 7.1: Communication Strategy; HIV/AIDS Signs and Symptoms Management at Home

Session Seven: Management of HIV Signs and Symptoms at Home				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Symptoms of HIV/AIDS Associated Infections • How To Manage Symptoms At Home • Know When To Make A Case Referral	• Caregivers	• Presentations • Trainer-Led Discussions • Group Discussion	• Posters • Flip Charts • Markers	• 240-300 Minutes

Table 7.2: Session Activities; HIV/AIDS Signs and Symptoms Management at Home

Activity	Time (minutes)	Content	Materials	Pictures
1	Will vary	Discussions of signs & symptoms and treatment of various illnesses associated with HIV and AIDS Role plays by participants with at least one focusing on referral.	Flip Charts/White board and Markers	

The following material for this session is included at the end of this chapter:

Reference Materials:

Box 4.1: Key Points; Managing HIV and AIDS Symptoms at Home

- It is advisable to see a health-care provider as soon as any symptom is noticed before trying to treat the infection(s) at home
- Follow the health-care provider's advice carefully
- Do not discontinue treatment until the full duration is complete
- Always use gloves/plastic bags to cover hands while handling wounds, blood, and body fluids
- Medicines and other things (cotton wool, gauze, potassium permanganate and gentian violet crystals, ORS packets, etc.) should be kept in a safe and clean place that is away from children and pets
- Bedpans/commodes should always be clean

Note: This is a long session. Based on what is most convenient, it can be split into 2 or 3 sessions or it can be done continuously with breaks in between. If you want to do it in 2 sessions, 1 session can be done in the morning and the other in the afternoon. If you want to do it in 3 sessions, the third session can be carried over to the next day. The following is an example of how the content could be divided:

Table 7.3: Training Sessions for Home-based HIV Symptoms Management

Two Sessions

Session 1	**Session 2**
7a: Fever, Diarrhoea, Dehydration, Nausea and Vomiting, Tiredness and Weakness **7b:** Skin problems	**7c:** Mouth and Throat Problems **7d:** Respiratory problems **7e:** Pain, Anxiety and Depression, Mental Confusion and Dementia

Three Sessions

Session 1	**Session 2**	**Session 3**
7a: Fever, Diarrhoea, Dehydration, Nausea and Vomiting, Tiredness and Weakness	**7b:** Skin problems **7c:** Mouth and Throat Problems **7d:** Respiratory problems	**7e:** Pain, Anxiety and Depression, Mental Confusion and Dementia

Activity 1: Group Discussion, Demonstration, and Role-play

Topic: Symptoms and treatment of various illnesses associated with HIV and AIDS

Instructions:

Step 1 (Time depends on the number of topics covered)

Start the discussion by asking the trainees questions such as:

- What are the types of infections you have come across among family members and other people with HIV and AIDS?
- What remedies were used to treat these infections?

- At what point do you take the person to the hospital or health-care provider?

The infections and the remedies stated for that particular infection should be noted down one by one by the trainer on a flip over. A health-care provider should preferably facilitate or co-facilitate these sessions. He or she should add more information and expert knowledge about the particular infection when necessary. The Presentation will be helpful in showing the trainees the symptoms associated with different infections. If there are counter-indicators or possible harms for any of the remedies used, the trainer or health-care provider should explain.

Note on the presentation: The presentation/series of images provided in the reference material is a guide to aid your talk. You can use the pictures as examples of types of signs and symptoms, and as a visual aid to explain to the trainees how to identify and manage them, and when to seek additional medical attention.

Note: Be sure to stress the importance of **seeing a health care provider and following his or her advice.**

Step 2

After you have finished the discussion about the various symptoms of infections, you can test the trainees' understanding through group work based on the lecture and discussion. You can divide the trainees into 4-6 separate groups and give each group a topic (examples below) to role-play. Ensure everyone has an active role in this process, and that trainees work together.

Topic 1: Taking care of a person with fever and loss of appetite.

Topic 2: Managing itchy skin and skin rash.

Topic 3: Taking care of a person with diarrhoea and dehydration

Topic 4: Cleaning wounds

Topic 5: Taking care of a person with respiratory problems.

Topic 6: Taking care of a person with mental confusion, dementia and pain

Topic 7: Taking care of a 3 year old child with temperature of 37.5^{o}C, diarrhoea and vomiting or a 40 year old man with shortness of breath and swollen feet - role plays should focus on referral

Note: You can change/add topics according to the trainees' needs or group size

Step 3 (30 minutes)

Recommend that trainees use approximately 15 minutes to discuss among themselves and prepare, and the next 15 minutes to carry out the role-play.

Step 4 (20 minutes)

After each group presents its role-play, the other trainees should discuss:

- If the treatment was correct
- If the caregiver was kind and considerate
- If there is anything the caregiver missed that should have been added

Step 5 (20 minutes)

Ask if the trainees have any questions and summarise the session with the help of the slide

Reference Material

Managing HIV and AIDS Symptoms at Home

This section deals with the common health problems faced by PLHIV and the likely causes of these problems. It also deals with ways in which these illnesses can be managed at home.

Note: Because of the complexity of some of the subjects within this session, the trainees should be made aware and thoughtful to what extent these problems can be addressed at home. It is advisable to have consensus in the HBC-team regarding to what extent a home visitor or caregiver is allowed to perform the described activities.

Common Health Problems PLHIV Face

I. Fever

When a person's body temperature is too high, he or she has a fever. Fever is not a disease in itself but a sign that something is wrong with the body. Fever may indicate one or a combination of many illnesses. The body's production of a fever is thought to help its natural defences fight infections. Having a fever usually makes the patient feel bad. The patient may feel intermittently hot and cold, with 'goose bumps' or shivering, and often drained of energy. The fever process itself causes aches and pains (often backache) in the muscles and joints, as well as headache.

In people with AIDS, fever often comes and goes. It is difficult to know whether the fever is a symptom of a treatable infection or whether it is due to the HIV infection itself. Some causes of fever may include:

- AIDS-related opportunistic infections such as tuberculosis or another infection
- Malaria
- HIV infection

How to check the temperature

Note: The patient may be hot when he or she is being touched without necessarily having a temperature above the normal range. At other times, patients may feel cold even though their temperature is raised, so it is always worth taking their temperature with a thermometer to be sure. (Trying to decide if the patient has a temperature by touching the forehead of the patient with the back of your hand is notoriously unreliable).

The usual way in Ghana of using the thermometer is under the armpit.

How to use a mercury thermometer

- Clean the thermometer with soap and water and wipe it dry with a clean cloth or some cotton.
- Hold it firmly by the end opposite the tip where the bulb is, and turn it slowly against the light until you see a dark or silver line running down the middle. If it stops well before the small arrow mark indicating normal body temperature ($37^{O}C$ or $98.6^{O}F$) then it is calibrated and you can use it straightaway. If not, shake it with flicks of the wrist – remember to hold it firmly – and check the silver line again until it stops well before the normal arrow mark.
- Place the tip well under the armpit and keep the upper arm firmly against the side of the chest.
- Leave the thermometer in place for about 2 minutes. Then, remove and read it.

Note: If you have a gun thermometer, use by holding it about 2 to 3 cm from the forehead and pressing the knob to take the temperature.

What can be done at home to lower fever?

- Remove extra clothing and blankets.
- Check the temperature at regular intervals – at least four times a day – and note down the data to keep track of any improvement, changes and patterns. This check-up can be done by the home caregiver or the patient his or herself, if he/she is capable.
- Open windows to let fresh air in, as breezes help in lowering fever.
- Provide plenty of fluids: water, juice, weak tea, or broth. This also prevents dehydration.
- Cool the skin by taking baths or applying cloths soaked in tepid water to the chest and forehead, or by just wiping the skin with wet cloth and letting the water evaporate. Make sure the water is not too cold.
- Use medicines that reduce fever, such as 500 to 1000 mg paracetamol. (Children should be given a lower dose depending on their weight).

When should they seek help?

The person should be encouraged to seek help when:

- Fever is very high (37.5 degrees Celcius and over).
- He or she has had fever for more than two days.
- Fever is accompanied by other symptoms such as coughing, diarrhoea and weight loss
- Fever is accompanied by symptoms such as stiff neck, severe pain, and severe headache, and confusion, loss of consciousness, yellow colour in the eyes, sudden severe diarrhoea, or convulsions.
- Client is pregnant or recently had a baby.

II. Diarrhoea

Diarrhoea is very common in people with AIDS. A person is defined as having diarrhoea if he or she has 3 or more watery stools a day, which may be accompanied by abdominal cramps and vomiting. The most common causes of diarrhoea in people with HIV infection are:

- Intestinal infection from food or water that is not clean and fresh.
- Opportunistic infections related to AIDS.
- Side effects of some medicines.

Diarrhoea is dangerous because prolonged diarrhoea can cause dehydration and malnutrition. Dehydration is caused by the loss of large amounts of water and salt from the body and can be fatal if not treated. It can also lead to malnutrition because:

- Nutrients are lost from the body in the stools.
- People with diarrhoea usually do not feel hungry.
- Some people incorrectly think that they should not eat or drink when they have diarrhoea.

Prevention of diarrhea

- Drink clean water – strain water using a clean cloth. Bring to a boil and then continue boiling for another 20 minutes to kill the germs. Store water in clean containers and keep it covered.

- Eat clean, safe food - Make sure that all meats are cooked properly. Try to eat freshly prepared foods and try not to eat from outside if possible.
- Wash all raw foods well with clean water before cooking. Always cook raw foods.

Wash your hands with soap and water:

- After using the latrine
- Before preparing food or drink for yourself or for others
- Before and after eating

How to treat diarrhea at home

- Drink as much fluid as possible (at least 1½ times more than what you normally drink) to avoid dehydration.
- After each loose stool, drink at least a cupful (children ¼ to ½ cup) of:
  - ORS (from readymade packet)
  - Rice water (salted)
- Take lots of clean water. The patient can eat "*koko*" or light soup without pepper, tender coconut milk, ice kenkey and unsweetened fresh fruit juice. AVOID sweetened fruit drinks, sweetened tea, coffee, and soft drinks.
- Breast-fed infants should continue to be breast-fed (at least every 3 hours)
- The sick person should drink even if not thirsty. Children, especially, should be encouraged to drink.
- Eat small amounts of nutritious and easily digestible food (bland and soft food). Some examples are bananas, avocado, plain rice, kafa/aboloo or plain biscuits.
- Avoid high-fibre foods, e.g., raw vegetables and unpeeled fruits
- In addition to ORS and fluids, other ways to hydrate include fruits and home remedies

Box 5.1: Instructions for Homemade ORS

A. Preparing an Oral dehydration drink from ORS packet

- Follow the instructions on the packet; dissolve the content of the packet in the amount of clean water stated on the packet.
- Stir well and drink after every watery stool.

Instructions on the packet should be followed precisely so that the ORS is neither too strong nor too dilute, which could cause further problems.

B. Preparing a homemade sugar and salt solution (when ORS packet is not available)

- To one litre (1.5 beer bottle or 3 Fanta bottles) of clean water, add 8 level teaspoons of sugar and 0.5 level teaspoons of salt.
- Stir well and drink after every watery stool.

Note: Do not add milk, soup, fruit juice or soft drinks to solutions A and B.

Other Problems That May Come with Diarrhoea

Prolonged diarrhoea can cause skin irritation in the rectal area. To manage this:

- Clean the rectal area gently with clean water after each bowel movement. Pat dry and apply lotion or vegetable oil.
- Relax during bowel movements. Try not to strain or push too hard.
- Sit for 10 min in warm water containing a pinch of salt 3 or 4 times a day.

For babies in nappies who have diarrhoea, the buttocks area will need special care. The caregiver should:

- Leave the baby’s bottom exposed to air as much as possible.
- Soak the baby’s bottom with warm water between nappy changes.
- Remove or change nappies as soon as they are wet or soiled.

- Avoid wiping the buttock area — instead squeeze water from a washcloth or pour water over the area and then pat dry.
- Apply an ointment like Vaseline to form a protective layer.

Note: Always wash hands with soap and water afterwards

When to seek help

If the person…

- Continues to be very thirsty
- Has a fever
- Cannot eat or drink properly
- Has diarrhoea for more than 3 days
- Is vomiting and cannot keep down fluids
- Has blood in the stools
- Has more than 4 stools in 2 hours
- Is vomiting and confused

To help someone with diarrhoea who cannot get out of bed:

Use a bedpan or any suitable plastic or metal container, which can be easily slipped under the person in bed. Empty the contents frequently. Do not use this container for any other purpose once it has been used as a bedpan. Change wet or soiled bedding and clothes immediately to prevent damage to the skin, wearing gloves. The soiled clothes must be kept separate. By holding the unstained part of the cloth, rinse out stains (preferably with bleach solution) and then wash it with soap and water and dry in the sun.

Note: Always use gloves or a plastic bag over hands while handling soiled or wet clothes.

III. Dehydration

Dehydration means the loss of water and salts. Just like a plant that is not watered, we will dry out, get weak, and slowly die if we don’t have enough water in our bodies. People with advanced HIV disease are in danger of becoming dehydrated because they lose water through diarrhoea, vomiting and sometimes severe sweating. At the same time, patients may have problems getting enough fluids into their bodies because of nausea, sore mouths, fear of further diarrhoea or vomiting, depression, and weakness.

Note: Dehydration develops more quickly and is most dangerous in small children.

Signs of dehydration

If any of the symptoms below occur then the dehydration is already severe and the person needs to be referred immediately

- Thirst is often a first, early sign
- Dark-coloured urine
- Weakness
- Loss of elasticity (stretchiness) of the skin
- Sunken eyes
- Confusion
- Fits
- Less-frequent urination (the body fights dehydration by keeping water in the body as long as possible) or absence of urination
- Sagging-in of the “soft spot” in infants

What to do at Home in the Case Where Dehydration is not accompanied by one of the above

Give the dehydrated person sips of ORS every 5 minutes, day and night, until he begins to urinate normally. A big person needs 3 or more litres a day. A small child usually needs at least 1 litre a day, or 1 glass for each watery stool. Keep giving the drink often in small sips, even if the person vomits. Not all of the drink will be vomited.

When to Seek Help

If dehydration gets worse or the person is feverish, confused, or has fits, seek medical help immediately.

IV. Nausea and Vomiting

Nausea and vomiting may be caused by:

- Medicines
- Infections
- HIV infection
- A problem with the stomach or intestines
- Kaposi’s sarcoma in the intestines

In some people with AIDS, nausea and vomiting are present for a short while and go away on their own or after treatment. In others they are long-lasting and become a part of life.

What to do at home

Nausea

- Seek available foods that the patient likes that subdue nausea, such as dry foods, roasted yam/plantain, bread, boiled egg, biscuit etc.
- Drink at least 8 cups of water during the day in small quantities.
- Offer snacks the patient likes throughout the day to keep the stomach from being empty
- Don't serve liquids with meals – instead, offer the liquid 1 hour before or after the meal
- Avoid serving sweet, greasy, or acidic foods
- Encourage the patient not to lie down for a while after eating
- If possible, avoid cooking smells and cooking near the patient
- Make the person smell a lime (helps to lessen nausea)
- Ginger tea (tea boiled with crushed ginger) helps reduce nausea
- Take medicine prescribed by health-care worker.

Vomiting

- If the patient vomits during the meal, have them rinse their mouth out and wait 15 to 20 minutes before trying to eat again.
- Offer a lot of clear fluids (not milk) to replace those that were lost with vomiting

If vomiting is severe the person should:

- Not eat any food or drink any fluids for 1 or 2 hours. Then gradually start drinking water, ORS, weak tea, or other clear liquids or suck on ice made of clean water
- Then increase the amount of fluids. They should force themselves to drink even if not thirsty to replace fluids lost

- As the nausea decreases, small quantities of dry food like rice, bread, or roasted potatoes should be eaten frequently

Note:

- The mouth should be rinsed frequently and the tongue and gums cleaned with a soft toothbrush or a cloth to remove the foul taste caused by vomiting. The mouth can be rinsed with lemon water.
- Ventilating the patient's room may make a person feel better and less nauseated.
- Although HIV is not present in vomit, it is still advisable to wear gloves/plastic bags when cleaning it up.

When to Seek Help

- If vomiting occurs repeatedly and fluids cannot be kept down – in such cases the sick person is at risk of becoming severely dehydrated.
- If regular vomiting lasts more than 24 hours, particularly if it is accompanied by pain in the abdomen.
- If the person has fever in addition to the vomiting.
- If the sick person is vomiting violently, especially if the vomit is dark-green, brown or smells like faeces.
- If the vomit contains blood.

V. Tiredness and Weakness

AIDS can often make a person feel very tired and weak, particularly in the last stages of the illness. This can have many causes and to some extent is unavoidable. People should do what they can to keep their strength up and not take on activities that could be dangerous to them (like walking too far).

Weakness and fatigue in a person with HIV and AIDS could be a result of some or all of the following:

- HIV infection or HIV-related illnesses (particularly respiratory illnesses)
- Poor nutrition

- Depression
- Anaemia

What to do at Home

If no treatable infection or other problem is found, it is important for people to learn how to adjust to their limited ability. The following advice may be of help:

- Let the sick person do the chores he or she can so that he or she remains involved with the activities in the family.
- Rest should be taken as often as needed.
- Activities should be made easier – sitting rather than standing to bathe or cook; using a bedpan or a suitable container rather than going to the toilet; buying or making a walker, cane, or wheelchair.
- It should be made known to the sick person that family members are willing to help whenever it is needed. They should not hesitate to ask for help.

If the person is too weak to get out of bed:

- Move the sick person's arms and legs gently several times a day to prevent bed ulcers (decubitus)
- Provide a bedpan or suitable container every few hours, or more often if needed, to allow the person to empty their bowels or bladder
- The caregiver should help with his or her personal hygiene – bathing, going to the toilet, changing position in bed, eating, and drinking.

Though weak, the person should be kept involved in the activities within the home to make them feel useful. If the person is weak but able to move, safety precautions can be very important. Some of the safety precautions to be taken are:

- Move loose or dangerous objects out of the way.
- Assist the person when walking or provide a walking stick or cane.
- Try not to leave the person alone for long periods.

When to Seek Help

When the sick person suddenly becomes very weak and particularly if it is accompanied by high fever, headache, or confusion

VI. Common Skin Problems

The following skin problems are common in people with AIDS and unfortunately tend to be chronic. They can be controlled with the right treatment, but are rarely completely cured.

- Rash
- Itching skin
- Painful sores on the skin
- Increased dryness of the skin
- Boils and abscesses

The most common causes of some of these problems include:

- Yeast infections (thrush, candidiasis)
- Other fungal infections (e.g., ringworm)
- Bacterial infections
- Herpes zoster
- Infected scabies
- Poor hygiene
- Allergic reaction to medicines; skin irritants
- Bed sores
- Kaposi’s sarcoma

Itchy skin

Itchy skin is very common and can be due to infections.

What to do at Home

Cleaning the skin frequently with soap and water and keeping it dry between washing will help prevent common problems.

Almost all skin problems involve the sensation of itching. Scratching the itching skin with fingernails can make things worse, either by breaking the skin or by introducing or spreading infection. This can be avoided by keeping nails short. Try to encourage people not to scratch any type of skin lesion or sore. However, rubbing with the flat of the fingers or gentle slapping can give some relief.

The sick person can get some relief by trying any of the following:

- Cooling the skin with water (water boiled with neem leaves and cooled) or fanning it.
- Applying lotions such as calamine that are soothing and prevent the skin from becoming too dry.
- Not letting the skin get hot and not applying warmth to itching areas.
- Rubbing cucumber slices gently over the affected parts.
- Avoiding scratching, which causes more itching and sometimes infection.
- Cutting fingernails short and keeping them clean to avoid infection.
- Putting one tablespoon of vegetable oil (coconut oil, sesame oil) in 5 litres of water when washing the sick person.
- Applying oil or glycerine after bathing.
- Taking the medicine prescribed by the health-care provider. These medications may have to be continued even after symptoms disappear.

When to Seek Help

- If skin problem persists or becomes worse.
- If the skin becomes infected and starts oozing

VII. Wounds

What is a Wound?

Closed wound: A closed wound is a red, raised painful lump in the skin. They are most common in the groin, buttocks, armpits, back, and upper legs. They may appear as one single lump or in groups of lumps.

How can I Care for Wounds?

Use warm salt-water compresses over the area for 20 minutes 4 times a day. The warmth of the compresses will help the boil or abscess to “mature” or to harden and drain its contents.

Use the warm compresses as explained below:

- Boil water with salt (1 teaspoon of salt in one litre of clean water) and allow it to cool until you can just hold your hand in it.
- Fold a clean cloth so that it is slightly larger than the area to be treated. Wet the cloth in the hot water and squeeze out the extra water.
- Put the cloth over the affected skin.
- Cover the skin with a sheet of thin plastic.
- Keep the affected part covered and raised.
- When the cloth starts to cool, put the cloth back in the hot water and repeat the process.

If the wound is on the legs or feet, raise the affected area as high and as often as possible. Walk when possible. Once the liquid in the boil drains, it becomes an open wound and can become infected. Keep the wound clean to avoid infection.

Signs of Infection

- The wound becomes red, swollen, hot, if skin appears shiny and is painful
- It has whitish, yellow fluid draining from or visible under the skin
- It begins to smell bad

If the wound is infected, you should clean and wash the wound by doing the following:

- A salt wash of one spoonful of salt in a cupful of clean water (water that has been boiled) or gentian violet solution (one teaspoonful of GV crystals in half a litre of clean water)
- Wash around the edge of the wound first, then wash from the centre out to the edges using separate little pieces of clean cloth for each wipe if possible.
- Cover the area with a clean piece of cloth and bandage if the wound has yellow or white fluid or blood. If the wound is dry, do not put a cloth cover on it since the wound will heal faster this way.
- If the wound is on a leg or foot, keep the limb raised as much as possible.
- To avoid infecting yourself and others in the household, use gloves, plastic bags, or a leaf when handling any cloth that has touched the wound.

People who are not immunized against tetanus should seek medical help immediately if they are wounded or develop open sores.

Tips on Covering Wounds

- Never apply a dressing tightly.
- Make sure dressing is clean.
- Change the dressing at least once a day. Be sure to look for signs of infection.
- After changing the dressing, rinse the soiled cloth and bandages in water and soap and put them in the SUN to dry or put them in boiling water for a short period and hang them to dry. If the dressings are not to be reused, always dispose of them properly by burning them or burying them.

When to seek help

- When the wounds become infected.
- Fever occurs.
- There is a red line above the wound.
- The lymph nodes under the skin in the neck, armpits, or groin become swollen and tender.

These symptoms show that the infection is spreading to other parts of the body. (Treatment of skin infections should be continued even after symptoms disappear. Follow the doctor’s instructions).

VIII. Bedsores

Bedsores are caused by a rubbing away of the skin from lying in bed for a long time. These chronic open sores appear in people who are so ill that they cannot roll over in bed. It is especially a problem for those who are thin and weak. The sores form over the bony parts of the body where the skin is pressed against the bedding. They most often occur on the buttocks, back, hips, elbows, and feet.

How can I prevent bedsores?

- Get out of bed as much as possible.
- Change position every 2 hours from one side onto the back; from the back onto the other side, in order to prevent prolonged pressure and lack of circulation to any one area of the body.
- Put cushions or a soft, rolled-up cloth rolled up placed under against the shoulder, back, or below and between the knees.
- Sheets should be hung to air daily and changed each time the bedding is soiled with urine, vomit, or sweat. Try to always straighten the bedding, as wrinkles can hurt the skin.

A bedridden child who has a chronic illness should be held on someone’s lap.

Note: To change the bed sheets for a person who cannot be lifted from the bed, turn him over to one side and push half the sheet in from the other side; then turn him back and pull out the other half from underneath. Make sure there are no creases or wrinkles.

How can I treat bed sores?

- Gently wash all the sores with clean water mixed with a little salt or antiseptic solution
- Protect the sores with sterile gauze.
- If the sores are not deep, leave the wound open to the air.

When to Seek Help

- If pus, redness, or fever accompanies the sores.
- If the wound has a bad smell, if brown or grey liquid oozes out, or if the skin around it turns and forms air bubbles or blisters — this could be a very dangerous infection.
- If there is severe pain from the sores and the person is unable to sleep or function during the day.

IX. Scabies

Scabies is a disease caused by a type of tick or bug that cannot be easily seen. The disease spreads through direct physical contact with the infected person and through clothing and bedding. Scabies is a very common illness that can be easily treated at home.

Symptoms

- Tiny bumps all over the body, but most commonly between the fingers, around the waist, and on the penis and scrotum in males, and around the vaginal opening in females.
- Itching

Itching: Scratching can cause the bumps to get infected and form sores with pus. Infection causes fever and areas under the armpit and groin to become swollen and painful.

What can I do at home?

- If one person in the family has scabies, the whole family should be treated, even if they do not have symptoms.
- Towels and soap should be kept separate. Good hygiene is very important.
- Use medication as prescribed by the doctor.
- The whole body should be washed and scrubbed with soap. Fresh clothes should be worn.
- Next morning, no bath should be taken and the medicine prescribed by the doctor should again be applied all over the body. The same thing should be done in the evening.
- The second morning, a bath should be taken and fresh clean clothes should be worn.
- The used clothes and the towels should be boiled, washed, and put in the sun. If the bedding cannot be washed, it should be put in the sun. This action will kill the insect.

- Treat the infected sores as explained in treatment of wounds that are infected and follow the advice on washing or cleaning an infected wound.

When to Seek Help

- If there is severe itching
- If the sores are infected

X. Herpes zoster

Herpes zoster is a viral infection. It is very common in people with AIDS and it may be one of the first symptoms of HIV infection or AIDS. Herpes zoster begins as painful rash with small blisters, usually on the face, limbs, or trunk. Herpes zoster on the face may affect the eyes, causing pain and blurred vision. The blisters often join together, resulting in a large eroded or broken area. There may be in an intense feeling in the affected area. Healing takes place over several weeks and leaves discoloured areas on the skin.

What to do at home?

- Apply calamine lotion twice daily to relieve pain and itching, which promotes healing.
- Keep the area dry and if possible; do not let clothes rub on them.
- Wear clean, loose-fitting, cotton clothing.
- Use paracetamol to relieve pain, although sometimes the pain may be so severe that stronger medicine may be needed.
- Use the medication as prescribed by the doctor.
- Prevent the skin from becoming infected by bathing the sores with warm salt water four times a day or applying gentian violet solution once a day.
- Watch to make sure the sores do not become infected. If they do, they will turn red or have liquid inside them.

The pain usually stops after 3 to 4 days, but some people may develop a persistent pain and scarring over the affected area.

When to Seek Help

- If pus, redness or fever accompanies the sores.
- If there is severe pain from the Herpes zoster, and the person is unable to sleep or function during the day.
- If shingles affects the eyes.
- If the person with Herpes zoster does not respond to treatment.

XI. Mouth and Throat Problems

Soreness in the mouth, usually accompanied by white patches on the tongue, is a common symptom in people with AIDS. Sometimes it may progress into the throat and oesophagus, causing painful swallowing, thereby interfering with eating and drinking. Other associated problems are blisters and sores on the lips, and dental problems.

Oral Candidiasis (Thrush)*:* Thrush is a fungal infection that causes small white patches on the inside of the mouth and tongue. If the white patches scrape off with a brush or with a fingernail it is probably thrush. If they do not, it may be another condition called hairy leukoplakia.

Someone with Oral Candidiasis should:

- Gently scrub the tongue and gums with a soft toothbrush at least 3 or 4 times a day, then rinse the mouth with salt water or lemon water.
- Suck a lemon if it is not too painful – the acid of the lemon slows down the growth of the fungus.
- Apply gentian violet solution (1 teaspoonful of gentian violet crystals dissolved in a half litre of clean water).
- Take medication as prescribed by the doctor.

Hairy Leukoplakia

Hairy leukoplakia may look like thrush but it does not cause pain nor can it be scrubbed off the tongue or gums. It should not be confused with thrush, as it does not need any specific treatment. It does not interfere with the ability to eat or with a person's general comfort.

Herpes Simplex Sores

These are painful blisters or ulcers on the lips, which may appear after a fever. In people with AIDS these sores may appear without a fever and may last a long time. Gentian violet solution can be applied to the herpes sores on the lips and mouth, which will help in preventing the sores from getting infected.

Dental problems

Many people with AIDS suffer from inflammation of the gums, tooth abscesses, and infection. They should be encouraged to make regular visits to the dentist when possible, and be particularly careful about oral hygiene.

What can be done at home?

Poor nutrition can cause problems in the mouth and can make existing problems worse. Encourage people to eat a healthy diet or take vitamin supplements.

To Help Prevent Problems in the Mouth and Throat:

- The mouth should be rinsed with warm salt water (half a teaspoonful of salt in a cupful of water) or with a mouthwash solution (lemon water can also be used) after eating and between meals. The wash should be swished gently in the mouth then spit out (if swallowed, it may upset the stomach and cause nausea).
- Thorough cleaning of the teeth and gums is important, preferably after each meal.
- Brush the teeth and clean between the teeth to remove food particles.
- If someone does not have a toothbrush, they can use a tooth-cleaning stick (a neem twig)
- They can also tie a piece of towel around the end of a stick and use it as a toothbrush.
- If toothpaste is not available, a tooth-cleaning powder can be made by mixing salt and bicarbonate of soda (or ashes) in equal amounts. To make it stick, the brush should be wetted before being put in the powder.
- In case of toothaches, a pain reliever like paracetamol can be taken.

- Protective foods that are rich in vitamins, especially eggs, meat, beans, dark green vegetables, and fruits like oranges, lemons, and tomatoes, should be eaten. Sweet, sticky, and stringy foods that get stuck between the teeth should be avoided.

When to seek help

- If the sick person is unable to drink or is unable to swallow properly
- If there are symptoms of oesophageal thrush, such as burning pain in the chest or a deep pain when swallowing
- Smelly mouth and persistent sores
- If tooth infection is severe with fever, swelling, pus, etc.

Mouth Ulcers

Mouth ulcers are usually seen inside the lips and the inside of the cheeks. They cause redness in the area and are visible as tiny pustules.

What can be done at home?

- Gentian violet solution can be used as a paint.
- B-complex tablets should be taken (easily available at the pharmacy).

When to Seek Help

- If the ulcers do not get better
- If it is very painful and the person finds it difficult to eat

General tips for dealing with a sore mouth:

- Eat soft foods rather than hard or crunchy foods
- Eat bland foods
- Use a straw for liquids and soups. This may help to preventing food from touching the sore areas.
- Cold foods, drinks, or ice, if available, may help numb the mouth and ease discomfort.
- Remove bits of food stuck in the mouth with cotton wool, gauze, or soft cloth soaked in salt water

- One good home remedy is to chew guava leaves before eating. The leaves have pectin and this coats the ulcer and makes it less painful.

Sore throat

Most of the time sore throat begins with a cold. The throat may be red and may hurt when swallowing.

What to do at home

- Gargle with warm salt water (1 teaspoon salt in a glass of warm water)
- Take paracetamol
- Garlic tea for a sore throat: Chop 3-4 cloves of garlic. Add to one cup of boiling water. Boil for 10 minutes. Cover and allow to cool. Add honey or sugar to taste. Drink 1 glass 3 times a day. *(Ghana AIDS Commission, 2014)*

When to Seek Help

If pain and fever come on suddenly or continue for more than 3 days.

XII. Respiratory problems

Respiratory problems, particularly lung infections, are common in people with AIDS and can be serious. The most common symptoms are chronic cough, chest pain, shortness of breath, and increased production of mucus or sputum, a thick liquid in the lungs. The most common causes of respiratory problems include:

- Colds and flu
- Bronchitis
- Pneumonia
- Tuberculosis
- Heart problems

What can be done at home?

- Keep the person active by having him or her walk around, turn in bed, and sit up. This encourages the lungs to drain.
- It is helpful to massage or gently pat the person on the back of the chest over the lungs. This is particularly good for young children.

- If there is pain in the chest or ribs during coughing, a pillow or hand should be held tightly over the area that hurts while coughing. This helps make the cough less painful.
- Warm compresses held to the area where there is maximum discomfort can be soothing. Very mild pain-reducing medicines (paracetamol) can be taken.
- It is helpful to cough and clear the lungs at least 4 times during the day. Coughing may cause discomfort but it is an important way to clear the lungs of the accumulated mucus and disease-causing bacteria.
- Place pillows behind the patient so that he or she can sit up. This eases breathing.

Effective Home Remedies:

Ginger and Hwenteaa (tea for chesty coughs)

Add half teaspoon chopped fresh ginger and 2 fingers of hwenteaa to one cup of boiling water. Boil slowly for 10 minutes. Cover and allow it to settle for 5 minutes. Drink one glass 3 times a day. Start drinking the tea as soon as you feel a cold coming.

Lemon tea for flu

Squeeze a lemon to extract the juice. Add the juice to half cup of water that has boiled and cooled slightly. Add sugar or honey to taste. Drink 1 glass as hot as possible 3 times a day.

Onion tea for a blocked or running nose

Put 0.25 onion into a glass of boiling water. Cover and leave for 5 minutes. Strain. Throw the onion away. Drink 1 cup 3 times a day.

Cough syrups

Adults:

Mix 1 part honey with 1 part lemon juice. Add 2 finely garlic cloves. Shake or stir well. Take 1 teaspoon 3 times a day.

Children:

Mix equal amounts of honey, lemon and water. Shake or stir well. Give children 1 teaspoon 3 times a day.

Some tips to help loosen the mucus and allow it to come out

- Drink lots of water. This works really well to get the mucus to loosen up.
- Sit down on a chair with a bucket of hot steaming water at your feet. Place a sheet or towel over your head and cover the bucket so that you can inhale the vapours as they rise. Breathe the vapours deeply for 15 minutes. Repeat this several times in a day. (Eucalyptus leaves can be added to the hot water.)
- Soothe the throat by sipping warm tea with sugar or honey and crushed ginger
- Home-made cough syrup – onion juice + ginger juice + juice of mixed with honey or sugar crystals.

If there is difficulty breathing,

- Help the sick person into the position that eases breathing; usually sitting is the best.
- Leaning slightly forward and resting arms on a table may help.
- Use extra pillows and back support.
- Open windows to allow in fresh air.
- If it is hot, you may fan with a newspaper or clean cloth.
- In children, clear the nose if it is congested with a thin, moist cloth.

When to Seek Help

- If there is an onset of fever or a change in the regular fever pattern of the sick person
- If there is blood in the sputum
- A sudden or rapid worsening in their ability to breathe or catch their breath after normal activity
- A change in the colour of their sputum from clear to grey, yellow, or green Pain in the chest

Note:

- **The bacteria or infectious agents in the sick person's sputum can be passed on to other people** through the air, especially when coughing. When someone is coughing, they should always cover their mouth with their hand or with a cloth that can be cleaned or disposed of.
- **All homes and other places where people meet should be ventilated**. Make sure there is a way in and a way out for fresh air.
- **A constant cough can be very tiring and interfere with a person's rest**. If coughing keeps someone from being able to sleep at night, they should get a cough suppressant from the doctor so that they can get enough rest.
- **Pain in the chest without signs of infection and difficulty in breathing are common problems** in people with AIDS. Very often the cause is not known. It is important to take steps to help relieve the pain so that they can be helped in their efforts to keep active, moving, and coughing.
- **If a lung infection with cough is present, it is important that plenty of fluids are taken;** first, to replace the extra fluids lost through the lungs by rapid breathing and, second, to help keep the mucus in the lungs from becoming too dry and sticky and more difficult to cough out. Children should be encouraged to drink more fluids by increasing the frequency, giving additional fluids by spoon or cup.

XIII. HIV and AIDS Related Pain

For some people in the later stages of AIDS, pain becomes part of daily life. For others it is only occasional and easily controlled.

Kinds of pain:

1. **Acute pain** is sharp and intense. It occurs in one specific area. Signs of acute pain:
    - Restlessness or agitation
    - Fast breathing
    - Moaning, crying or screaming

  - Rubbing, cradling or guarding the place that hurts
  - Tense muscles or fear of any movement
  - Sweating
  - Facial grimaces

2. **Chronic pain** is usually the result of prolonged illness and is dull and aching and often can't be recognised as originating from any particular spot. Such pain can stay constant and can leave a person so weak that eating and sleeping or walking becomes intolerable. Signs of chronic pain:
   - Frustration
   - Anxiety
   - Decreased appetite
   - Depression
   - Irritability
   - Suicidal thoughts

Some people tolerate pain better than others, but while caring for someone with a long illness, one should never assume that the person does not experience pain, even if it is not expressed. **Pain can be caused by;**

- Immobility
- Infection, such as herpes zoster
- Swelling of the legs and arms caused by poor circulation brought on by problems with the heart or Kaposi's sarcoma
- Headache alone or associated with meningitis
- Nerve problems, including pain with or without weakness.
- Feeling depressed or anxious may increase the sense of being in physical pain.
- Side effects of medicines

What to do at home

- To control and relieve the pain, people will need to know that pain is also influenced by the person's emotional state. Pain can be frightening. The sick person may need extra reassurance and care. She or he should be given a chance to talk about the pain.
- People can take an active role in controlling their pain by:
    - Learning deep and regular breathing techniques, which may help them relax.
    - Learning to deal with the pain, through distraction, e.g. remembering pleasant places and events.
    - Taking medicines for pain according to an organised schedule.
    - Engaging in physical activity or receiving a gentle massage.
- A person may experience a strong burning sensation, particularly in the hands or feet, which may be due to nerve problems. This type of pain is made worse by extremes of temperature, touch (even bed sheets or clothing) and dryness.
- Putting the hands and feet in bearably warm water sometimes relieves the pain. If the skin seems to be sensitive, plan things so that all the care and activities that require touching are done at the same time, to allow periods of rest in between. The sick person's bed can be lined with soft blankets or cushions.
- If a person experiences any swelling, they should raise their legs or swollen parts on pillows, or raise the foot of the bed on blocks. They should also keep changing their body position.
- Treatment for pain of all types may include mild medicines for pain, which are commonly used at home, such as **paracetamol** or rubbing **Vicks** Vaporub or **tiger balm** over the area (for headaches). It is important that the sick person take the mild pain medicines regularly, at least every 8 hours, if the problem is long-lasting or chronic.

Some more advice for those caring for people with AIDS to help to calm them:

- Talk slowly to the sick person, and use gentle tones.
- Avoid using bright lights.

- It is also helpful to talk with the person, and to provide comfort and distraction from the pain, by:
    - Applying a cool cloth on the forehead, or giving a massage.
    - Asking what relieves the pain and then doing it.
- Some people like to have the painful area wrapped in cloth or a bandage. When someone lifts a child who is in pain, the palms of the hand should be used rather than the fingertips (which can sometimes feel like a pinch).

When to Seek Help

- If the pain becomes unbearable or is associated with new symptoms such as headache or weakness.
- If the pain greatly affects movement.
- If there is a sudden or recent occurrence of pain in the hands or feet.
- If there is persistent headache lasting more than 2 weeks, a severe headache that is getting rapidly worse and is not relieved by the usual methods, a headache associated with vomiting, or a headache that affects the sick person's ability to think or move

XIV. Anxiety and Depression

Anxiety is an uncomfortable feeling of tension or dread. HIV infection brings the infected person face to face with many uncertainties that cause anxiety. This is normal, but when these feelings are very intense or last a long time, so that normal daily activities are interrupted, they are considered abnormal.

Anxiety can cause severe physical symptoms, and may lead people to believe that they are quite ill. These symptoms may often be difficult to make out from those caused by infections, or side effects of medication or malnutrition.

Some physical and mental symptoms of anxiety:

- Lack of appetite
- Sweating
- Inability to concentrate

- Shortness of breath
- Tingling sensations
- Shaking
- Feeling faint
- Feelings of worry
- Inability to sleep
- Feeling jumpy

What to do at home

- Talk calmly to the anxious person, and use gentle tones
- Avoid bright lights, loud sounds, or stimulating activities.
- Provide comfort and distraction by:
    - Applying a cool cloth on the forehead, or giving a massage
- Use relaxation therapy – meditation, yoga, etc. if possible

For more suggestions look under the section on depression 'What to do at home'

Depression

Feeling depressed occurs when a person turns his anger or guilt inward. An HIV-infected person experiences many losses in a short period of time – loss of health, loss of physical beauty, loss of job or ability to function in the community. This could make him or her unhappy. The symptoms of depression are:

- A feeling of hopelessness
- Feeling tired and generally without energy
- Inability to find pleasure in anything
- Irritability
- Inability to concentrate
- Inability to get enough sleep

- Eating too much or being unable to eat

What to do at home

- Encourage the patient to talk without being patronising.
- Listen and give them time to talk.
- Empathise, which means understanding how someone else feels about their situation, without imposing personal values and thoughts.
- Elderly people in the community can be of great help.
- It may be helpful if someone else with a similar problem who has adjusted to his or her life speaks to the sick person.
- Do things at home together that would be relaxing both physically and mentally – playing a musical instrument, playing cards, etc.
- Involve the ill person in planning for daily care activities and decision making as much as possible.
- Discourage using alcohol and other drugs.
- Some medicines can be useful but should be taken under supervision and with doctor's advice.
- Communication is the key to care.

It is important for a caregiver/home visitor to possess a degree of emotional stability. They need to be non-judgemental and able to keep confidentiality, to listen, and to express ideas/advice clearly. Training in counselling skills is very useful for anyone who provides care and support - from doctors and nurses to volunteers!

When to seek help

- If the family or patient believes that the anxiety or depression is severe enough that the patient may commit suicide or otherwise harm himself or herself or someone else.
- If there is prolonged disruption in the sick person's ability to function such as in sleeping, eating, or going about their daily life.

XV. Mental Confusion and Dementia

It is very common for people with AIDS to have some kind of mental confusion and dementia. This may be caused by infection of the brain with HIV. The mental changes may be barely noticeable or they may become very debilitating.

People with AIDS may describe feeling “dulled’ or “slow” in their thinking. It is usually the family that is the first to notice the changes. These problems often start in a mild, barely noticeable way but may gradually worsen over time. It is not possible to predict whether the symptoms will become severe.

The mental changes may include difficulty in one of the following areas:

- The ability to think clearly: This may be noticed as a problem in concentrating, and losing track of conversations or tasks.
- Behaviour: The person may become irritable, disinterested or unpredictable.
- Strength or coordination: The person may start dropping things more often, falling, or may develop slowness in movements or shakiness.

What to do at home

A person who has a sudden change in thinking, behaviour, or ability to move should seek help. Some of the sudden mental changes may be treatable and the person will recover. However, if such changes are allowed to continue, they may contribute to the rate of mental deterioration.

There is no specific treatment for symptoms of mental confusion. People must learn to live with them and provide a safe environment for the sick person.

Some approaches to manage confusion or anxiety:

- Talk calmly to the anxious person, and use gentle tones
- Avoid bright lights, loud sounds, or stimulating activities.
- Provide comfort and distraction by:
  - Playing favourite music quietly
  - Reading aloud or telling stories
  - Applying a cool cloth on the forehead, or giving a massage

- Use relaxation therapy – meditation, yoga, etc.
- *For more suggestions look under the section on depression 'What to do at home'*

To prevent accidents in the home, people should:

- Pay attention to open fires or boiling water.
- Provide canes or walkers for people who are weak or off balance.
- Remove loose and potentially dangerous objects, like rugs. Keep walkways clear.
- Avoid rearranging furniture.
- Store poisonous or toxic substance safely out of reach.
- Keep medicines out of reach and only give them according to the prescribed schedule.
- Store sharp objects like knives, scissors, razors, and saws. Try not to leave the sick person alone and unattended for long periods.

To help make the confused person feel better:

- Try to interpret the feelings the person is trying to express rather than just the words.
- Give the person a lot of time to respond to questions, directions, or conversations.
- Use a low-pitched tone of voice. Provide reassurance.
- Ask questions that can be answered "yes" or "no."
- Talk about the distant past; the person's memory of events that happened long ago may be good and this will be pleasurable.
- Keep a calm manner by speaking softly.

To help a confused person who is upset or angry feel comforted, you can try to distract them with the following methods:

- Change the subject, provide music, or switch on the radio.
- Give the person an easy task, such as folding clothes.
- Leave the room for a few minutes; the person may forget why he or she is angry.
- Keep calm and do not try to challenge or "reason with" the confused person.

Importance of referrals and networking in Home-based care (AMREF, 2007 p.59-62)

If you are a health worker then am sure you have referred a client at one time or the other, why did you refer him or her? I am sure it was for one of the following reasons

- When services or resources within reach are not able to meet the clients' immediate needs;
- In cases where the acute phase of the disease 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 or client for example, 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 client is deteriorating;
- For continuity of care from the health facility downwards or from family level back to the health facility

Resources Needed for Referral

What you need for referral is:

- Referral form that contains information on client's personal history and the reason for referral;
- Information about where you can refer your clients to (directory);
- A record system that can track referrals;
- Resources to ensure transport;
- Necessary resources at all level of care.

How do we refer clients?

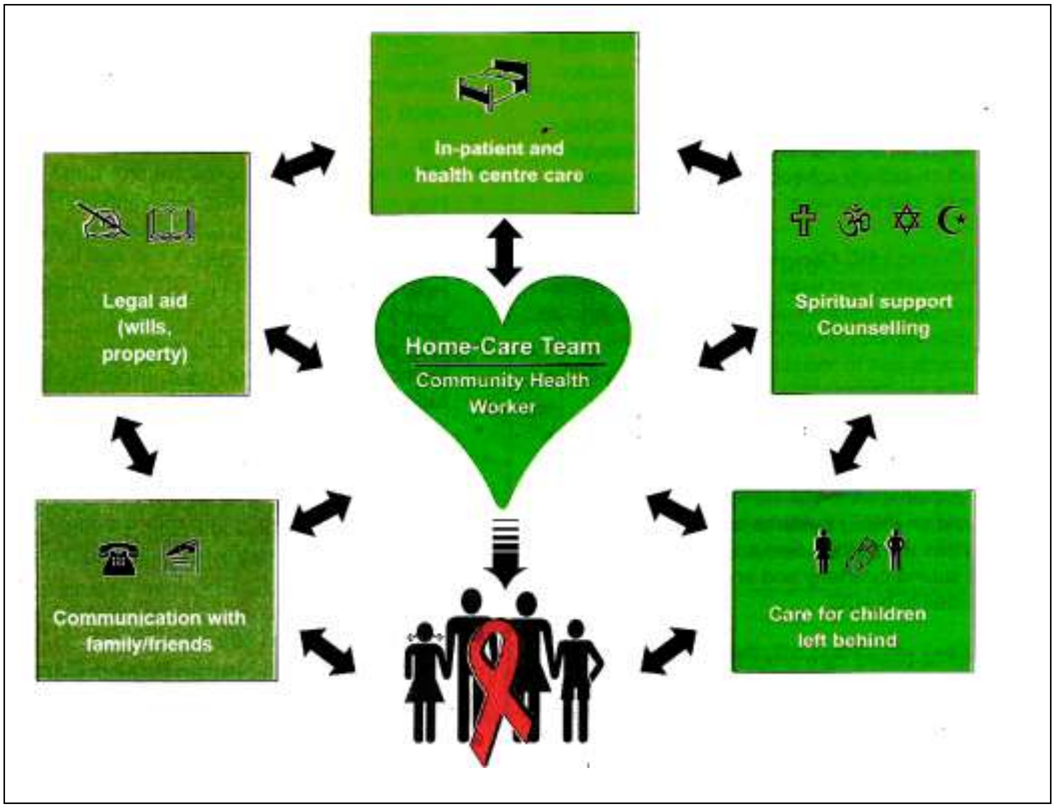
- Identify early the need for referral;
- Choose with the client appropriate referral points and make arrangements by calling in advance;
- Explain to the person why he needs to be referred;
- Make referral arrangements for example transport, what time to leave and how they will travel;
- Prepare the patient for referral. If the patient will be admitted they need to carry certain items, such as, X-ray reports, lab reports, medication and other things required by the institution or the client himself.
- Allow the client to express themselves and try to answer their concerns genuinely;
- Fill in the referral form;
- Ask your clients to give you feedback about actions taken.

Referral Points

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

- Recognized health institutions: government, private or mission hospitals
- Social support groups
- Spiritual leaders
- Legal agencies and local administration, for example, for writing wills, settling property disputes, and addressing burial disputes and arrangements.
- Any other relevant agencies depending on the client's needs.

Figure 1.1: A Simple Home-Based Care Referral Network:



Source: NACP, (2002)

However despite the importance of referral and networking processes, there are many constraints to their effectiveness. Let us look at some of the limitations in the context of HBC and how we can overcome them.

Constraints/Limitations in Referral and Networking

There are a number of constraints that hinder effective referral and networking. These include:

- Competition among various organizations, so that they do not disclose what they are doing and which services are offered. 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 clients to travel from one point to another;
- Lack of referral and networking guidelines as well as 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 and AIDS, which makes PLWHAs reluctant to accept referral to certain facilities;
- Poor mobilization and sensitisation 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.

As a care giver, you can address the constraints we have just mentioned by taking the following steps:

- Holding collaborative meetings among various referral and networking partners;
- Giving correct/proper information on referral to the PLHIV and a proper client history to the referral point;
- Ensuring confidentiality;
- Lobbing and advocating for the rights of the client.

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 PLHIV.

Session 8: Demonstration of Home-Nursing Procedures

Time: 2 hours forty minutes - (160 minutes)

The Aim of this session is to teach the trainees about the client's medication and practice the various procedures used in home nursing.

Learning Objectives

By the end of the session, the trainees will be able to:

- Demonstrate the various procedures useful in home-care nursing
- Be familiar with the Basic Home Healthcare kit
- Know the basic medication used by clients (HIV/TB & OI's)
- Identify and know who can provide home nursing services under HBC.

Table 8.1: Communication Strategy; Demonstration of Home-Nursing Procedures

Session Eight: Demonstration of Home-Nursing Procedures				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Various Useful Procedures in Home-Care Nursing • Basic Home Healthcare • Basic Medication Used by Clients	• Caregivers	• Small Group Discussion • Role Play	• Home Health-Care Kit • Pictures/Posters • Flip Charts • Markers	• 160 Minutes

Table 8.2: Session Activities; Demonstration of Home-Nursing Procedures

Activity	Time (minutes)	Content	Materials	Pictures
1	160	Small group demonstrations and role-play about the healthcare kit and various home nursing procedures	Home health-care kit that contain • OTC medicines (painkiller, ORS) • Wound dressing supplies - cotton wool, plaster, gauze, scissors, antiseptic, gentian violet etc. • Toiletries and other items for personal hygiene • Household cleaning materials • Bedpan/commode • Closed containers • Thick plastic bags/garbage bins	

The following material for this session is included at the end of this chapter:

Reference Materials:

Key Points; the Home Health Kit, its Content and Use

- All medicines should be kept out of reach of children
- All medicines should be kept in a dry, insect-free place
- Expiry date of medicines should be checked periodically
- The home-care kit should have medicines for pain, fever, wounds and skin infections, ORS packets, gauze and cotton wool
- Bed pans and commodes are useful for people who are very weak
- Home nursing requires certain skills while caring for a person who is ill with HIV infection:
    - Feeding client mostly in a chair or in bed
    - Washing/bathing the client in bed/in a chair/in the bathroom
    - Assisting clients move from one position to the other (e.g. from bed to chair)

  - Assisting the client to walk a bit if this is possible
  - Cleaning wounds and sores
  - Changing the bed sheet when the patient is bedridden
  - Use of bedpan for one who cannot get out of the bed
  - Washing soiled clothes
  - Changing positions in bed
  - Cleaning a bathroom
  - Cleaning commodes and bedpans
  - Cleaning the kitchen
  - Disposal of wastes
  - Preparing and/or administering ORS
  - Removing gloves / plastic bags
  - Cleaning up spills
  - Preparing milk for a baby using milk powder
  - Sterilising feeding bottles, needles, sharp instruments, and other utensils

Note to trainer: This is a long session. You can have a short break after each group's presentation. Since there will be a lot of physical activity involved, they may not be interested in games and may just want to chat or stretch.

Tips for an effective training:

- The trainer should be a health-care provider.
- Demonstration of techniques can also take place in homes where people with HIV infection have wounds and sores or are bedridden.
- First and foremost, the contents of the health-care kit should be explained to the trainees (the name and what it is used for). If there are enough trainees they can be divided into 4 groups, otherwise you can have smaller groups.

- It will be helpful to get images of the procedure so these can be shown to trainees or better to actually let them practice these through role plays

Activity 1: Small group demonstration/role-play (2 hours 40 minutes)

Topic: Demonstration of Home-Nursing Procedures

Instructions:

Part 1: Introduction to Kit Items and Medicines

Open the kit and explain important items within, holding them up or passing them around, familiarizing the trainees with the contents. Then, review a list of medicines, their purposes, relevant doses/instructions or contraindications. Be sure to review painkillers, ORS, creams and other basic medicines like ointments.

Part 2: Role Plays

1. Divide the trainees into groups of 3 or 4.
2. Give each group a home health-care kit.
3. Tell them briefly about each procedure. Use pictures while explaining the procedures.
4. Ask each group to perform one or more procedures (choose procedures according to availability of supplies and appropriateness). The trainer may also provide feedback and instruction as needed.
5. Each group will role-play/demonstrate the procedures, including use of content of home based care kit in front of all the trainees. In role-play, one trainee will be the caregiver and the other the person with the problem.

Feedback

After each group finishes their presentation, the trainer(s) and others can give feedback on:

- If the procedures were clear to them
- If the procedures were performed correctly
- If communication was good in role-play
- If the caregiver was kind and sensitive

For each of the activities the trainer can develop a checklist to evaluate the performance of the trainees. If they like, the trainees can also use the checklist during the activity. The trainee can check his/her partner following the points covered on the checklist.

Session Summary (20 minutes)

Finally, the trainer summarises the session. Showing all the pictures might take too long, so only the key points should be explained. You can ask the trainees if any procedure was not clear. If they have any doubts about any of the procedures, only those pictures can be shown and explained.

Home Health Care Kit

Home-based Care projects need homes with basic facilities and equipment for care. The reality is that most homes do not have such facilities and for many people home is a small shack or one roomed building where the person who needs care has little privacy and the extra costs of care are a great burden on their family. Therefore a health-care kit is needed, to improve the quality of HBC. The kits include toiletries, items for personal hygiene, household cleaning materials and basic medication. The kits need to be lightweight, transportable, heat and waterproof, and biodegradable.

How to care for your medicine kit

- Keep all medicines out of the reach of children. Any medicine taken in large doses can be poisonous.
- Be sure all medicines are well labelled and that directions for use are kept with each medicine. If caregiver/family members are illiterate, medicines should be kept in containers of different colours to differentiate the use of the medicines or pictures can be stuck on different containers, e.g. a picture of a wound.
- Keep all medicines and medical supplies together in a clean, dry, cool place free from cockroaches and rats. Protect instruments, gauze, and cotton wool by wrapping them in clean plastic bags.
- Keep an emergency supply of important medicines on hand at all times. Each time one is used, replace it as soon as possible before the need for it arises.

- Notice the date of expiry on each medicine. If not able to read, ask the health worker who visits you to check it. If the date has passed or the medicine looks spoiled, destroy it and get new medicine.

Each home visitor is advised to have the following things in their health care kit:

For wounds/skin problems/infection control	
Sterile gauze pads and plasters	20
1-, 2-, and 3-inch gauze bandage rolls	2 each
Clean cotton	1 small package
Soap	1bar
Scissors (clean, not rusty)	1 pair
Rubber gloves or plastic bags	
Calamine lotion	1 bottle
Bleach powder	500gm
Towels or clean cotton cloth	
Petroleum jelly or Vaseline	1 jar
Gentian violet solution	1 packet or bottle
Betadine ointment	
Prevention materials/HIV commodities	Condoms, lubricants, IEC materials

Oral medications

Paracetamol – for fever and pain relief

ORS (includes ready-made packets/recipe card for making ORS at home) – for diarrhoea

Other items required at home:

- Toiletries and other personal hygiene supplies, bedpans etc.

- If a commode is unavailable, an old chair can be cut in the centre and a bucket put under to serve the same purpose.
- Home Visitor Manual

The set of items mentioned above is not exhaustive and others that are allowed to be handled by the home based caregiver can be added.

Session 9: Conditions that need Special Care – TB, MALARIA AND STIs

Time: One and a half hours (90 minutes)

Aim: This session will teach the trainees to recognise symptoms of TB and STI's and malaria to be able to provide appropriate referral care

Learning Objectives

At the end of the session the trainees will be able to recognize:

- Signs of a person with tuberculosis (TB) so that they can refer them to the appropriate health facility.
- Signs of a person with malaria or sexually transmitted infections (STI's) so that they can refer them to a health facility.

Table 9.1: Communication Strategy; Conditions Needing Special Care – TB, Malaria, STIs

Session Nine: Conditions That Need Special Care – TB, Malaria and STIs				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Understanding Symptoms of o TB o Malaria o STIs	• Caregivers	• Trainer-Led Group Discussions	• Flip Charts • Markers • Pictures/Posters	• 90 Minutes

Table 9.2: Session Activities; Conditions Needing Special Care – TB, Malaria, STIs

Activity	Time (minutes)	Content	Materials	Pictures
1	30	Group Discussion about the signs and symptoms and treatment of TB	Flip over/whiteboard and markers	
2	30	Group Discussion about the symptoms and treatment of STI's	Flip over/whiteboard and markers	
3	30	Group Discussion about the symptoms of malaria	Flash cards, flip over/whiteboard with markers	

The following material for this session is included at the end of this chapter:

Reference Materials:

Box 6.1: Key Points; Conditions that Need Special Attention: TB and STI's

- Home care alone is not enough in treating TB and STI's.
- TB is a contagious disease that can be cured by the right medication.
- Prompt, complete treatment is the best way to prevent further infection.
- Medicines for tuberculosis are given free in government hospitals/clinics.
- The medicines should be taken for the duration specified by the doctor.
- TB accelerates the progression of HIV infection to AIDS.
- Eating well at regular times is as vital to recovery as medicines.
- Medicines should not be stopped because of side effects, consult a doctor immediately.
- STI's are infections that are transferred from one person to another during a sexual act.
- If STI's are detected and treated early, they do not cause serious problems.
- A person who is HIV-positive and also has an STI may progress to AIDS more quickly.

Activity 1: Group discussion on TB (30 minutes)

Topic: Symptoms and treatment of TB

Instructions:

Start the session by asking the trainees:

- Do you know the meaning of contagious diseases?
- Can you give the names of the diseases you think are contagious? (If they have mentioned TB and STI's, ask them first about TB and later about STI's.)
- Do you know the symptoms of TB?
- Is TB curable?
- Are there any home remedies for TB?

- How can you prevent the spread of TB?
- Do you think you have to spend a lot of money on TB medication?
- For how long should TB medicines be taken?
- Is it okay if you stop the medicines as soon as the symptoms go away?

If they have a family member or are otherwise familiar with TB, they may be able to answer some of the questions. The trainer should write down the answers. If they mention home remedies, be sure to tell them that there are no home remedies for TB.

The trainer should then give them the correct information about TB. Importance of adherence to the medicines along with the reason should be explained repeatedly.

Note: The fact that TB is curable should also be emphasised**.**

Activity 2: Group discussion on STIs (30 minutes)

Topic: Symptoms and treatment of STI's

Instructions:

- Repeat the format of Activity 1 (beginning with introductory questions and then giving a lecture). Important STIs to cover include chlamydia, gonorrhoea, syphilis, HPV, Hepatitis B and herpes.
- The importance of using a condom during sexual intercourse should be stressed.
- Trainees should also be informed which doctors/sites in their locality treat STI's, if possible.

Activity 3: Group discussion on malaria (30 minutes)

Topic: Symptoms and treatment of malaria

Instructions

Use the same format as the previous activities. Through the course of the discussion, cover topic areas of transmission, prevention (e.g. mosquito nets), symptoms and treatment of malaria.

Session Summary (15 minutes)

Ask the trainees if they have any questions. Wind up the session by summarising with the help of pictures.

Conditions that need special attention – TB, STIs and Malaria

Tuberculosis, sexually transmitted diseases and malaria are three conditions for which home care alone is not enough and help from a health-care worker should be sought.

Tuberculosis

Tuberculosis is a long-lasting, contagious disease caused by a bacterial infection. If someone has HIV infection they are more likely to get tuberculosis. TB also accelerates the progression of HIV to AIDS. It can be cured with the correct treatment. It mostly strikes young adults (15 to 35 years old), especially those who are weak, poorly nourished or have been in contact with someone with the disease.

The most common symptoms are:

- Chronic cough for more than 2 weeks, which is often worse just after waking up, and may involve coughing up blood.
- Loss of weight and increasing weakness.
- Mild fever.
- Sweating at night.
- Pain in the upper back or chest.
- Loss of appetite.
- In children, the lymph nodes can be infected, most often in the area of the neck and shoulders.

Prevention

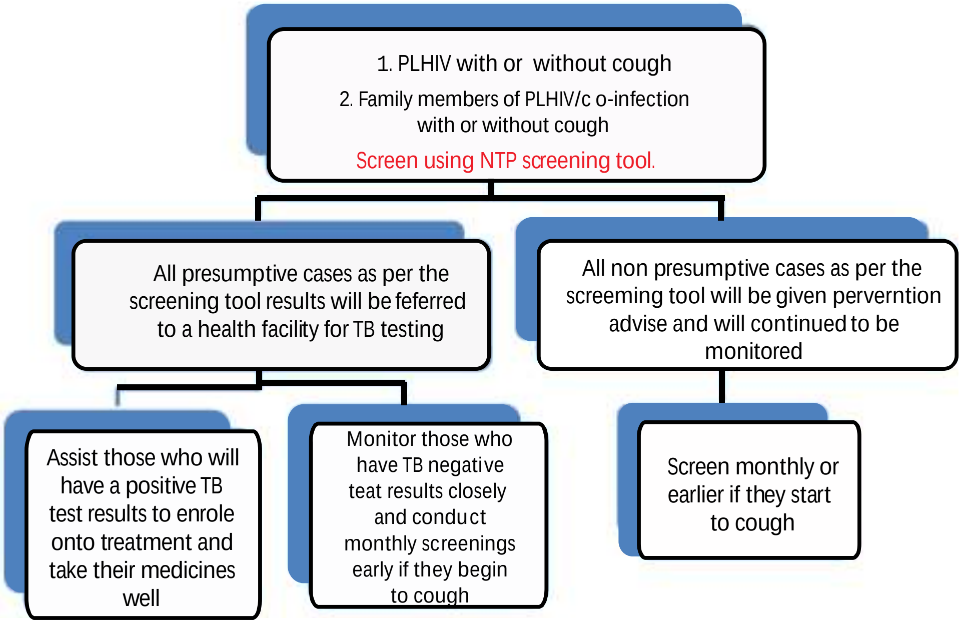
- Everyone – without exception – should seek early assessment and health care if coughing for 3 weeks or more.
- Everyone – without exception – should cover their mouth when coughing.
- Everyone – without exception – should spit into a closed container, not on the ground. The contents should be thrown into a fire or covered with mud.

- Everyone—without exception—should avoid being in an unventilated space with a person who has been coughing for more than 3 weeks.
- All homes, health facilities, workplaces, and other places where people meet should be ventilated—make sure there is a way in and out for fresh air.
- All newborn babies and young children should be immunised against tuberculosis with BCG vaccine.

Screening for TB

A simple screening algorithm can be used at the home level to make sure no one with TB is missed.

Figure 2.1: TB Screening Algorithm



Treatment:

The treatment of tuberculosis involves the use of mostly a combination of 4 different medicines with some in fixed dose tablets. Depending on one's weight, he/she has to take a certain number of these medicines. All the medicines prescribed for a client should be taken regularly without fail for the full course (as determined by the health-care provider), to be completely cured. Otherwise, the symptoms will reappear.

Note: People with Tuberculosis should know;

- Which medicines they must take to cure tuberculosis
- How to take the medicines
- How long they need to take them
- What side effects they should watch for
- That they **should not stop** treatment when they feel better
- That prompt, complete treatment will cure tuberculosis
- That prompt, complete treatment is the best way to prevent further infection
- Medicines for tuberculosis are given free in government tuberculosis hospitals / clinics
- Women should know that they should avoid pregnancy while on treatment as their condition may worsen after childbirth and that they may infect their newborn.
- Eating well at regular intervals is as vital to treatment as medicines
- People with tuberculosis should always spit in spittoons and not wherever they feel like

Normal reactions to the drugs:

- Nausea and loss of appetite
- Orange/red urine
- Burning sensation or pain in the stomach
- Vomiting

If you have these side effects **do not stop** the medications prescribed! See your doctor immediately for advice.

When to Seek Help

- If the sick person has AIDS and has a cough or other signs and symptoms that suggest they might also have tuberculosis.

- If the sick person has a reaction to the anti-tuberculosis medicines. Severe reactions are:
    - Joint pain or a burning sensation in the feet
    - A new skin rash and itching
    - Yellow skin or eyes
    - Repeated vomiting
    - Deafness, dizziness, or eyesight problems

Sexually Transmitted Infections (STIs)

STIs are infections that are transferred from one person to another during a sexual act. Most STIs are easy to treat. If they are detected and treated early, they do not cause serious problems. If they are not detected or treated early, the infection may spread and cause complications such as infertility.

If an HIV-positive person has an untreated STI, the potential to spread the infection grows. A person who is HIV-positive and also has an STI may also progress to AIDS more quickly. Therefore, treating an STI during the asymptomatic stage (when the symptoms of infection are not visible) is important, since this can keep the person healthy for a longer time.

STIs may have few symptoms. A person may be infected for some time and not know it. This is particularly so for women. The danger is that one can spread the disease during this time to others without realising it. Sexually transmitted infections of the genital area are common in both men and women with AIDS. They often cause pain and discomfort.

There are six (6) common ways that such genital problems appear in men and women:

- An unusual discharge (mucus or pus-like substance) from the vagina.
- An unusual discharge from the urethral opening of the penis.
- Open sores or ulcers in the genital, groin, and rectal areas, which sometimes start as blisters.
- A rash in or around the genital area.
- Warts in the genital area or around the anus.
- Swollen glands in the groin.

- Burning or painful urination, especially in men.

Seek a doctor's help immediately if;

- An STI is suspected
- Difficulty or pain while passing urine is experienced
- Genital warts are present
- Genital ulcers are present
- There is an unusual vaginal discharge that is foul-smelling, itchy, very plentiful, or green, yellow, or grey in colour
- A pain develops in a woman's lower abdomen, particularly if it is accompanied by a fever
- A woman's periods stop or become irregular or erratic
- There is a discharge from the penis
- There is swelling and/or pain in the scrotum

Note: Know where to go see a doctor for treatment of STI's in your locality

What to do at Home

- Always use a condom each and every time during sexual contact.
- Always keep private parts clean (wash with clean water).
- Wash hands before and after touching the genital parts.
- After going to the latrine, wipe/wash the anus in a direction away from the vagina so that faeces don't get into the vulva/vaginal region.
- Open wounds and sores should be cleaned with soap and water and kept dry.
- Blisters should be bathed with salt-water solution (one teaspoonful of ordinary salt in half a litre of clean water).

- Soreness and redness in the vulva or penis can be treated by applying gentian violet solution internally and externally to the affected area (one teaspoon of gentian violet crystals dissolved in one litre of clean water) using a soaked piece of clean cotton wool, cloth, or gauze. Apply once daily for 3 days.
- A rash on the penis or under the foreskin will often respond to soaking in a dilute salt-water solution. Put the penis in the water and soak for 5 minutes. Repeat 2 or 3 times a day.

Malaria

Malaria is a life-threatening blood disease caused by parasites transmitted to humans through the bite of the *Anopheles* mosquito. Once an infected mosquito bites a human and transmits the parasites, those parasites multiply in the host's liver before infecting and destroying red blood cells. Destruction of these essential cells leads to fever and flu-like symptoms. Malaria occurs mostly in poor, tropical and subtropical areas of the world.

Transmission

When a mosquito bites an infected person, a small amount of blood is taken in which contains microscopic malaria parasites. About 1 week later, when the mosquito takes its next blood meal, these parasites mix with the mosquito's saliva and are injected into the person being bitten.

Signs and Symptoms

Malaria is an acute febrile illness. In a non-immune individual, symptoms appear 7 days or more (usually 10–15 days) after the infective mosquito bite.

The first symptoms – fever, headache, chills and vomiting – may be mild and difficult to recognize as malaria. If not treated within 24 hours, P. falciparum malaria can progress to severe illness, often leading to death.

Children with severe malaria frequently develop one or more of the following symptoms: severe anaemia, respiratory distress in relation to metabolic acidosis, or cerebral malaria. In adults, multi-organ involvement is also frequent. In malaria endemic areas, people may develop partial immunity, allowing asymptomatic infections to occur.

Diagnosis and Treatment

Early diagnosis and treatment of malaria reduces disease and prevents deaths. It also contribute to reducing malaria transmission. The best available treatment, particularly for *P. falciparum* malaria, is artemisinin-based combination therapy (ACT).

Prevention

WHO (2016) recommends protection for all people at risk of malaria with effective malaria vector control. Two forms of vector control – insecticide-treated mosquito nets and indoor residual spraying – are effective in a wide range of circumstances.

Session 10: Women, HIV and AIDS

Time: 2 hours - (120 minutes)

Aim: This session will teach trainees to recognise the various problems faced by women with HIV and equip them with the requisite information to deal with them.

Learning Objectives

- By the end of the session, trainees will be able to:
- Understand the sociocultural problems faced by women
- Understand the problems faced by Female Sex workers especially in relation to HIV
- Recognize the symptoms in a woman (including during pregnancy) that require medical help through referral
- Understand steps needed to facilitate disclosure
- Understand and describe the importance of the continuum of care for an HIV positive woman, during pregnancy, childbirth and postnatal and managing HIV exposed infants (HEI)

Table 10.1: Communication Strategy; Women, HIV and AIDS

Session Ten: Women and HIV/AIDS				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Sociocultural Problems Faced by Women • Problems faced by FSW • Symptoms Related to Women • Importance of Care Continuum for an HIV Positive Woman, pre and post-natal. • PMTCT	• Caregivers	• Case Study • Role Play • Trainer-Led Discussions	• Flip Chart • Picture/Posters • Markers	• 120 Minutes

Table 10.2: Session Activities; Women, HIV and AIDS

Activity	Time (minutes)	Content	Materials	Pictures
1	75	Discussion about the problems faced by women with HIV or AIDS - Story to be told the facilitator	Flip chart / whiteboard and markers	
2	45	Discussion about breast feeding, bottle feeding and mixed feeding - Practical Role-play by participants Discussions about HIV positive women and family planning - Case study	Flip chart / whiteboard and markers	

The following material for this session is included at the end of this chapter;

Reference Materials:

Box 7.1: Key Points; Women and HIV

- Women sometimes have less control in a relationship power-dynamic
- Women are traditionally not encouraged to talk about their sexuality and may find it difficult to make decisions involving safer sex.
- Women end up engaging in transactional sex due to poverty and other circumstances
- Women are biologically and socially more prone to STI's including HIV infection
- Women are willing to disclose their status to their partner but mostly do not know how or are afraid of the consequences
- Women need to know more about family planning options
- Women with HIV may face additional physical and medical problems like:
    - Loss of menstruation
    - Skin and hair changes
    - Anaemia
    - HPV infection
    - Cervical cancer
- Benefits and risks of exclusive breastfeeding.
- Benefits and risks of exclusive bottle feeding.
- Risks of mixed feeding.

Activity 1: Group Discussion (1 hour 15 minutes)

Topic: Problems faced by women with HIV and AIDS

Instructions

Begin by initiating a discussion by asking an open-ended question such as:

- What are the problems faced by women with HIV infection?
- What are some issues FSW face in general and why are they at particular risk of HIV transmission
- What are the problems faced by women who are HIV positive and pregnant
- What if an HIV positive woman does not want to get pregnant? What does she do?

Trainees may talk about social and medical problems. Add information that is incomplete or missing, using slides if you like.

Guide the discussion fluidly with follow-up questions.

Points to cover

- Loss of menstruation
- Skin and hair changes
- Anaemia
- Fear of getting pregnant as they might infect the baby
- HPV infection
- Cervical cancer
- Gender based violence
- Counselling an HIV positive woman who wants to have children
- Counselling an HIV positive woman who does not want to have children
- Counselling an HIV positive woman regarding disclosure
- Risks for women who engage in commercial sex and HIV

- Health risks for the mother and baby when HIV positive and pregnant
- How to reduce mother to child transmission of HIV
- Other sociocultural issues such as relationship power dynamics, caring for children, HIV in the context of marriage

Discussion points

- Do women have a say in the use of condoms? Should they have a say?
- Do you know why women are more vulnerable to HIV infection? (Most of them may not be able to answer this question so you may have to answer it) tie this in to FSWs (stress here on gender inequality, intimate partner violence, lack of access to education, etc)
- What should someone who is HIV- positive or who thinks she may be HIV- positive do before getting pregnant and / or if she finds out she is pregnant/ or if she does not want to get pregnant?
- What to do to avoid reinfection with HIV and other STIs when HIV positive and pregnant
- What signs and symptoms should alert the caregiver to refer an HIV positive woman for further care?
- What are some cultural or social reasons women are particularly vulnerable to gender based violence (GBV)?
- What resources can a woman access if she is a victim of GBV?
- What is the role of the community in preventing and addressing GBV?
- How does an HIV positive woman go about disclosure?

Activity 2: Group Discussion and Role-play (45 minutes)

Topic: Breast feeding, bottle feeding, and mixed feeding

Instructions:

1. Educate trainees about breast feeding, bottle feeding, and mixed feeding. Encourage them to ask questions and let the other trainees answer these questions if possible.
2. Divide the group into 2 groups
3. Ask each group to choose a leader.
4. Give Group 1 the statement: "Exclusive breast feeding is better than exclusive bottle feeding for a child whose mother is HIV+." Give Group 2 the statement: "Exclusive bottle feeding is better than exclusive breast feeding for a child whose mother is HIV+."
5. Give each group 15 minutes to prepare a 2-minute advertisement for the radio or TV. If it is a TV advertisement they may have to act it out.

Ensure trainees understand this is not a competition but a fun activity. Trainees should concentrate on the learning the complex social aspects of the different perspectives, not winning or losing

Activity 3: Group Discussion - Case Study (30 minutes)

Topic: HIV positive women and Family Planning

Instructions:

Tell the case of a 40 year old woman who has 3 teenage children. Her husband and father of the children died of AIDS a few years ago which was when she found out about her status. She is self-employed and can take good care of herself and her children. However since 7 months she has started dating a man who is aware of her status but who is HIV negative. Although they practice safe sex, they both are sincere in saying that sometimes they forget to use a condom. They are not necessarily looking to having a child and the woman does not want to get pregnant again. What does she do? What options are there for her? Discuss this case study with the group and note down their suggestions. Make input into these ensuring to cover the various Family Planning methods available and where these can be acquired.

Reference Material

Women, HIV & AIDS

Biological vulnerability

Research shows that the risk of becoming infected with HIV during unprotected vaginal intercourse is as much as 2 to 3 times higher for women than men. One major reason for this is that women have a larger surface area of mucosa (the thin lining of the vagina and cervix) exposed to their partner's secretions during sexual intercourse (Tigawalana, 2010).

Women are also at more of a risk of other STI’s (multiplying the risk of contracting HIV tenfold). They may not note the early symptoms of HIV, as ulcers inside the genitals may not easily be noticeable. There is also evidence that women again become more vulnerable to HIV infection after menopause. In addition, tearing and bleeding during intercourse, whether from rough sex or rape, multiply the risk of HIV infection, as does anal intercourse. Anal intercourse often tears the delicate anal tissues and provides easy access for the virus.

Lack of control in relationships

Many women lack economic resources, and are fearful of abandonment or of violence from their male partner. Thus they have little or no control over how and when they have sex, and hence have little or no control over their risk of becoming infected with HIV. Even when a woman suspects her partner has HIV, she often cannot risk losing his support by refusing sex or insisting on condom use. Although some men agree to use condoms, many react with anger, violence, and abandonment.

Condom use and pregnancy

Couples who want children need to know their HIV status. However, couples are often unwilling to openly discuss issues of sexuality, and HIV counselling and testing services are not always available.

STIs and HIV

Because STI’s carry an especially heavy social stigma for women, women may tend to avoid STI clinics and treatment. Women are often known to accept ill health and women's troubles as their lot in life.

Women and stigma

The impact of HIV on women is particularly acute. In Ghana, like other low to middle income countries, women are often economically, culturally, and socially disadvantaged and lack equal access to treatment, financial support, and education. HIV-positive women are treated very differently from men in many developing countries. Men are likely to be "excused" for the behaviour that resulted in their infection, whereas women are not. For example, the husbands who infected them may abandon women living with HIV or AIDS, but it is usually the wife who is the caregiver when the husband is infected. In addition, families may blame the woman for the infection, even when the source of infection is not established. Women find it difficult to disclose for fear of losing their marriages and this has serious implications in terms of re-infection.

In Ghana, families (usually women and young girls) are the primary caregivers to sick members. There is clear evidence of the positive role that the family plays in providing support and care for people living with HIV/AIDS. However, many families do not respond positively. Infected members can find themselves stigmatized and discriminated against within their own home.

Female-specific Medical Issues

Women living with HIV may experience irregularities in their cycles, even if they are not going through menopause. They may also show symptoms similar to menopause such as:

- **Loss of Menstruation**

  This may occur because of severe weight loss or pregnancy.

What to do

If 1 or 2 periods are missed she should go to the health-care centre to be examined. A woman may feel that loss of menstruation means a loss of capacity to bear children or a loss of femininity and may feel sad or depressed. She should be helped to overcome this loss of self-esteem by being told that a lot of women experience loss of menstruation for a variety of reasons. They should be encouraged to be with friends, to involve themselves in the people and activities around them, and to remember that they are still worthwhile and have a great deal to give.

- **Skin and Hair Changes**
    - Hair becomes thinner and more brittle.
    - Sudden or abnormal hair loss can result from taking anti-HIV medicines.
    - Stress can also affect hair growth and the health of hair. Take steps to reduce stress and anxiety.
    - The skin becomes less firm and drier.

What to do

- Take steps to reduce stress and anxiety.
- B-complex vitamins can help relieve dry skin and hair.
- Continue quality adherence counselling

Anaemia

Anaemia can be very common in women with HIV infection. There may be many causes: low vitamin B12, iron deficiency, a thyroid that may not be functioning correctly, heavy blood loss during menses, low hormone levels, an effect from medication, or an infection that invades the bone marrow.

A particularly common cause of anaemia and fatigue is iron deficiency. Many women lack the necessary amount of iron. A poor diet, as well as heavy menses, can cause a deficiency of iron every month. Frequent or heavy menses can be very common in women who are HIV infected. This leads to a great deal of blood loss and anaemia.

What to do

- Eat foods rich in iron (green leafy vegetables, liver – refer to section on nutrition)
- Take iron tablets as prescribed by the doctor (A normal effect of iron tablets is darkening of the stool)

Often, women become so accustomed to feeling fatigue that they may never report it when they see their health-care provider. As a woman’s immune system weakens, she will be prone to a lot of gynaecological problems. The most common problems are:

Human Papillomavirus (HPV)

This virus causes infections that cause genital warts. These can be seen as warts usually in the genitals and sometimes on the hands and feet. This is a sexually transmitted virus. HPV is not always detected with visible breakouts. Many forms of HPV are non-wart inducing but may still cause cervical cancer.

Cervical cancer

Some HPV infection can eventually lead to cervical cancer (cancer of the cervix).

A woman should see the doctor if:

- She has any abnormal discharge with a foul smell.
- There is spotting of blood in between her periods.
- She has irregular periods.
- She has pain in the lower abdomen.
- She feels tired in spite of getting enough of rest.
- She finds any warts in her private parts or anywhere else.
- Her periods have stopped.
- She thinks she has STI.

PMTCT

ARVs lower the risk of transmission from mother to child and so all women who are HIV positive should be on ARVs ideally before they get pregnant and otherwise as soon as possible when they find out they are HIV positive. The HIV positive woman should therefore be under the care of a health-care provider as soon as she knows about her condition. ARVs are administered at all major government hospitals, many private hospitals and some mission hospitals and some CHPS compounds across Ghana.

Infant Feeding

An HIV-positive mother can transmit the virus to her baby through breastfeeding. However, breast-milk is generally the best food for the baby, as it has all the good nutrients and protects against many other diseases.

To minimise the chance of transmitting HIV to the baby, there are 2 choices:

- Exclusive bottle feeding
- Exclusive breast feeding

The decision to practise either of the two should be based on the current country's guidelines or recommendation.

Exclusive bottle-feeding

This means no breast feeding at all.

Benefits:

- The baby won't get HIV from breast milk
- The father and other relatives can also feed the baby

Risks:

- The baby may not grow well if the parents cannot afford good quality infant's milk powder or cow's milk
- The baby is more likely to develop diarrhoea if there is no safe, clean water or if the bottle or cup is not cleaned properly
- The relatives may get upset if the mother does not breast-feed the baby
- Others may think the mother has HIV or another disease if they don't see the mother breast feeding the baby, and she may be stigmatized

Questions for the mother to consider before deciding on bottle-feeding:

- Can she afford to buy enough infant milk powder/cow's milk?
- Does she have access to clean water?

- Can she prepare the milk safely (including boiling the water first)?
- Can she clean and sterilise the bottles (with detergent and boiling water)?
- If the answer to any of these questions is NO, then the child may be at risk of getting very sick from diarrhoea and malnutrition. She should consult the doctor about this.

Exclusive breast feeding

Exclusive breast feeding means giving the baby only breast milk. In such a case: give the baby only breast milk for the first 6 months of life. This means no other food or drinks, such as water, juice, tea, animal milk, should be given to the baby. When the baby is 6 months of age, replace breast feeding by powder milk/ other milk and foods in a short transition period. According to the new PMTCT protocol, breastfeeding should only be given for a maximum of 12 months.

Benefits:

- Breast-milk is very nutritious for the baby
- Breast-milk prevents many other diseases (diarrhoea and chest infections)

Risks:

- There is a chance of the mother transmitting HIV to the baby
- The risk increases when:
  - The mother is already sick with AIDS
  - The mother has cracked or bleeding nipples
  - The mother has breast infection

Go to the doctor if you get sores, lumps, or pain in your breast or if your baby has mouth sores.

Avoid mixed feeding

If the baby is breast-fed and also given other baby foods, then there is more chance of the baby becoming HIV-infected. This may be because mixed foods may irritate the linings of the mouth and stomach and make it easier for HIV to enter the baby's system.

Post-natal care of the HIV-infected mother and her infant

Postnatal care is the care given to the mother and baby after the baby's birth. In many instances, the basic postnatal care of the HIV-infected woman and her infant will be no different from routine postnatal care. However, the mother (and possibly partner/family) might need additional counselling and support. HIV-infected women are more prone to medical complications such as urinary tract infections, chest infections, and infection of the wound after a Caesarean. The caregiver should be alert for signs of infection such as fever, rapid pulse, lower abdominal pain, and foul-smelling vaginal discharge. HIV-infected women should be taught about care of their genital area and safe handling of blood and vaginal discharge. Also, it is required for the HIV exposed infant (HEI) to be followed up at the health facility and screened for HIV infection at 6th week (EID).

Postnatal counselling for HIV-positive mothers may specifically include:

- Contraceptive advice - The only contraceptive methods that will prevent the spread of HIV are barrier methods such as condoms. Other contraceptive methods can assist the mother in better spacing of her children to allow for her to take better care of them and herself
- Discussion about disclosure of her HIV status to her partner, family, and trusted friends.
- Information about the possibility of infection in the child and details of how and where the child can be checked and put on treatment. (Early Infant Diagnosis, EID)
- Support for her infant feeding choice and further education as appropriate.

If there is a need for postnatal counselling it is important that the home visitor or caregiver refers to the counsellor.

If a woman is HIV-positive, she is more likely to have problems during her pregnancy, during delivery or thereafter. Such problems may include:

- Miscarriage - loss of the baby during pregnancy
- Fevers and infections
- Anaemia - less blood in the body characterized by weakness and breathlessness and fatigue

- Premature labour - delivery occurring earlier than it should, often causing the death of the baby.
- A smaller baby - the weight at birth of even a full-term baby can be much lower than normal (2.5kg); babies with a low birth-weight are more likely to have subsequent problems.
- Infections after birth - women with HIV are more susceptible to infections in general, and might have severe infections after delivery (puerperal sepsis), which do not respond to the usual treatment with antibiotics.

What to do at home

Antenatal care

"Antenatal" means the time from conception until delivery. All pregnant women should receive antenatal care. This is even more important if they are HIV-infected. Women infected with HIV should be advised to follow the routine recommendations for all pregnant women. These include:

- No medicines should be taken except those prescribed by a health-care worker (women should always tell their health-care worker that they are pregnant if they see them for another reason). Some medicines can be harmful to both the mother and her developing baby so it is best not to take any risks.
- The mother should eat for herself and for her growing child. She should eat from the 3 main groups of foods described in the section on nutrition.
- Good hygiene should be practised.
- If possible, heavy weights should not be lifted and heavy work should be avoided. This may lead to premature labour and make one feel easily tired.
- Medicines to prevent mother-to-child-transmission of HIV are administered by various public hospitals, private clinics/hospitals, mission hospitals and some CHPS compounds in Ghana.
- Pregnant mothers should ensure that they are properly immunised against tetanus to protect themselves and the baby (two doses if you have not been immunised earlier and

one dose if immunised within the past 5 years). It is important that the home visitor or caregiver refers to the doctor in such cases.

It is strongly recommended that the HIV-infected mother should plan to deliver in a health centre or hospital.

During pregnancy, help should be sought immediately if any of the following occurs: Bleeding from the vagina

- Excessive vomiting that does not respond to home remedies
- Headaches
- Swelling of the feet
- Sharp pain in the abdomen
- Convulsions
- The baby stops moving

After childbirth, help should be sought if any of the following happens to the mother:

- Severe bleeding from the vagina
- Fever
- Foul-smelling vaginal discharge
- Severe abdominal pain

Session 11: Men, HIV and AIDS

Time: 1 hour 45 minutes - (105 minutes)

Aim: The aim of this session is to teach trainees about problems faced by men with HIV as well as how to involve them more in HIV prevention and control

Learning Objectives

By the end of the session, trainees will be able to:

- Understand sociocultural problems faced by men with HIV infection
- Understand and describe medical problems faced by men who have sex with men
- Recognize signs of conditions of HIV positive men that require medical intervention
- Give comprehensive counseling to HIV positive men regarding their role in ensuring their families' are healthy with specific emphasis on condom use

Table 11.1: Communication Strategy; Men, HIV and AIDS

Session Eleven: Men and HIV/AIDS				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Sociocultural Problems Faced by Men • Medical Problems Faced by Men Who Have Sex With Men • Symptoms and Conditions of HIV Men • Comprehensive Counselling to HIV Men	• Caregivers	• Trainer-Led Discussions • Group Discussion • Role Play • Case Study	• Flip Chart • Markers • Pictures/Posters	• 105 Minutes

Table 11.2: Session Activities; Men, HIV and AIDS

Activity	Time (minutes)	Content	Materials	Pictures
1	30	Questions and Discussion about the problems faced by Men with HIV and AIDS - Story to be told by facilitator	Flip over / whiteboard and markers	
2	45	Group Discussion and Practical Role Play by participants on Medical problems faced by MSM (Men having Sex with Men)		
3	30	Case Study on how to recognize signs of HIV positive men		

Activity 1: Group Discussion (30min)

Topic: Sociocultural issues related to Men with HIV and AIDS

Instructions:

Begin by initiating a discussion by asking an open-ended question such as:

- Why access to HIV services for men/boys seem to be worse than that for women/girls?
- How this poor access leads to more infections, more death amongst men
- Vulnerability of MSM and bisexual Men
- Whether or not there are differences in signs and symptoms between HIV positive men and women
- How HIV positive Men can be educated to ensure they practice safer sex - stress on more involvement in PMTCT as well as use of condoms

Trainees may talk about social and medical problems. Add information that is incomplete or missing.

Discussion points to consider:

- How can men be better involved in condom negotiation during any sexual intercourse with their partner?
- Do you know why most men find it difficult to disclose their HIV status to their partner?

- What should someone who is HIV- positive or who thinks he may be HIV- positive do before getting married?

Activity 2: Presentation and Role-play (45 minutes)

Topic: Medical Challenges faced by Men having sex with men (MSM)

Instructions

Educate trainees on the medical challenges faced by men having sex with men in society. Encourage them to ask questions and let the other trainees answer these questions if possible.

Point to Consider

- Lack of access to quality health care due to stigma
- Other Infectious diseases
- Lack of proper adherence and clinical counselling

1. Divide the group into 2 groups – **Group 1 and Group 2**.
2. Ask each group to choose a leader and a secretary
3. Give group 1 the topic "How can health workers be more acquainted with special needs of MSM so as to enhance their to quality health care
4. Give group 2 the topic, "How to conduct effective counselling including adherence Counselling to MSM
5. Give them between 10 to 15 minutes to prepare a 5-minute sketch or demonstration on how to deal and overcome those topics listed above.

Activity 3: Case study (30 minutes)

Topic: Recognizing signs of HIV in Men and how to ensure their families remain healthy

Instructions

Case studies are useful if you want to know if the trainees have understood the topic.

1. Divide the trainees into 2 groups.
2. Give them a situation that has to be discussed among themselves and presented in front of the other trainees. You might have to explain the case to them briefly and the points they have to cover:

Case study 1 (Group 1)

Mr Thomas Aidoo is a truck driver and lives in Accra with his wife and two children. He travels to other regions in the country due to the nature of his work as a truck driver. While staying in these regions, he engages in an unprotected sexual intercourse with different sex partners. After 5 months, Mr Aidoo start feeling very sick and weak, has skin diseases, fever coupled with other illnesses. He conducted different laboratory test and it proved that the other test were negative but HIV turned out to be positive. Since he cannot bear the shame in the community, Mr Aidoo plans to commit suicide.

Questions for Discussions

- What is the main cause of Mr Aidoo's HIV infection
- Did you notice some early signs of HIV? Outline some of the signs and any other signs you know
- What advice or solution will you give to Mr Aidoo

Case study 2 (Group 2)

Nana Yaw is a 23 year old young man who is in a sexual relationship with a lady from his office. They spend most weekends together. In the meantime, Nana Yaw and his girlfriend do not practice safe sex (they do not use condoms) based on the fact that they are faithful to each other. Recently Nana Yaw has started engaging in unprotected sex with a male colleague of his from high school. He hasn't mentioned this to his female partner with fear of being stigmatized. However, he still continues to have sex with her. (Participants together should discuss the following points and see how the situation may be related to HIV & Men)

- Under which group of men will you place Nana Yaw and why?
- Identify the various behaviours of Nana Yaw in this scenario that makes him vulnerable to getting infected with HIV
- Discuss the steps Nana Yaw must take to prevent HIV infection of both himself and his partners (male and female)

Session 12: Children, Adolescents, the Aged and HIV and AIDS

Time: 1 hour 30 minutes - (90 minutes)

Aim: The aim of this session is to teach trainees about the problems faced by children, adolescents and the Aged infected and affected by HIV and AIDS, and ways in which to deal with them.

Learning Objectives

At the end of the session trainees will be able to:

- Explain how HIV is transmitted in children (describe the differences with transmission in adults)
- Describe the major and minor signs of HIV infection in children (only differences with adults)
- Understand the needs of a child with HIV infection
- Explain the general rules of caring for a child with HIV infection (only the difference with adults)
- Understand the needs of infected and affected orphans
- Understand the issues adolescents infected with HIV face and how to help them address these
- Understand the issues the Aged with HIV face and how to help them address these issues
- Discuss single parenthood
- Explain steps in disclosing children’s status

Table 12.1: Communication Strategy; Children, Adolescents, the Aged and HIV and AIDS

Session Twelve: Children, Adolescents and HIV and AIDS				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• HIV Transmission in Children • Major and Minor Signs of HIV in Children • Caring for a Child with HIV Infection • Needs of Orphans • Issues faced by HIV adolescents including disclosure • Issues faced by the Aged with HIV • Single Parenthood • Disclosing Children's Status	• Caregivers	• Trainer-Led Discussions • Case Studies • Group Discussions	• Poster Paper • Flip Charts • Markers	• 90 Minutes

Table 12.2: Session Activities; Children, Adolescents, the Aged and HIV and AIDS

Activity	Time (minutes)	Content	Materials	Pictures
1	60	Questions and Discussion about the problems faced by children & adolescents and the Aged with HIV and AIDS	Poster paper and markers Handouts	
2	30	Case studies to test trainees on care of children, adolescents and the Aged with HIV and AIDS.	Flip over / white board and markers	

The following material for this session is included at the end of this chapter:

Reference Materials:

- Children, HIV and AIDS
- Adolescents, HIV and AIDS
- The Aged, HIV and AIDS

Key Points; Children, Adolescents, the Aged and HIV and AIDS

- Most children contract HIV infection from their parents, specifically their mothers. (Emphasize the differences with adults)
- Major signs of HIV infection in children are:
    - Weight loss or abnormally slow growth
    - Chronic diarrhoea for more than 1 month
    - Prolonged fever for more than 1 month
- Minor signs of HIV infection in children are:
    - Generalised lymph node enlargement
    - Fungal infections of mouth and/or throat
    - Recurrent common infections (e.g. ear, throat)
    - Persistent cough
    - Children with HIV and AIDS should be treated like any other child. They need to be well fed – at least 4 to 5 small meals a day.
    - They should be immunised.
    - They should be allowed to mingle with other children and also allowed to continue school.
    - They should be kept away from children and adults who are ill.
    - Infections, especially diarrhoea, should be dealt with immediately.

In some children the progression of HIV is faster than in others (reason unknown). Adolescents are a vulnerable group in general and more so when they are infected with HIV. Many a time, their status has not been disclosed to them. They continue to wonder why they are always swallowing medicines. If they know their status they find it very difficult to engage in normal activities. Again, they find it difficult to understand how to engage in future relationships and even if that will ever be possible. The Aged tend to have multiple condition that are sometimes missed by others including care givers. The Aged may have been on ARVs for a very long time already and are vulnerable to long term side effects of the medicines. As people age they tend to have multiple conditions that require different medicines and this can lead to pill burden and sometimes drug interactions.

Conditions and symptoms more common in the Aged can be worse to being HIV positive. Some of these are:

- Memory and Brain function
- Frailty or weakness
- Bone health such as osteoporosis
- Heart disease
- Lung disease including Tuberculosis
- Kidney diseases
- Sexual Health

Activity 1: Group discussion (60 minutes)

Topic: Problems associated with children with HIV and AIDS

Instructions

In this exercise, trainees will discuss the various problems faced by children & adolescents with HIV and AIDS in their community and suggest remedies for each of the items they have listed. Once this is done, the trainer will provide (or guide trainees in seeking out) further information or resources. The trainer may invite a specialist to answer questions (e.g. paediatric or adolescent issues) during this session. Pictures may be used to show the trainees how medicine can be given to a child.

The trainer will lead the session by introducing the topic. He or she will use a participatory approach by asking a series of questions to elicit answers from the trainees. Here are a few sample questions:

“How many of you know children in your community that have HIV or AIDS?”

“What are the problems faced by (these) children and their caregivers?” (Use poster paper to write down the problems)

- “How do you deal with them?”
- “What will you do if a child has diarrhoea?”
- “Is there a health-care provider (doctor or nurse) or ART site near your community for an emergency?
- “What are the barriers children in particular encounter in seeking ART treatment?”

Points to cover: (emphasize the differences with adults)

- Most children contract HIV infection from their parents, apart from the modes of transmission as in adults.
- Some children’s illnesses progress faster than others
- The major and minor signs of HIV infection
- Feeding infants:
    - Breast-feeding information
    - Care of breast-fed infants
    - Bottle-feeding information
    - Care of bottle-fed infants
    - Dangers of mixed feeding
    - Other foods
- Immunisation
- Preventing injuries
- Preventing infections
- How to give a child medicine
- Emotional support
- Treating the child as normal
- Disclosing child's status
- Care of orphans affected by AIDS
- Care of orphans infected with HIV
- Care of adolescents infected with HIV
- List of orphanages in the region

Breast-feeding information will already have been given during the session *Women and HIV*, so this session will give you an opportunity to make sure they have understood the information. Encourage participation in order to review the material.

Activity 2: Case study (30 minutes)

Topic: Understanding and providing solutions for problems faced by children with HIV

Instructions

Case studies are useful if you want to know if the trainees have understood the topic. Trainees who are too shy to ask or answer questions will also learn a lot from this exercise.

1. Divide the trainees into several groups.
2. Give each group a case study to discuss amongst themselves and then afterwards have them present their main thoughts and conclusions in front of the other trainees. If necessary, explain the case to them briefly, make any clarifications, and identify the points they should cover.
3. Ask each group to make their presentation or do the role-play while the other group gives their feedback.

Case study 1

Grace had a baby recently and the baby is HIV+. She does not know how to care for him. She knows that you have attended a training programme on Home-based Care for HIV+ people and comes to you for advice. How would you counsel her?

Additional guiding questions

- What care would you recommend?
- What facilities can you direct her to?
- How would you offer emotional support?
- Does Grace have family members who can support her and the baby?

Case study 2

Ama's daughter is 3 years old and is HIV+. The doctor has given her some medicines that have to be taken regularly. She does not like taking the medicines and Ama beats her to make her take her medications. What advice will you give to Ama?

Additional guiding questions

- How do you respectfully approach Ama to ensure her child is safe?
- What additional support or resources can you recommend for Ama?

Case study 3

Sarah is a young single mother living with HIV. She has just had a healthy baby who is HIV-free. Sarah is deciding whether she should bottle-feed or breastfeed her baby. What advice will you give?

Additional guiding questions:

- How do you talk to Sarah in a way that doesn't impose your own opinion?
- What questions can you ask Sarah to help her make the best informed choice for herself?

Case study 4

Kobi is an adolescent who is HIV-positive. He contracted HIV when his HIV-positive mother gave birth to him 14 years ago. He has been on treatment, but often experiences days of illness. Kobi has been skipping school and has been abrupt and angry with his parents and siblings. How do you counsel Kobi?

Now Kobi, even though he is being given medicines everyday has never been told why he takes them. Every now and then he goes to the hospital but the health workers are always nice and do not say anything about why he is there even though he is not sick. They however once in a while take blood samples and end up giving more medicines to his mother to be given to him. He is confused and asks his mother. How do you counsel both?

Now, Kobi, who now knows his status and has accepted it has just completed the BECE and has gotten his first choice of SHS. He is finally going to be in the boarding school and is extremely happy. But now his mother and Kobi himself are worried as to how he will be able to access treatment. How will he be able to ensure he always has enough medicines? Where will he keep these medicines? Are the other mates not going to be wondering why he is always swallowing medicines even though he is not sick? Kobi is worried and has a lot of questions. How can you help?

Additional guiding questions

- What emotions do you think Kobi may be experiencing in the various situations and why?
- How do you relate to an adolescent to be able to counsel them?
- Do you talk to Kobi's parents or family or to Kobi himself?

Case Study 5

Mr. Asare is a 55-year-old man who just moved to your community and has heard about the wonderful care you have been giving to Mrs. Asante in the same community. He approaches you with the request to help take care of him too. He tells you he was diagnosed with HIV many years ago but initially did not follow up with his HIV provider due to complicated social issues.

Later he moved to live with his daughter and things got more stable and so he started ART. He has been taking this for 5 years now and is has been compliant however now it is getting too much for him because he has just been diagnosed with hypertension, diabetes and hepatitis B and the medicines are just too many. He is not sure he can take all of them, gets confused even just by looking at the number of medicines he has to take and his body does not feel the way it used to feel. He is easily tired, sleeps a lot and finds it difficult to exercise as advised by the doctors because his entire body hurts. He feels very down and does not know what to do.

Additional guiding questions:

- What emotions are Mr. Asare experiencing and why?
- How do you relate to older person with HIV to be able to counsel them?

Session Summary (10 minutes)

Summarise the session, emphasising the information that might have been missed or misunderstood by the trainees.

Reference Material

Children with HIV and AIDS

Transmission of HIV in Children

Apart from the modes of transmission seen in adults, HIV is also transmitted to children from a HIV-positive mother during pregnancy, delivery (while passing through the birth canal), or breastfeeding (MTCT – mother-to-child transmission).

HIV and AIDS in children is very much like HIV and AIDS in adults. However, in children the disease is more difficult to diagnose correctly, and the blood test cannot be done with certainty until the child is 6 weeks old when a DNA PCR test can be done to determine the status of the child. Many times as mothers will continue to breast feed, even if an initial HIV test reads negative at age 6 weeks, a test is repeated at 18 months of age. At this point, an antibody test is normally performed all maternal antibodies that may have been in the child would have already disappeared.

Many HIV-positive children develop symptoms at about 3 to 4 months of age. Small babies and children with HIV often have fever, diarrhoea, coughing, and ear and throat infections. They do not gain weight properly. Their growth is slow and they may start crawling, walking, and talking very late compared to other children. These are common symptoms that may have other causes. If the parents are HIV-positive, the baby should also be cared for as if he or she has HIV infection until he or she is tested and confirmed to be negative. Even then, this child remains an at-risk child and needs continuous care to ensure it stays healthy.

Major signs of HIV infection in children:

- Weight loss or abnormally slow growth
- Chronic diarrhoea for more than 1 month
- Prolonged fever for more than 1 month

Minor signs of HIV infection in children:

- Generalised lymph-node enlargement
- Fungal infections of mouth and/or throat

- Recurrent common infections (e.g. ear, throat)
- Persistent cough
- Generalised rash

Babies with HIV infection usually develop the symptoms of AIDS more quickly than adults do. This is because their immune systems are less developed, and they cannot resist HIV or fight opportunistic infections as effectively as adults.

Most HIV-related illness is caused by common infections, which can be prevented or treated at home or in a health centre. However, the illnesses often last longer in HIV-infected children and are slower to respond to standard treatments. Illnesses such as chicken pox and measles can be life-threatening in these children. The standard treatments are nevertheless the most appropriate treatments.

Care of new-born infants of mothers infected with HIV is no different from that of any other new-born baby. Babies need to be picked up, held, and cuddled. Even if a child is HIV-infected, there can be years of life and steps can be done to make life as healthy and long as possible.

Each child is different. Some children with HIV show no symptoms of AIDS for years and some progress very fast. ARV drugs are also beneficial to children.

General rules for caring for a child with HIV infection or AIDS:

- Feed the child well
- Breast feeding
- For a child less than 4 to 6 months old the best food is breast milk.

Though an HIV-positive mother can transmit the virus to her baby through breast feeding, breast feeding should be encouraged if possible, as it gives the baby protection against many types of infections. The risk of transmission of HIV by breast feeding is low compared to the risk of the baby dying of other infectious diseases if not breast-fed..

If a mother decides on breast feeding, she should be counselled about ways to prevent cracked nipples, which may increase the risk of infection. The mother should be advised to clean the breast with clean water.

Bottle-feeding

- The mother has to make a choice keeping in mind:
    - The affordability and easy availability of milk substitutes (milk powder, cow's milk or infant feed)
    - Availability of clean boiled water
    - Ability to always use clean vessels to prepare the milk and feed the baby

If all of the above requirements cannot be fulfilled, all of the time, she should be advised to breast-feed her baby. If the mother does not want to breastfeed her baby, it is safer to use a spoon than feeding bottles.

Mixed feeding

Whatever the mother's choice, she should stick to it. It is not advisable to mix feeding methods (sometimes breast feeding and sometimes cow's milk/ powdered milk), because mixed foods may irritate the linings of the mouth and stomach and make it easier for HIV to enter the baby's system.

Once a child is 6 months old, breast feeding can be stopped and the child can be given some solid foods along with other milk:

- Well-cooked porridge made of any ground cereal like rice, wheat, etc., with some milk can be given.
- Boiled and mashed potatoes or sweet potatoes
- Fresh, peeled, and mashed fruits (remove all skin, seeds, and fibres)

Foods that are warm and either soft or mashed can be given with a spoon or your fingers (don't forget utensils and hands must be washed first!).

As the child grows, larger quantities of adult foods should be given. A combination of cereal-pulse, soup, well-cooked vegetables, egg, and fruits can be given. They should be fed 5 to 6 times a day. By age 1 year, all HIV-positive lactating mothers should stop breast feeding. If they can stop earlier, that is even better.

A 3 to 6 year old child needs half as much food as an adult does. The child needs to eat small, frequent meals (4 to 5 times a day).

Immunisation

All children should be immunised, whether infected with HIV or not. Vaccines give protection against many childhood diseases that can give rise to dangerous infections in the HIV-infected child. Children should receive the regular EPI immunizations which include measles, BCG, polio etc. Consult your health-care provider about this.

Preventing Injuries

Keep glass containers, blades, and sharp-edged toys away from the reach of children. Hold the sharp end away from yourself. Stuffed and furry toys can hold dirt and might hide germs that can make the child sick. Wash them often. Plastic and washable toys are better.

Emotional Support

Infants and small children with HIV and AIDS need the same things as other children. They need to be held, kissed, hugged, fed, and taken care of by their mothers. As they grow older, they need to play with friends and go to school. Frequent infections can make them angry, frustrated, scared, and lonely. Family members should talk to them and make them feel loved. Children always need a lot of attention, so give them attention and listen to what they have to say. If they are too ill to go out and play, family members can play with them.

Children who have lost a parent(s) may be unhappy if they are living with relatives or with people they are not familiar with. They might stop talking and withdraw into a shell. They may miss their parents and siblings (if they have been separated) and might feel lonely. Their caregivers have to make sure that these children get a lot of love and affection. They should also make sure that the children receive health care for common illnesses and eat nutritious food. They should not be stigmatised.

Older children who know of their parents' infection might start blaming the parents, especially the father, and pick up fights at home and outside. They might become depressed and may even run away from home. Such children should be counseled by a social worker.

- Keep the child well fed and loved.
- Promptly get any infection treated.

- Treat dehydration immediately.

Remember, the needs of an HIV-infected child are the same as all other children. Most important among these are love, care, and the chance to be with other children. HIV cannot be spread by the child’s urine, saliva, faeces, or vomit. A child with HIV cannot infect others by playing with them or sharing toys. Treat the child as a normal child.

Try to prevent infections by providing good nutrition, good hygiene, and by keeping the child away from sick children and adults.

Giving medicine to children

- Liquid medicines can be squirted slowly into the side of the child’s mouth using a dropper or syringe or may be poured from a spoon
- If the medicine tastes bad, tell the child in advance
- Praise the child after she or he has taken the medicines
- If a tablet cannot be swallowed, crush it and mix it with a small amount of milk, honey, sugar, or food
- If the child vomits immediately after taking the medicine, give the dose again
- If vomiting takes place after 20 minutes, don’t give the dose again

Children orphaned by AIDS

The home visitor should always work together with the counsellor in such cases.

Children orphaned by AIDS can be divided into 2 categories:

- Those whose parents were HIV-positive and they themselves HIV-negative (HIV-affected children)
- Those who themselves are HIV-positive (HIV-infected children)

In both cases, children need proper care and love. Ideally, close relatives who are familiar to them should care for such children, as children tend to feel secure with people they know.

When children who are orphans (whether HIV-infected or not), are cared for by other family members, this places added financial burden on these caregivers. After their parent's death, children can lose their rights to the family land or house. Without education, work skills or family support, children may end up living on the streets. These children are especially vulnerable, often becoming sexually active at an early age and at risk from HIV themselves. Poverty is an overwhelming problem. These orphans not only lack money but basics such as clean water, drugs, food, shelter, and medical supplies. They do not have information about how to protect themselves, and have poor access to doctors, nurses, and other health-care workers and facilities. Community-health workers and social workers can play an important role in arranging for care for such children.

In cases where the children are infected with HIV, it is found that it is usually the grandparents who look after them. However, this may be done very unwillingly. The main reason for this is the stigma of having HIV, as well as the health problems arising from HIV infection. Most of these caregivers (grandparents) themselves are old and weak, with no source of income. Nonetheless, most children are more comfortable with relatives than orphanages.

The options in caring for orphans may be;

- If relatives (usually grandparents) are willing, proper guidance should be given as to the care of HIV infected children, if the child is HIV-positive.
- When one of the children is an adolescent, the child might head the family and look after the siblings with support from the community. Their needs should be monitored regularly by CHW's, social workers, or support groups.
- If both these options are not viable, they can be cared for in the orphanages run by various organizations.

Adolescents and HIV and AIDS

Why are young people vulnerable to HIV?

Young people are vulnerable to HIV at two stages of their lives; the first decade of life when HIV can be transmitted from mother-to-child, and the second decade of life when adolescence brings new vulnerability to HIV. However it is not clear what the proportion of young people are infected at each stage therefore it is difficult to roll out HIV services specific to each group (Idele et al, 2014)

HIV Transmission in the First Decade of Life

As we have read above, children can be with HIV from their mother during pregnancy, childbirth or breastfeeding. We have seen that these children if linked to care as infants, need to be supported to adhere to their HIV treatment in adolescence and into adulthood.

This becomes difficult with pressures such as puberty, increased risky behaviours, changes to their HIV treatment needs and new responsibility for their own health. These explain why some young people stop adhering to antiretroviral treatment (ART) correctly during their adolescent years (UNICEF, 2013).

HIV Transmission in the Second Decade of Life

According to Idele et al (2014), unprotected sex is the most common cause of HIV among young people. Adolescence is often associated with experimentation of risky sexual increasing a young person's vulnerability to HIV.

For some, this is a result of not having the correct knowledge about HIV and how to prevent it, highlighting the need for HIV and sexual and reproductive health education excluded from national plans. Young people are often forgotten in national HIV and AIDS plans which typically focus on adults and children (UNESCO, 2014). Consequently, there is a lack of youth-friendly health services.

Vulnerability via Unprotected Sex

Adolescents may not have had the needed education to keep them safe. They may therefore engage in sex at an early age which will put them at a higher risk of acquiring an infection. They may also not use a condom and may have sex with a number of others. In addition some adolescents engage in inter-generational sex (that is when young people have relationships with older people) and this is thought to be a driver of the HIV epidemic in sub-Saharan Africa. Older partners are more likely to be living with HIV, therefore risking exposure to young people. Young women also find it harder to negotiate condom use with older partners who have greater power in the relationship and may use gifts or money to encourage girls to have unprotected sex (UNESCO, 2013)

Adolescents living with HIV have it also difficult as some have issues in relation to disclosure. Others find it difficult to have a normal life with their peers and get very worried about relationships and other things like going to boarding schools and how they will be able to comply with treatment.

The Aged and HIV and AIDS

Now that effective treatment for HIV is available, it is considered to be a long-term condition and many people are living long and healthy lives with HIV. A recent study suggested that over 4.2 million people living with HIV worldwide are aged over 50 years (Mahy et al, 2014). Growing older with HIV has an impact on one's health such as the consequences of having been on ART for a long time or ART in combination with other medical conditions.

Many of the drugs used to treat HIV have not been around for very long. Whereas short-term side-effects are well researched and documented, longer-term side-effects are less well understood. Some HIV drugs affect the kidneys, liver, bones and heart mild ways and as we grow older, we are more likely to experience other health conditions. There are also issues that affect our health that are associated with ageing even in people who are otherwise completely healthy, such as gradual hearing loss, menopause for women and general weakness.

Growing older with HIV does appear to increase the risk of experiencing illness, when compared to people who do not have HIV, but the reasons for this are not well understood. It could be that there are some long-term effects of having HIV, and/or long-term effects of taking HIV treatment.

As we age, and experience other health issues, it’s more likely that we will be taking more medication. The Aged who are HIV positive may see one healthcare professional for HIV and another healthcare professional for something else. In some cases, drugs for another condition can interact with HIV drugs, making one or both of them less effective or giving more side effects. Others get fed up with the many medicines they are taking which could lead to non-adherence.

Session 13: Care for the Dying and the Dead

Time: 1 hour 45 minutes - (105 minutes)

Aim: The aim of this session is to teach trainees how to take care of a person nearing death and the precautions to be taken while handling a body of someone who has died of AIDS.

Learning Objectives

By the end of the session, trainees will be able to:

- Recognise the signs of a person nearing death
- Understand the needs and worries of a person nearing death
- Care for an adult or child nearing death
- Know the precautions to be taken with the body of someone who has died of AIDS
- Know the needs of the family after the death
- Know how to prevent infections (refer to session 5B on prevention of infections)

Table 13.1: Communication Strategy; Care for the Dying and the Dead

Session Thirteen: Care of the Dying and the Dead				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Signs of a Person Nearing Death • Caring for the Needs and Worries of an Adult or Child Nearing Death • Precautions with Body of One Who Died of HIV/AIDS • Needs of Family after Death	• Caregivers	• Trainer-Led Discussions	• Flip Chart • Markers • Posters/Pictures	• 105 Minutes

Table 13.2: Session Activities; Care for the Dying and the Dead

Activity	Time (minutes)	Content	Materials	Pictures
1	60	Questions and Discussion about death	Flip over/whiteboard and markers	YES
2	15	Summary	Flip over/whiteboard and markers	

The following material for this session is included at the end of this chapter:

Reference Materials:

Box 8.1: Key Points: Care of the Dying and the Dead

After AIDS has progressed to a certain point, medications become ineffective.

- At this point we know that the person is approaching death.
- After this point, the goal of all care is to see that the person is comfortable.
- Keep the person within community and family groups for as long as possible.
- Provide physical contact by touching, holding hands, and hugging.
- Appropriate arrangements must be made with relatives or orphanages to take care of the children, to ease the person's worries.
- The family of a child nearing death will need emotional support. Support groups or community-care providers can be a source of great support.
- Children nearing death, like adults, may be sad, angry, afraid, or anxious. They may express these emotions through their behaviour.
- In very young children non-verbal communication is very important (holding or touching).
- Hands must be protected with gloves or plastic bags while laying out the body, as blood and diarrhoea may be present.
- HIV can live only in a person who is alive.
- The dead body can be buried or cremated according to the family's customs.

Activity 1: Discussion (60 - 90 minutes)

Topic: Caring for someone who is dying and dealing with death.

Instructions

Death is a challenging but important topic, so it is important to conduct discussion sensitively and respectfully. Invite the trainees to follow up with questions or concerns after the session.

1. The trainer should start the session by talking about:
    - The inevitability of death
    - That certain diseases cause premature death and that AIDS is one of them.
2. The trainer will then initiate a discussion by asking these questions:
    - How do you know that a person is nearing death?
    - What type of care should be provided for a person who is dying?
    - Where can you provide care for someone who is dying?
    - How do you prepare a person for death?
    - What are the goals of caring for someone who is dying?
    - What can you do to meet these goals?
    - What precautions should be taken with the body of someone who has died of AIDS?
    - How can the family be helped after the death?

Other points to cover:

- Care of a dying child
- Needs of a child/children whose parent is nearing death
- How to talk about death
- Taking care of future concerns, especially about children
- Pain management

- How trainees can manage their own emotions surrounding the HIV and AIDS related deaths they encounter

All the answers should be written down on the flip over by the trainer.

Activity 2: Summary (15 min)
The trainer will summarise the session and answer any remaining questions.

Reference Material

Care for the Dying and the Dead

At some point in the disease process of HIV and AIDS, there is nothing more that can be done to effectively treat the opportunistic infections or completely relieve the symptoms that they cause. The infections or illnesses have progressed beyond what medicines can cure. At this point, the goal of all care (medical, nursing, religious, and psychological) is to keep the person as comfortable as possible and to maintain their dignity. This is what we call palliative care with TLC (tender loving care). Palliative care also helps caregivers to work through their own emotions and grief. Central in this philosophy is the belief that every person has a right to be treated, and to die, with dignity and that the relief of pain, in any form, is a human right and essential to this process. Palliative care ideally combines the professionalism of an interdisciplinary team, including the patient and family. This kind of care should be available throughout the patient's illness and during the period of bereavement.

However, where AIDS is concerned, palliative care faces some extra challenges and the stigmatisation that many AIDS patients throughout the world deal with. There are also often complex family issues. For example, both partners and sometimes also their children may be infected. HIV and AIDS involves balancing acute treatment of opportunistic infections and the management of chronic conditions due to the unpredictable course of the disease and wide range of complications that come with it. Educating the patient is an essential part of palliative care; the patient should be helped to understand the limits of any treatment and its outcome.

At this point of time support group members and other members of the HBC team may have to step in. The realisation that death of a loved one is not very far away will cause a lot of distress to the caregiver, who in most cases is a family member. In such cases members of support groups, peer educators, or social workers who are close to the family may have to spend a lot of time with the family during this period. They may have to help with the funeral arrangements and last rites according to custom. It is important to be alert for burnout in the caregivers.

When does palliative care begin?

It is often difficult to decide when the focus on medical treatment should stop and care for the dying should begin. The change in care may begin, for example:

- When medical treatment is not available or is no longer effective
- When the person says he or she is ready to die and really does appear to be very sick; this is clearly different from someone who is depressed for a time and who must be encouraged not to give up
- When the body's vital organs begin to fail; this has to be diagnosed by a doctor.

What are the signs of imminent death?

- Decreased social interaction – sleeps more, acts confused, coma.
- Decreased food and fluid intake – no hunger or thirst.
- Changes in elimination – reduced urine and bowel movements,
- Incontinence.
- Respiratory changes – irregular breathing, "death rattle".
- Circulatory changes – cold and greyish or purple extremities,
- Decreased heart rate and blood pressure.

Signs of death

- Breathing stops completely.
- Heart beat and pulse stop.
- Totally unresponsive to shaking, shouting.
- Eyes fixed in one direction, eyelids open or closed.
- Changes in skin tone—white to grey.

Where can you provide care for someone who is dying?

Care for the dying can be provided in a hospital or in the home. Most people prefer to remain at home. However, some people may not want to actually die in the home. They want to stay at home until the last moment but either because of their own or the family's wishes they may want to go to the hospital to die. If this is the case, a plan for transporting them will need to be thought out.

What are the goals of caring for someone who is dying?

The main goals of caring for someone who is dying is to keep the patient comfortable and protected from problems that can make him or her feel worse. In session 2 we mentioned the range of emotions a person can go through. Counselling is a vital part of caring for people who are dying, and supporting their caregivers. Someone who is dying may suffer from great psychological stress. Appropriate emotional and spiritual help should be offered. Counselling can help someone understand and explore his or her reactions to death and dying, and accept the fact that death is near.

You can do this by:

- Helping the patient to maintain independence for as long as possible.
- Helping the dying person to grieve for, and cope with, the continuing losses he or she experiences.
- Helping the patient and other family members to prepare for death: This may include tending to relationships in the family or the community, and arranging for the transfer of responsibilities (especially children).
- Keeping the person within community and family groups for as long as possible: Family members can include the patient in activities and events in their lives even when it seems the person is too ill to enjoy or understand what is going on.
- Give comfort.
- If the person is in constant pain, make sure that pain medication is available in regular doses. It should not be taken just when the pain is severe. Pain is what the patient says hurts; it is always subjective, never what others, such as caregivers, think it ought to be. Pain guidelines have recognized that pain in AIDS patients is very like that of cancer pain.

- Encourage relaxation techniques like deep breathing; give back rubs or body massages.
- Continue basic care to keep the person clean and dry and to prevent skin problems and stiffness of joints.
- Encourage communication within the family and community. People with AIDS and those they love need to feel that they are not outside the love and life of their community. Help them use this time as a chance to heal old wounds and to make peace with each other. This will help to increase the comfort and acceptance of the whole family.
- Provide physical contact by touching, holding hands, and hugging.
- Provide or arrange for spiritual counselling with a representative of the patient's religion if this is agreeable to the patient. Also be accepting if the patient has no spiritual wishes.
- Accept the person's own decisions such as a refusal to eat or get up, or even a demand to get up when you think that resting would be better for them.
- Respect requests; for example, not wanting to see visitors.
- Ask them what they are feeling. Listen when they tell you how they feel.
- Accept the person's feeling of anger, fear, grief, and other emotions. It is important to remember that emotional pain, can be as real and hurt just as much, as physiologically inspired pain.
- It is important for family members to give the person opportunities to talk about their feelings, enabling them to cope better with anxiety, fear, loneliness and guilt - feelings that often worsen as someone becomes weaker.
- Fear of death is a normal reaction. Caregivers should not give false reassurances, but can help the person to talk about their fears. Fear can make people angry about their situation, and aggressive towards people they are close to.
- Loneliness is very depressing for the sick person. Friends and relatives often stop coming to see them, or, when they do visit, they act like strangers. People should be encouraged to visit, but need to be given opportunities to discuss their feelings about being with someone who is dying.

- Feelings of guilt and regret are very common, in part because of the stigma often associated with AIDS. A person may want forgiveness or to discuss ways of resolving problems they feel responsible for.

Good counsellors, whether trained or untrained, from a religious faith or not, understand that they are being invited into the living space of other people. The conversations that happen there are often painful and difficult, and they know that their role is to support not to judge.

Care of a dying child:

- When death is near, the family of the child will need emotional support. Support groups or community-care providers can be a source of great support.
- Be willing to talk and answer questions about his or her illness.
- Help the child to feel loved and not alone.
- Ensure that family members are around to play when the child is able.

Special Points to Consider: Care for a Dying Child

- In very young children, non-verbal communication is very important (holding or touching).
- Before the age of 5 it may be difficult to explain to a child that they are dying. But children often understand more than we think about what is going on. If a parent has died they may already be familiar with death.
- Children, like adults, may be sad, angry, afraid, or anxious. They may express these emotions through their behaviour.
- They must be encouraged to talk. Just because they are silent does not mean that they do not have questions or are not worried.
- Their questions must be answered honestly.

Taking Care of a Child Whose Parent is near the end of Life:

- Children need to talk about the loss of their parents. If you don’t talk to them, they may suffer later

- Talk in a simple and direct way so that the child can understand.
- Do not take children away from their dying parent; they need to be close to each other.
- Help children feel that they will still be loved and cared for, even after their parent dies.

Preparing for Death

Talk about death if the person wishes to. Many people feel that it is not good to talk about the fact that someone is going to die, as if mentioning death is a wish for death. But by discussing death openly, those around are helping the dying person to prepare for death. It may take great courage to talk about it but it can be a big help for the person to feel that his or her concerns are heard, that wishes will be followed and that he or she is not alone.

To avoid talking about death is a form of denial. One of the most common worries is for the future of the children in a family. People may fear that their children will be hungry or lack money for school fees after they have died. Begin planning with relatives, friends, or orphan programmes for the future of the children. It will ease such worries if the person knows that suitable arrangements have already been made (**see: creating a will**).

Practical Issues to be discussed before Death

- Custody of children
- Family support
- Making a will
- Funeral costs
- Future school fees.

Emotional Issues to be discussed before Death

- Resolve old quarrels
- Tell patient and loved ones that they are loved
- Share hopes for the future
- Say goodbye to caregivers and providers.

The person may be worried about being in pain as he or she nears death. Knowing what it will be like can lessen the fear. If the person asks, describe what might happen, such as difficulty in breathing, or passing in and out of consciousness. If pain medications are available, reassure the person that they will be used in order to prevent unnecessary pain.

The person may be worried about what will happen after they die. The anxiety can be lessened by helping them to write a will, by planning and writing down details such as funeral arrangements. Bringing a spiritual leader of the patient's religion to pray or talk with the person during his or her last moments might give them peace.

Making a Will

A will is a written document that makes clear what a person wishes to happen after their death. Making a will is easy. But many people do not make one, because they think that it is difficult or they believe that it will make them die more quickly. A will must be made in accordance with local law, although the principles are similar everywhere.

A will can;

- Ensure that property, land and valuables are passed on to people that the person would like to receive them.
- Make clear who has custody of children, and if there is no partner, appoint guardians. Specify who will ensure the will is acted upon (trustees or executors).
- Provide instructions about funeral arrangements.

To be valid, a will must be;

- Written in permanent ink or typed.
- Signed by the person and clearly dated.
- Witnessed by persons present at the same time as signing and dating. The number of witnesses required depends on the country. Those who will benefit from the will should not be witnesses.
- Written when the person is of sound mind and is not being forced to do so by someone else.

Precautions before a Funeral

After death, you need to follow the same rules in dealing with the body as you did when helping the person through his or her illness. Hands should be protected with gloves or plastic bags when cleaning and laying out the body, particularly if there are body fluids such as diarrhoea or blood, and washed with soap and water afterwards. Wounds on hands or arms should be covered with a plaster or bandage.

Shortly after the person dies, the virus will also die. HIV can only live and reproduce inside a living person. Therefore you do no need to worry about special precautions during the funeral itself. The person can be either buried or cremated according to local custom.

How can the Family be helped after the Death?

Immediately after a person has died, the family may need help to arrange practical matters. They will also need emotional support to cope with the loss of a dear one. Members of support groups, peer educators and social workers can be of great help. They can assist the family with funeral arrangements in accordance with the customs and regulations of the area in which they live. The family often needs more emotional support than the person themselves, because they find it difficult to accept what is happening. Unless invited to stay, the caregiver should then leave the family to contact other relatives and to mourn the dead person according to their cultural traditions. Family members should be offered counselling to help them cope with grief and other feelings, as well as support for practical problems.

The death may continue to cause practical difficulties for the family. This is particularly true if planning for the death was not done properly. Also, the family and loved ones will continue to grieve for many months. Any care or practical help that you can give during this time can be useful. Setting aside time to visit and asking how they are doing will help them to think of life beyond this painful time. Support group members can also help in cooking or looking after smaller children at this time of grief. Existing home visits should not be ended immediately after death, but continue for a while. In this period, the home visits can be reduced slowly. As such, the family can be guided in picking up and rearrange their lives again. It is very well possible that with time going by, new needs arise that were not clear or foreseen by the family. The home visitor can do a new need assessment, or refer the person/family to other healthcare providers if necessary.

The need to offer counselling to partners and family following the death of a family member or friend is often overlooked, particularly in developing countries. Bereavement counselling can help the bereaved person to discuss and reflect the changes brought about by the loss, to mourn appropriately and to look to the future.

Session 14: HBC Project - Organizational Structure

Time: 1 hour - (60 minutes)

Aim: This session will enable trainees to understand the organizational structure of a Home-based Care Program.

Learning Objectives

By the end of the session, the **participants** will be able to identify:

- Which organizations/institutions are working together on any HBC- project in Ghana?
- The importance of teamwork. .
- How and whom to report to
- How their knowledge, network and communication with support organizations and external bodies can be applied.
- Who to contact in case of problems, doubts, questions

Table 14.1: Communication Strategy; HBC Organizational Structure

Session Fourteen: HBC Organizational Structure, Communication Strategy and Monitoring and Evaluation Framework				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Disciplines Working on HBC in Ghana • Teamwork and Reporting Systems • Communication Strategies • Monitoring and Evaluation Framework	• Trainees	• Presentations • Trainer-Led Discussions • Group Discussions	• Laptop • Projector • Flip Chart • Markers • Organogram	• 60 Minutes

Table 14.2: Session Activities; Organizational Structure

Activity	Time (minutes)	Content	Materials	Pictures
Discussion/ Presentation	60	Group Discussion: Organizational Structure	Flip chart, markers	

The following material for this session is included at the end of this chapter:

Reference Materials:

Box 9.1: Key Points; HBC Organizational Structure

- The disciplines of the HBC- team are: Caregiver, Nurse, Prescriber, counsellor.
- They have to work together.
- They need to evaluate.
- Funding comes from the government and donor organizations.
- Funds can be attained by writing proposals and running a structured and transparent program.

Activity 1: Group Discussion: Organizational structure (1 hour)

Topic: Structure of the National HIV HBC Program,

Instructions

- Use the white board to draw figure 1 of the 'Reference Materials'.
- Begin drawing the circle of the patient and continue with the caregiver circle by explaining that the circle is presenting the caregiver who is taking care of the patient. Followed by the next two circles and their explanation.
- Now write the 3 disciplines below each other on the white board.
- Ask the trainees if they can fill in the specific tasks the disciplines fulfil in the HBC-project, starting with the caregiver. You can choose to write the answers yourself or ask the trainee to write it down on the white board

- At the end the trainer summarises the drawing and its answers, and evaluates the trainees' opinion and knowledge on the subject.

Reference Materials

National Home-Based Care Organizational Structure

To run a HBC- project in a structured manner, all the disciplines need to know from each other what they are doing (job description) and who to contact for information. Because home-based care includes working with lives of sick human beings, it is important to know very well what is allowed and not allowed to do within each discipline. To keep up to date about the activities of each discipline, the HBC- team would be recommended to evaluate monthly. Besides this we want to stress on the importance of regular evaluation of patients, especially the unstable patients. The Home Care Team should indicate/decide how often a patient needs to be evaluated so that problems can be detected on time for the appropriate action to be taken.

Below are the different disciplines of the National HIV HBC Program and their responsibilities. . This is an estimated set of tasks provided and is not exhaustive. These can be adjusted in the future where necessary.

Caregiver

- Provides basic home based care.
- Documents care provided in a designated form. .
- Refers to the prescriber
- Evaluates problems, doubts, suspicions etc. with the nurse.
- Is responsible for the contents and material state of his/her home health care kit.

Prescribers

This refers to all health workers who can supervise caregivers. These include Nurses, Doctors, Public Health Nurses, Midwives, and Disease Control Officers etc. The Prescribers responsibilities are:

- Responsible for the training of the caregiver.
- Does the intake of the patient

- Makes an indication of patients' needs.
- Makes a patient file based on information from the intake
- Appoints and instructs a caregiver for a specific home and client/ patient.
- In case of problems, doubts, suspicions etc. by the HBC service provider, the nurse, does a check-up on the patient and refers to the doctor who: Handles all the medical problems a nurse is not authorized to handle

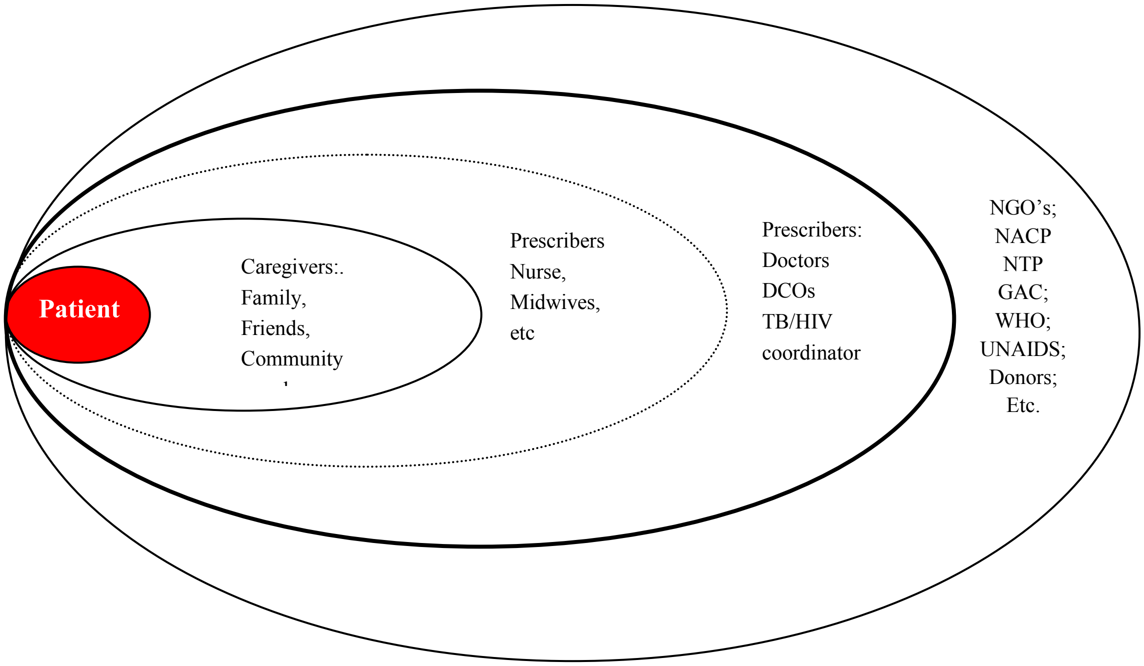
HBC Organogram

The simple diagram below will help in understanding the concept of the Home Based Care program and how it should be implemented.

It starts off by the client/patient who is the core of Home Based Care. This is the person who needs care and various disciplines will at various levels do what they have to do to make that care possible.

Directly around the client/patient are the direct family members, friends and community members. They are the ones who can be trained to directly give care to the client/patient. This group of care givers are to be supervised and this supervision is done by the next level of individuals who are the Prescribers. The Prescribers are made up of Nurses, who work directly with the care givers and who are their direct supervisors. However the nurses in turn need to be supervised and/or assisted in areas that go beyond them and that is where the next level of Prescribers comes in - the Doctors. Amongst the Prescribers we also have others and these are Disease Control Officers, TB and HIV coordinators etc. These individuals will work directly with both the supervisors of the care givers as with the caregivers too. This level of service providers in turn report to entities such as DHMT, NACP, NTP, GHS and GAC.

Figure 3.1: HBC Organogram



Session 15: Care of the Caregiver

Time: 1 hour - (60 minutes)

Aim: This session will enable trainees to understand what caregivers go through while caring for another and how they can also be cared for.

Learning Objectives

By the end of the session, the **participants** will be able to:

- Understand that Care givers do also need to be cared for
- Understand the stress caregivers can go through and how they can help

Table 15.1: Communication Strategy; Care of the Caregiver

Session Fifteen: Care of the Caregiver				
Messages/Topics	**Audiences**	**Training Methods/Activities**	**Resources/Tools**	**Timescales**
• Signs of caregiver stress • Strategies for dealing with caregiver stress	• Trainees	• Presentations • Trainer-Led Discussions • Case Studies	• Laptop • Projector • Flip Chart • Markers	• 60 Minutes

Table 15.2: Session Activities; Care of the Caregiver

Activity	Time (minutes)	Content	Materials	Pictures
1	45	Questions, Discussion and active role play by participants about Case Study on - Caring for the Care Giver	Flip over/whiteboard and markers	
2	15	Summary	Flip over/whiteboard and markers	

The following material for this session is included at the end of this chapter

Reference Materials:

- Care of the Care Giver
- Case Study

Instructions:

- Read out the case study to the group
- Divide the group into 2 and let them discuss the case study.
- Let each group put a role play together. One group will role play whilst the other observes and then vice versa.

Case study 1

Two Family members, a sister and a cousin alongside 2 very good Friends of Kwame had been caregivers for Kwame, a 26 year old accountant who died of complications of HIV and AIDS two weeks ago. Kwame had become very ill about six months after the death of his long-time girlfriend, Joyce. Kwame's caregivers took care of him 24/7 for the past 5 months (which included taking care of him during a long stay at the hospital). A formal caregiver, and nurse from a nearby CHPS compound, has helped intensively, but only for the past month as before she only gave supervision to the caregivers. Kwame's parents, who never approved of Kwame dating his late girlfriend, arrived in town shortly before Kwame's death. They stayed for the funeral and to clean out his apartment, then left. At no point did the family acknowledge Kwame's relationship with his girlfriend or talk about HIV and AIDS.

Identified Problems

- The primary caregivers feel grief but have nowhere to go
- The caregivers try not to be as depressed as they feel. They did all they could and after all, the rest of the family, especially the parents did not seem to care. Nonetheless, they feel anger at the Parents

- The family has cleared out the apartment leaving very little for the caregivers to have." The primary caregivers have a few photos and items from Kwame and his girlfriend that the family did not want.
- The CHN also became fond of Kwame and his caregivers, and also wants to be able to express grief in some way.

To help;

- In a role play demonstrate a situation where the caregivers (informal and formal) can express their sadness and work through their grief.
    - Where will they go for such help?
    - As there might be no funds, what resources can they access?
    - What can they do?

Care of the Care Giver

Caregiving is rewarding but stressful

Caregiving can have many rewards. For most caregivers, being there when a loved one needs you is a core value and something you wish to provide.

But a shift in roles and emotions is almost certain. It is natural to feel angry, frustrated, exhausted, alone or sad. Caregiver stress — the emotional and physical stress of caregiving — is common.

People who experience caregiver stress can be vulnerable to changes in their own health. Risk factors for caregiver stress include:

- Being female
- Having fewer years of formal education
- Living with the person you are caring for
- Social isolation
- Having depression
- Financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and difficulty solving problems
- Lack of choice in being a caregiver

Signs of caregiver Stress

As a caregiver, you may be so focused on your loved one that you don't realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:

- Feeling overwhelmed or constantly worried
- Feeling tired most of the time
- Sleeping too much or too little

- Gaining or losing a lot of weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

Too much stress, especially over a long time, can harm your health. As a caregiver, you're more likely to experience symptoms of depression or anxiety. In addition, you may not get enough sleep or physical activity, or eat a balanced diet — which increases your risk of medical problems, such as heart disease and diabetes.

Strategies for dealing with Caregiver Stress

The emotional and physical demands involved with caregiving can strain even the most resilient person. That's why it's so important to take advantage of the many resources and tools available to help you provide care for your loved one. Remember, if you don't take care of yourself, you won't be able to care for anyone else.

To Help Manage Caregiver Stress

Accept Help

Be prepared with a list of ways that others can help you, and let the helper choose what he or she would like to do. For instance, one person might be willing to take the person you care for on a walk a couple of times a week. Someone else might offer to pick up groceries or cook for you.

Focus on what you are able to Provide

It's normal to feel guilty sometimes, but understand that no one is a "perfect" caregiver. Believe that you are doing the best you can and making the best decisions you can at any given time.

Set Realistic Goals

Break large tasks into smaller steps that you can do one at a time. Prioritize, make lists and establish a daily routine. Begin to say no to requests that are draining, such as hosting holiday meals.

Get Connected

Find out about caregiving resources in your community. Many communities have classes specifically about the disease your loved one is facing. Caregiving services such as transportation and meal delivery may be available.

Join a Support Group

A support group can provide validation and encouragement, as well as problem-solving strategies for difficult situations. People in support groups understand what you may be going through. A support group can also be a good place to create meaningful friendships.

Seek Social Support

Make an effort to stay well-connected with family and friends who can offer nonjudgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend.

Set Personal Health Goals

For example, set a goal to establish a good sleep routine or to find time to be physically active on most days of the week. It's also crucial to fuel your body with healthy foods and plenty of water.

See Your Doctor

Get recommended immunizations and screenings. Make sure to tell your doctor that you're a caregiver. Don't hesitate to mention any concerns or symptoms you have.

Conclusion

HIV CHBC today forms an important component of care for PLHIV and those living with TB and many countries have taken the lead in establishing policies, guidelines as well as formal trainings for service providers to ensure harmonized HBC services that are adequately implemented and monitored.

Having put together a National HIV CHBC Policy and Guideline, Ghana, now needed a training manual that would align with the definition of HIV HBC within the Ghanaian context which says that HIV HBC is ‘the holistic and collaborative effort to enhance the quality of life of persons infected and affected by HIV and AIDS by care and support providers including the family, the community and the client’.

The Ghana AIDS Commission in collaboration with the West Africa AIDS Foundation and with the support of many stakeholders, individuals and partners have put together an HIV CHBC Training manual that tackles every aspect of the continuum of care for PLHIV and those living with TB that can be managed in the home setting.

We look forward to using this manual to offer comprehensive trainings to service providers to enable them in turn adequately take care of PLHIV and those living with TB to ultimately ensure the best of health and care for their clients as well as contribute meaningfully to the National Response.

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List of Appendices

Appendix 1: Monitoring and Evaluation Framework

Sessions	Key Content	Output Indicator	Means of Verification	Person(s) Responsible
Baseline	• Establishing number of ToT existing and their training capacity • Establishing pre training capacity of the facilitator • Establishing the number of trainers to be trained • Establishing the number each ToT is to train	• Baseline assessment report • Pre test • Number of trainers participating in the zonal HBC training • Number of trainees trained trainers aim to train after their training	• Baseline assessment report • Pre-test score result • Zonal HBC training participants list • Reports from zonal training	GAC
• Course Introduction, Concept of HBC and Support	• Course Content Overview • Understanding the Important Elements and the Concept of HBC	• Number of trainees who demonstrated ability to; o Describe course goals and objectives o know the components of HBC o Discuss the levels and key players in home-based care services for PLHIV o describe safety precautions needed in providing HBC o provide HBC services	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Skills in Training Community Home based Care Givers	• Identifying the skills required to complete a training course for Training HBC providers	• Number of trainees who demonstrated ability to; o Appreciate the concept of training home-based caregivers o Know the role of CHBW in skills transfer to primary caregivers o Identify primary caregivers and PLHIV to be trained o Explain the principles of learning and teaching non-literate adults. o Demonstrate ability to transfer skills to caregivers o Use appropriate evaluation techniques to assess the learning process during and after the lesson	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF

• Facts About HIV/AIDS	• Basic Facts on HIV and AIDS and TB	• Number of trainees who demonstrated ability to; o Know the prevalence and impact of HIV/AIDS globally and nationally o Examine common beliefs, values, and opinions, myths and misconceptions o Describe HIV/AIDS infection, transmission, progression, and signs and symptoms o Understand the relationships between HIV infection, OI's and STI's o Identify ways to prevent the spread of HIV/AIDS	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Problems PLHIVs Face in General	• Psychological and Social problems faced by PLHIV	• Number of trainees who demonstrated ability to; o Explain the psychological problems faced by PLHIV and how they can be helped o Explain the social and economic problems faced by PLHIV	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Living Positively With HIV and AIDS, Nutrition and Prevention of Infections	• How PLHIV can live long and healthy lives • Good hygiene and prevention methods aimed at preventing the spread of HIV and other infections among family members and non-infected persons	• Number of trainees who demonstrated ability to; o Describe the importance of positive living in managing HIV Infection. o Know the people at risk of HIV Infection o Explain how to prevent infections in the home setting o Know how to maintain good hygiene inside and outside the home. o Understand and describe the importance of nutrition in managing HIV Infection	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Mobilizing the Community for Home-Based Care	• Importance of mobilizing the community for HIV HBC	• Number of trainees who demonstrated ability to; o Know terminologies related to community mobilisation o Know the importance of mobilising community for HBC Services o Discuss role of CHBC Facilitator in initiating HBC services for PLHIVs o Explain the process of initiating HBC activities	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Management of HIV Signs	• Common signs, symptoms and	• Number of trainees who demonstrated ability to; o Identify symptoms of the various infections	• Training Session Evaluation	• GAC/WAAF

and Symptoms at Home	complications associated with HIV infection and how to manage them at home	associated with HIV/AIDS ○ Treat these symptoms at home ○ Know when there is the need for referral	Forms/Reports • Periodic Post-Training Evaluation Studies	
• Demonstration of Home-Nursing Procedures	• Practical skills needed to care for a person who has HIV infection that can be managed in the home setting	• Number of trainees who demonstrated ability to; ○ Demonstrate the various procedures useful in home-care nursing ○ Be familiar with Basic Home Healthcare kit ○ Know the basic medication used by clients (HIV/TB and OIs)	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Conditions That Need Special Care – TB, Malaria, PMTCT and STIs	• Symptoms and precautions for TB, STIs, Malaria, and conditions commonly found in those who are HIV-Positive as well as Prevention of Mother to Child Transmission of HIV	• Number of trainees who demonstrated ability to; ○ Know the signs of a person with TB for linkages and referrals. ○ Know the signs of a person with Malaria and STIs for linkages and referrals.	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Women and HIV/AIDS	• Special considerations for women living with HIV infection	• Number of trainees who demonstrated ability to; ○ Understand the sociocultural problems faced by women ○ Recognise the symptoms in a woman (including pregnancy) that require medical help through referral ○ Understand and describe the importance of care continuum for HIV positive women ○ Understand and describe the importance of care continuum for HIV positive expectant women during pregnancy, childbirth and postnatal. ○ Understand the importance of managing HIV exposed infants	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Men and HIV/AIDS	• Special considerations for Men living with HIV infection	• Number of trainees who demonstrated ability to; ○ Understand the sociocultural problems faced by men ○ Understand and describe medical problems faced	• Training Session Evaluation Forms/Reports • Periodic Post-	• GAC/WAAF

		by men who have sex with men o Recognise signs and symptoms of HIV positive men requiring medical intervention o Give comprehensive counselling to HIV positive men regarding their role in ensuring the families are healthy and protected from the spread of HIV/AIDS	Training Evaluation Studies	
• Children, Adolescents, The Aged and HIV/AIDS	• Special considerations for children that are infected with and affected by HIV • Understand the issues the Aged with HIV face and how to help them address these • Discuss single parenthood	• Number of trainees who demonstrated ability to; o Explain how HIV is transmitted in children o Describe the major and minor signs of HIV infection in children o Understand the needs of a child with HIV infection o Explain the general rules of caring for a child with HIV infection o Understand the needs of infected and affected children, orphans and adolescents o Explain steps in disclosing children's status o Understand conditions and symptoms usually faced by the aged PLHIV	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Care of the Dying and the Dead	• Considerations and precautions to be taken when caring for someone during the final stages of HIV-related illness as well as after their death	• Number of trainees who demonstrated ability to; o Recognise the signs of a person nearing death o Understand the needs of a person nearing death o Care for an adult or child nearing death o Know the precautions to be taken with the body of someone who has died of AIDS o Know the needs of the family after the death of an infected person.	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF
• Care of the Caregivers	• Signs of Caregiver Stress and how to deal with it	• Number of trainees who demonstrated ability to; o Understand the risks in the work of HBC caregivers. o Know the signs of caregiver stress o Demonstrate knowledge of strategies to use in managing caregiver stress	• Training Session Evaluation Forms/Reports • Periodic Post-Training Evaluation Studies	• GAC/WAAF

Appendix 2: HBC Pre and Post – Test Answer Sheet

1) What is Home Based Care?

- *Correct Answer:* **B** – Any form of care given to ill people in their homes

2) Who is a caregiver of Home Based Care?

- *Correct Answer:* **B** – Anyone can be a caregiver

3) What is a social problem faced by PLHIV?

- *Correct Answer*: **A** – PLHIV are stigmatized in the community

4) What can contribute to PLHIV living positively?

- *Correct Answer*: **B** – Having a positive attitude

5) How can HIV transmission be prevented in the home?

- *Correct Answer:* **A** - Don't share toothbrushes, razors, needles, or anything else that can cut or come into contact with blood

6) Why is good nutrition so important for PLHIV?

- *Correct Answer:* **B** - A well balance diet provides the body with energy and nutrients to help fight infections

7) Which symptom could be managed at home? Without seeking help from a professional

- *Correct Answer*: **A-** Dehydration

8) Tuberculosis (TB) is a coinfection of HIV whereby home care is not enough and health care should be sought. What is one symptom to look out for?

- *Correct Answer*: **C** – Pain in the upper back and chest

9) What is one key component that can reduce HIV transmission from mother to child?

- *Correct Answer*: **B** - HIV positive women should take Antiretroviral drugs before, during and after pregnancy

10) What is the most crucial role a HIV positive male can carry out to reduce the risk of HIV transmission?

- *Correct Answer*: ***A*** – Use a condom with all sexual partner

Appendix 3: Home-Based Care Course Evaluation Form (Adapted from CHBC Training/MYANMAR)

Note: Please answer the following questions (tick off options when indicated) and give any additional comments you may have regarding the training. We are interested in knowing how useful this training has been in terms of providing orientation on home-based care and for planning the work in relation to establishing the HBC programme. Any suggestions you may have in improving the future HBC workshops are very welcome. Thank you for your contribution.

Has the workshop been helpful in terms of understanding community home-based care? (Circle one option) Very much Somewhat Not much
As a result of the workshop do you think you are ready to put into practice the HBC program that was discussed in your group? (Circle one option) Yes Somewhat Not Much
What subject/topic was easiest to understand and why?
What subject/topic was hardest to understand and why?
What could be improved in the future HBC training?
Was the choice of subjects well chosen? (Circle one)

Yes No

If no, please comment on how this could be made better.

Do you have suggestions for other subjects to be included in the future HBC trainings? (Please specify)

Time spent on group work was (circle one):

Too much Just right Too little

More time should be spent on: (please specify)

What was the *least* useful part of the training and why?

What was the *most* useful part of the training and why?

How was the organisation of the training? (Circle one)

Good Average Not good

Any other comments?

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