

# HIV Prevention, Treatment, Care and Support – A Training Package for Community Volunteers

## Module 7



## PALLIATIVE CARE: SYMPTOM MANAGEMENT AND END-OF-LIFE CARE

# Acknowledgements

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The following people played a key role in the development of the tool:

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The professionals at SAfAIDS were responsible for the research, content development, layout and design of the training package. Those who played key roles include:

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The following independent evaluators conducted pre-testing activities:

- Dr. Exnevia Gomo – College of Health Science (University of Zimbabwe)-Consultant
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# Introduction

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Module Seven: Palliative Care: Symptom management and end-of-life care aims to provide CBVs with skills and knowledge regarding how to assist clients and their families to assist clients with symptom management and end-of-life care through the exploration of the following topics.

- Palliative Care The Basics
- Management of Pain
- Preventing Discomfort Before It Begins
- Management of Symptoms in PLWHA
- End-of-Life Care

Materials to be used in this module:

1. Module Seven: Palliative Care: Symptom management and end of life care (this module)
2. Participant's Handbook
3. Facilitator's Guide
4. Evaluation Tools Manual

Training time for this module is approximately 18 hours.

For a detailed discussion on the training methodology, evaluation techniques and glossary of important terms used for this module, facilitators should refer to the Facilitator's Guide.

The evaluation tools used in this module include:

## Evaluation of Module Content

1. Participants Evaluation
2. Facilitator Evaluation

## Participant Evaluation Tools:

1. Pre and Post Test Questionnaire
2. Demonstration of Core skills

Upon completion of this module, participants should demonstrate the following core skills:

1. Provide information to clients and family members on the services and resources available in their community that make up their palliative 'care team' **Session One; Tool 4**
2. Assess pain with clients using the pain assessment tools and describe the pain assessment tool to primary caregivers. **Session Two; Tool 2**
3. Accurately describe the analgesic ladder using a method that clients and family members will understand and use effectively. **Session Two; Tool 4**
4. Demonstrate the ability to provide clients and their families with accurate information on Universal Precautions. **Session Three; Tool 1**
5. Demonstrate to primary caregivers how to manage symptoms in clients by providing information on how caregivers can help, local remedies for symptom management and knowledge on when to contact a health professional. **Session Four; Tool 2**
6. Impart information to family members and/or primary caregivers on how they can help clients cope with feelings and emotions experienced during illness. **Session Five; Tool 3**
7. Assist bereaved family members to understand the possible emotional, physical and spiritual experiences after the death of a loved one through bereavement counselling. **Session Five; Tool 11**

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# 1 Session One: Palliative Care The Basics

**Purpose:** The purpose of Session One is to provide participants with knowledge of the goals of palliative care, when palliative care should begin for PLWHA and the individuals and organisations involved in palliative care in their community.

## Objectives:

By the end of this session, CBVs should be able to:

1. Discuss palliative care with their clients and how ART might change the need to provide palliative care for PLWHA.
2. Demonstrate awareness of the goals of CBVs in palliative care.
3. Provide information to clients and family members on the services and resources available in their community that make up their palliative 'care team'.
4. Demonstrate knowledge on why home based care is an important part of palliative care in their community.

**Duration:** 2 hours

**Required Materials:** Flipchart, markers.

Objective	Content	Time	Methodology
Discuss palliative care with their clients and how ART might change the need to provide palliative care for PLWHA.	1. What is Palliative Care	30 minutes	Mini Lecture
Demonstrate awareness of the goals of CBVs in palliative care.	2. Goals of Palliative Care	30 minutes	Mini Lecture  Tool One (K): Group Activity
Provide information to clients and family members on the services and resources available in their community that make up their palliative 'care team'	3. Who "provides" Palliative care?	40 minutes	Mini Lecture  Tool Four (ST): Group Activity and Role Play
Demonstrate knowledge on why home based care is an important part of palliative care in their community.	4. Home Based Care	20 minutes	Mini Lecture  Tool Three (K): Group Discussion

CBVs should note that previous modules of the training package have covered many of the parts of palliative care that make up the whole. CBVs should keep in mind important elements of palliative care that have been covered: HIV and AIDS information, Treatment Literacy, Treatment Preparedness, Adherence, Counselling and Nutrition.

This module will focus on specific ways that CBVs can improve the 'physical' quality of life for PLWHA and provide end-of-life care.

## 1. What is palliative care? (30 minutes)

### a) Defining Palliative Care (15 minutes)

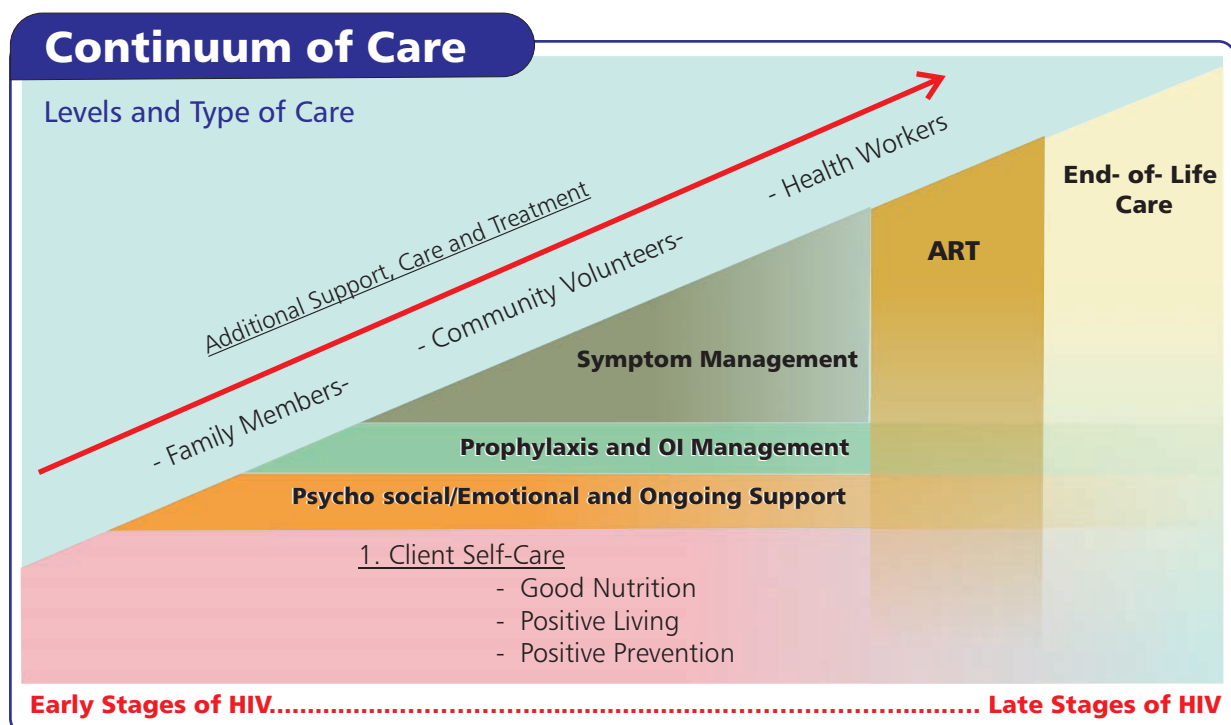
**Palliative Care** includes symptom management both during acute and chronic illness and at the end of life.

Many people believe that palliative care is only for clients who have advanced and incurable disease. Palliative care includes symptom management for anyone with troublesome symptoms. Palliative care is important for clients whose disease does not respond well to treatment, but also for clients who experience complications and side effects.

Palliative care is not only for clients with HIV, but it is also an important part of care for clients with cancer and with chronic diseases such as diabetes or stroke who require long-term care at home. With good treatment and support, palliative care can help many clients live comfortably with disease for many years. For those who have advanced disease, palliative care focuses on promoting the quality of life by providing good symptom management. This can help clients to continue to enjoy life at home for as long as possible.

### b) When does palliative care 'start'? (15 minutes)

Palliative care starts from diagnosis of infection. However, as HIV infection progresses to AIDS and PLWHA are less able to care for themselves, the need for palliative care increases in all forms (nutrition, counselling, ART, management of symptoms and end-of-life care). Review and discuss the following diagram:



## 2. Goals of Palliative Care (30 minutes)

### a) The Major Goal of Palliative Care for PLWHA (5 minutes)

The major goal of palliative care is to provide care and support that makes life comfortable for clients living with HIV, AIDS and other chronic diseases through all stages of disease so they can live as fully and comfortably as possible.

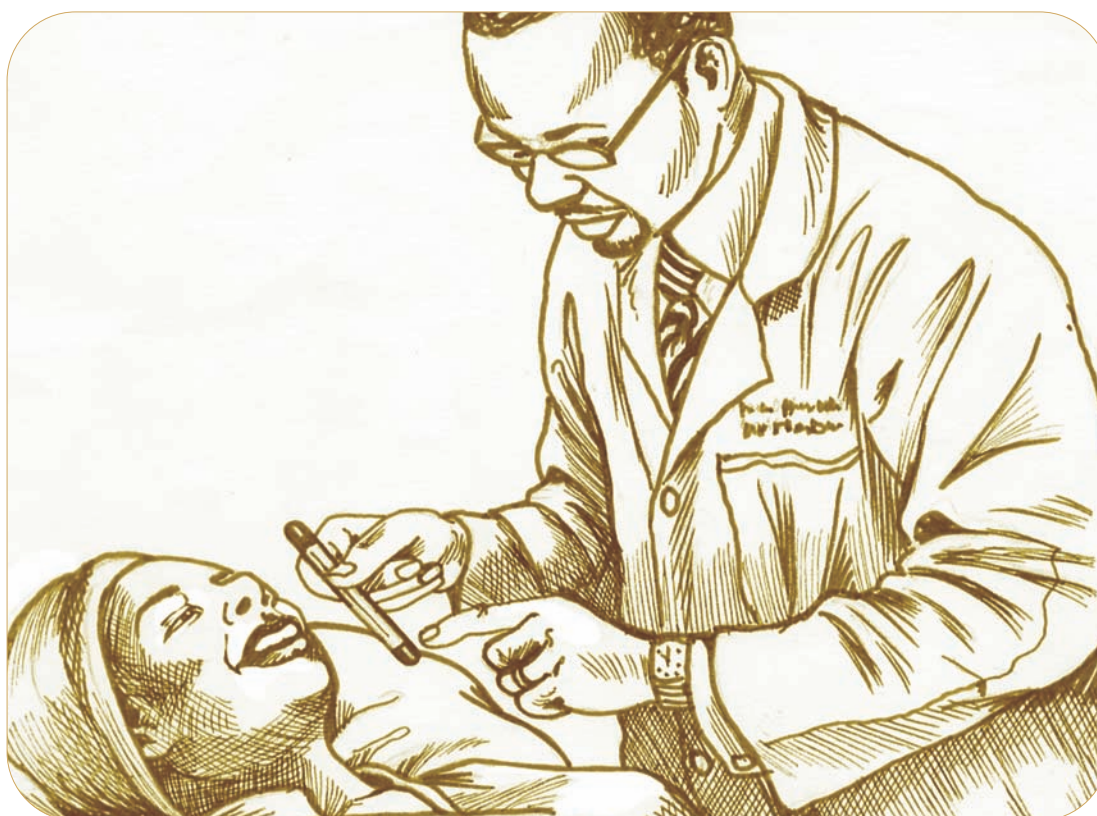
A major consideration behind the goal of palliative care is the belief that all people have the right to live, and to die, with dignity. The relief of pain in all forms (physical, emotional, spiritual and social) is seen to be a right that should be afforded to PLWHA and is central to principles behind palliative care.

### b) Principles of Palliative Care (25 minutes with Tool 1)

Providing palliative care involves many different 'parts', or principles, that when combined, will achieve the broad goal of palliative care.

#### **Palliative care should:**

- Provide relief from pain and other symptoms
- Affirm life and regard dying as a normal process
- Neither to hasten/postpone death
- Integrate the psychological and spiritual aspects of client care
- Offer a support system to help clients live as actively as possible until death
- Offer a support system to help the family cope during the client's illness and in their bereavement
- Use a team approach to address the needs of clients and their families, including bereavement counselling.
- Enhance the quality of life and also positively influence the course of the illness
- Starts early in the course of the illness, together with other therapies that are implemented to prolong life, such as ART.
- Include attempts to better understand and manage symptoms of HIV and AIDS.





## Tool 1: Common Goals for Palliative Care

**Task One:** Separate participants into three groups; ask each group to list their goals as CBVs providing palliative care for PLHWA.

**Feedback :** Have each group present its goals. As a whole create a set of common goals through which CBVs will operate in their community.

### 3. Who provides Palliative Care? (40 minutes with Tool 2)

Palliative care is generally seen as a **team approach**, involving medical personnel, community members and family members of PLWHA.

People that can be involved in palliative care include:

- Hospital staff, including doctors, nurses and other health care workers
- Hospice staff, including counsellors and social workers
- Red Cross/Red Crescent Society staff and volunteers
- Local clinics
- Community health workers
- Community based volunteers
- Family of PLWHA
- PLWHA themselves
- Spiritual care providers
- Other human service professionals (VCT services, legal and financial services, child care and social services).

The burden of providing quality palliative care never rests solely on one individual or institution. While CBVs will play an important part of palliative care for their clients, a team approach should be implemented, including support from Red Cross, local hospitals and clinics.



## Tool 2: Creating a Palliative Care Team

### PART A: Creating a Care Team in Your Community

Ask participants to list resources available in your community that can and should be used as part of a comprehensive palliative care team. Refer to the list of people that could be involved in palliative care above for guidance.

Have participants keep in mind that this list should not only include medical referrals, but referral services for other possible needs of PLWHA (legal, financial, spiritual). Following this session, copies of this list should be made and distributed to all caregivers.

### PART TWO: Sharing Care Team with clients and their families.

Once the Care Team list has been created, divide participants into pairs and ask them to role play how they would explain the Care Team to clients and their families. Highlight that CBVs should provide a copy of this list to each client household for clients and families to use.

## 4. Home Based Care (20 minutes with Tool 3)

Palliative Care can be provided in many different places; in hospitals or nursing homes or in the home of clients. Home-based care is often seen as one of the most practical and effective way to provide palliative care. Home-based care depends on the availability of shelter, food, safe water, sanitation, cooking utensils and clothing. Palliative care for pain and other symptoms is only part of the complete home-based care, which includes physical, psychological and spiritual activities. Basic physical care may include positioning, hygiene, skin care and nutrition support. Equally important are spiritual and emotional support as well as the promotion of death with respect and dignity. Supporting the family through the bereavement process can be an important role for the CBV.

### Reasons why home-based care is preferred in some settings:

- Clients are often unable to travel to a clinic every time they need treatment
- Home-based carers (such as CBVs) are able to help both PLWHA and their families
- PLWHA are often most comfortable at home, and can maintain relationships with friends and family while receiving care
- Home-based care involves not only medical facilities, but help from within a community, and provides access to other services
- Governments find the practice cost-effective by reducing strain on often already overwhelmed health-care systems.



## Kinds Of Care That Are Important For Chronically Ill Children

### Social Interaction



A sick child always feels loved when left to interact with others. Involve sick children including HIV infected children in all childhood activities.

### Playing



Playing brings happiness to sick children. Sick children need to play too or watch others playing if they are too weak to join.

### Spiritual Care



Praying gives hope to sick and also the sick caregivers. When strong, take the sick child to his/her religious centre.

### Nutritional Care



Praying gives hope to sick and also the sick caregivers. When strong, take the sick child to his/her religious centre.

### Home Based Nursing



Sick children feel happier when nursed at home. Know when the child is too sick to receive visitors.

### Tender Loving Care



Showing love and affection to a sick child promotes fast healing. Touching, hugging eliminates/reduces stigma but avoid handling potentially infective material with bare hands.

**Facilitator's Note:** Emphasise that while the list above is for children, adults also require similar kinds of care. Ask participants to list any other forms of care adults and children in your community may require.

### Tool 3: Role of Home-Based Care in Your Community



Ask a group to discuss specific reasons why home-based palliative care might make good sense in your community.

Consider available resources, impact of HIV and AIDS on the health-care system, strength of community support networks and possible reasons why PLWHA may be more comfortable being cared for in their own homes.

Write responses from CBVs on a flipchart entitled: 'Why Home-Based Palliative Care in the community?'

# 2 Session Two: Management of Pain

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**Purpose:** The purpose of Session Two is to provide CBVs with the knowledge and skills to enable them assist clients and family members to assess pain and methods of pain relief using medication and non-medicinal practices.

**Objectives:**

By the end of this session, CBVs should be able to:

1. Demonstrate an understanding of the ways in which pain could affect the quality of life of clients living with HIV or AIDS.
2. Assess pain with clients using the pain assessment tools and describe the pain assessment tool to primary caregivers.
3. Accurately describe the analgesic ladder using a method that clients and family members will understand and use effectively.
4. Provide clients and family members instructions on the correct use of oral morphine.
5. Describe to clients and families non-medicinal methods of pain relief that are appropriate in your community.

**Duration:** 3 hours 30 minutes

**Required Materials:** Flipchart, markers.

**Recommended Preparation:**

- Make copies of the 'How to Report Pain' Handout 7-1 for distribution to participants at the beginning of section two.
- Make copies of Handout 7-3, 'The Analgesic Ladder' for distribution in section 4. d)
- Make copies of Handout 7-2, 'Teaching Clients and their Families how to give Oral Morphine' for distribution to participants in Tool 3.

<b>Objective</b>	<b>Content</b>	<b>Time</b>	<b>Methodology</b>
Demonstrate an understanding of the ways in which pain could affect the quality of life of clients living with HIV or AIDS	1. Pain and Quality of Life for PLWHA	20 minutes	Mini Lecture  Tool One (A): Group Discussion
Assess pain with clients using the pain reporting tools and describe the pain assessment tool to primary caregivers	2. How to Assess Pain	50 minutes	Mini Lecture  Tool Two (ST): Group Role Play
Accurately describe the analgesic ladder using a method that clients and family members will understand and use effectively	3. What is pain relief?	10 minutes	Mini Lecture  Tool Three (ST): Group Discussion and Role Play
Provide clients and family members instructions on the correct use of oral morphine.	4. Treating Pain with Medication	1 hour 30 minutes	Mini Lecture  Tool Four (ST): Role Play
Describe to clients and families non-medicinal methods of pain relief that are appropriate in your community	5. Non Medicinal Methods of Pain Control	30 minutes	Tool Five (ST): Group Discussion and Role Play

## 1. Pain and Quality of Life for PLWHA (20 minutes with Tool 1)

One of the most important aspects of maintaining the quality of life and dignity of clients is managing pain. Clients should be assisted in every way possible to lead as pain-free a life as possible.

### Important things for CBVs to remember about pain and PLWHA:

- Pain is what clients say it is, not what CBVs or others think it should be
- Pain greatly affects the quality of life of clients
- Pain should be controlled in a way that helps clients stay as alert and active as possible
- If medication to relieve pain is not available, there are other methods to help the client deal with pain.

### Tool 1 How Pain Affects PLWHA

As a group, discuss ways in which pain could affect the quality of life of PLWHA.



## 2. How to assess pain

Distribute the 'How to Assess Pain' Handout 7-1

### a) Determine the Cause of Pain (10 minutes)

It is difficult to treat pain without knowing what is causing it. Some causes of pain might require special attention from doctors or other medical professionals (for example, pain of the internal organs). If a CBV is unsure of the cause of pain, he/she should refer the client to a doctor for a medical diagnosis.



### Questions CBVs can ask to help determine the cause of pain in PLWHA:

- Where is the pain?
- What makes the pain better or worse (e.g., hot, cold, darkness, elevation, pressure)?
- What type of pain is it (i.e., stabbing, aching)?
- Are you taking any medication for the pain? If so, what are you taking?

CBVs should encourage PLWHA to think about each of these questions and use them to describe the pain when visiting their doctor.

### b) Describing the Pain (40 minutes with Tool 2)

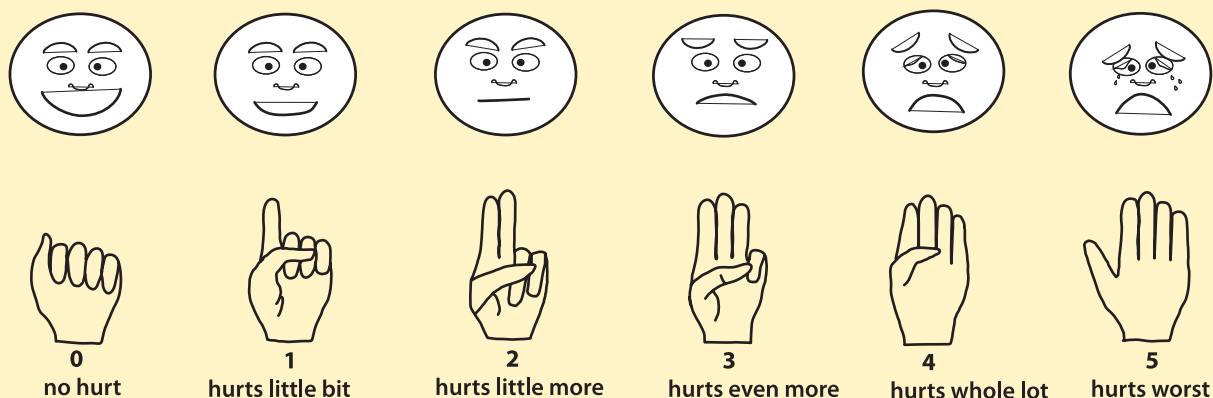
CBVs should understand that it is often difficult for people to understand their pain. CBVs can help their clients determine the level, or severity, of pain felt. Pain can be better or worse at certain times of day. Using one of the pain grading systems below, CBVs should encourage their clients to record the grade of

pain felt at certain times of day and provide this information to their doctors during appointments.

The role of CBVs is to support their clients to assess their pain so that PLWHA can accurately describe the 'where and how much' of their pain during medical appointments.



**Determine the type of pain - is it common (such as bone or mouth pain) or special pains (such as nerve pain, zoster colic or muscle spasms)?**



**Grade the pain with the faces (especially in children) or with your hand (with 0 being no pain, 1 finger very mild pain and 5 fingers the worst possible pain). Record your findings.**

**Note on Special Pain:** Clients experiencing special pain (shooting or sharp pains) should be immediately referred to a health facility.



## Tool 2 Helping Clients Report Pain

Separate participants into two groups. Have one group conduct activities described in Part One and the other group follow the instructions for Part Two.

### PART ONE: CBVs Helping Clients to Report Pain

Have the group provide a demonstration on how they would help a client to report and document pain using the handout:

1. Determine the cause of their pain.
2. Describe their pain

The presentation should have one group member playing the role of caregiver and the other as the client.

**Facilitator's Note:** In assessing this skill, facilitators should ensure that special pain (sharp, shooting pains) is very serious and CBVs should refer clients experiencing special pain, immediately to the nearest health facility.

### PART TWO: Describing Pain Assessment to Client Families

The second group should provide a demonstration on how they would describe the pain assessment tool to client families in a manner that would help carers in the home to report pain with their family member.

**Facilitator's Note:** During each presentation, have participants provide suggestions on how reporting pain with a client and/or explaining the pain assessment tool to client families could be improved upon based on the knowledge levels of client households. Remind participants that they should encourage clients and family members to keep a record of pain to discuss with doctors or other medical professionals during appointments.

When assessing this core skill at the end of the module, facilitators should have participants demonstrate both Part One and Part Two in a manner that clients and family members will find easy to understand.

### 3. What is Pain Relief? (10 minutes)

Pain relief involves many different aspects of care for clients. Firstly, pain relief involves managing physical symptoms of pain through medication and non-medicinal methods of pain control. Secondly, pain relief involves supporting the emotional and spiritual well-being of clients.

**Analgesics** are the broad name given to medications used to treat physical pain.

Analgesics include:

- **Non-opioids:** aspirin, paracetamol or ibuprofen
- **Opioids for mild to moderate pain:** codeine
- **Opioids for moderate to severe pain:** morphine

**Facilitator's note:** The types of analgesics used, particularly for opioids, may differ depending on availability and government policy.

### 4. Treating Pain with Medication (1 hour 30 minutes)

Medication is an effective way to relieve pain in PLWHA. CBVs, family of clients and other people involved in the care and treatment of PLWHA should not withhold pain medication because they fear the client will become addicted to pain killers. Instead, pain medication should be reviewed frequently by a health professional and increased or decreased when necessary.

CBVs should be aware that special pain will not respond to medication. Clients experiencing special pain should be referred to a health facility and CBVs should not try and treat this type of pain at the household level with medication.



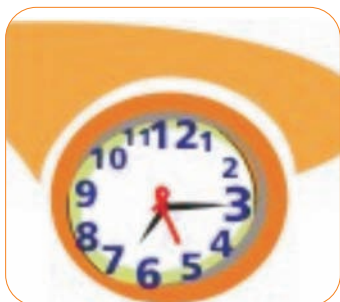
**Methods CBVs should use to treat pain with medication:**

#### a) By mouth (5 minutes)

When possible, CBVs should give pain medications orally (swallowed by the client themselves).

#### b) By the clock (10 minutes)

**By the Clock** means giving pain medications in the appropriate doses and at the appropriate times in an attempt to provide continuous relief of pain.



#### **Recommendations for CBVs to give pain killers 'by the clock':**

Pain killers should be given at fixed time intervals throughout the day, for example;

- Every 4 hours or once in the morning, afternoon and at bedtime
- Start with small doses and titrate (or change) dose according to the client's pain until the client is comfortable
- The next dose of analgesics should be given **BEFORE** the previous dose has worn off.

### c) By the individual (10 minutes)

Giving pain medication **by the individual** means giving each client medication according to his/her specific needs and ensuring that both clients and their families understand when and how pain medications should be taken.

#### Steps in treating pain by the individual:

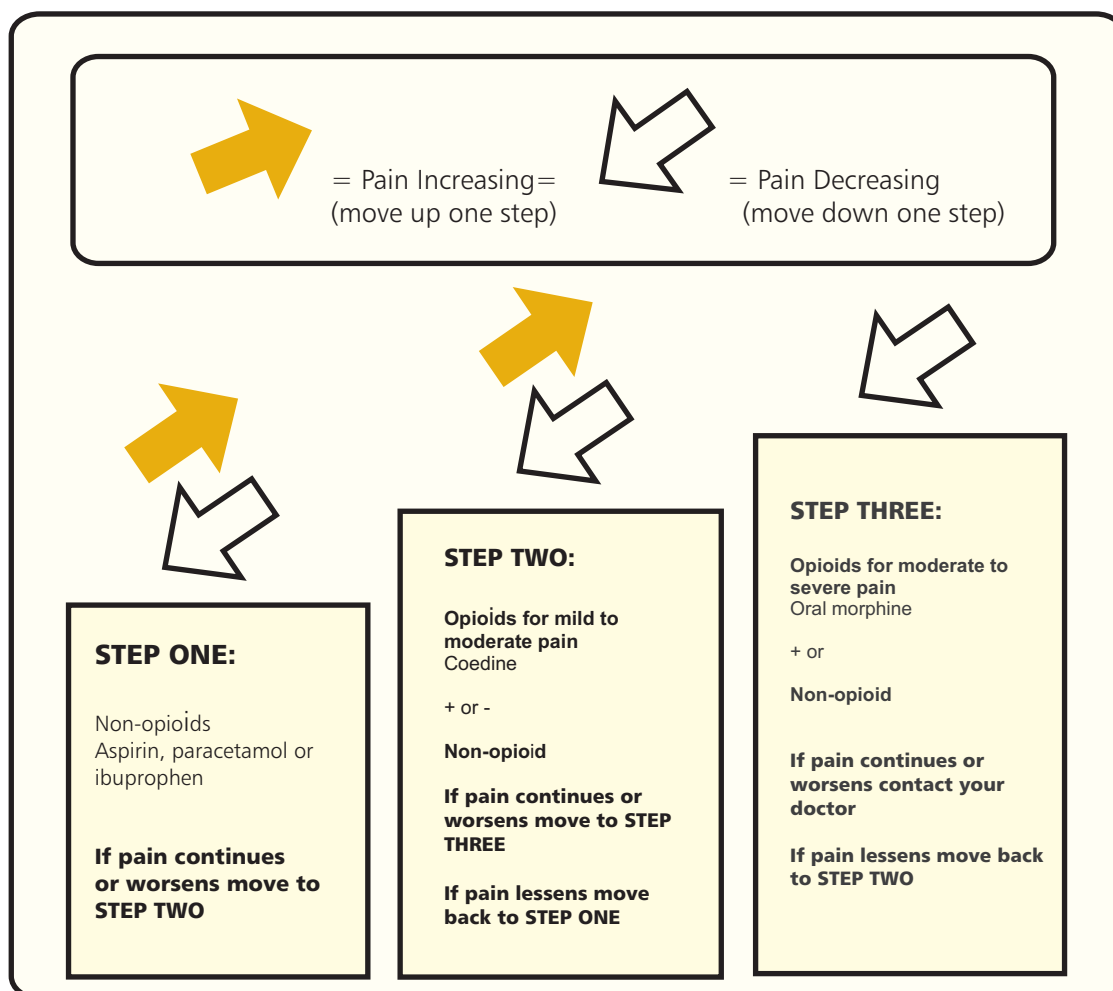
- Regularly grade the client's pain
- The first and last dose of analgesics each day should be linked to the waking and sleeping times of your client
- Write out the drug regimen for your client, and ensure that PLWHA and their families understand how and when to take medications
- Do your best to ensure that the client does not feel the pain and administer the drugs at a level that keeps your client as alert and active as possible.



### d) Giving Medication Using the Analgesic Ladder (1 hour with Tool 3 and 4)

The **Analgesic Ladder** is a tool developed by the World Health Organization (WHO) to help people determine when to increase and decrease pain medication and what kind of pain medication to give.

Distribute copies of the Analgesic Ladder from Handout 7-3. Review the ladder as a group to ensure that participants understand what each level means.





### Tool 3: Explaining the Analgesic Ladder to Client Households

**PART ONE:** As a group discuss the best way that the analgesic ladder can be explained to clients and family members in a way they will understand. Discuss how complex terms can be explained so that they remain accurate, but suit the knowledge levels of client households.

**PART TWO:** Once the group agrees on a suitable method for explaining the analgesic ladder to client households, divide participants into pairs. Have each pair role-play the explanation with one client playing the role of CBV and the other as client/family member.

**Facilitator's Note:** In assessing this core skill, facilitators should have participants conduct this role play. The ability of participants to explain the ladder in a way that will suit the knowledge level of client households should be used to determine success.

**Facilitator's Note:** Depending on the availability & legal use of oral morphine in your country, facilitators should provide information in the following section in line with country protocol.

Clients maybe be given morphine at the clinic/ hospital to manage severe pain related to their specific condition. It is important for CBVs to know how morphine should be taken at home. CBVs should **ONLY** help to support clients to take morphine as instructed by the health facility and **CANNOT CHANGE THE DOSE**.

### Tool 4: Teaching Clients and Families to Give Oral Morphine



Hand out copies of the 'Teaching Clients and their Families How to Give Morphine' Handout 7-2. Divide participants into pairs and have participants role-play how they would describe to a client and their family members how to provide morphine by reviewing each of the instructions on the handout. Ensure each participant has the opportunity to play the role of both CBV and client/family member in the role-play.

After role-plays discuss any areas in need of clarification by CBVs that will assist them to explain how to give oral morphine in a manner that both clients and family members will understand.

**Facilitator's Note:** The legal use and/or availability of oral morphine may depend on country protocols.

## Teaching PLWHA and their families how to give oral morphine:

Morphine is a very strong pain killer and CBVs should instruct PLWHA and their families on how to take it properly.

When to give oral morphine:

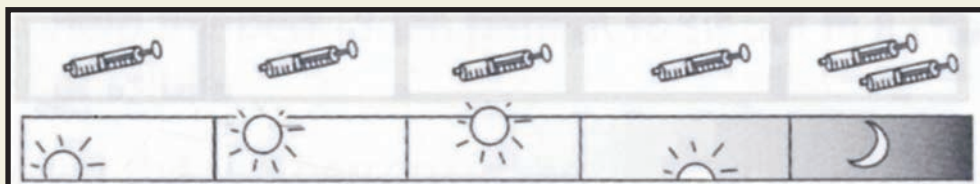
Oral morphine should be given to the sick person by the mouth at regular time intervals.



### How to give oral morphine:

- Pour a small amount of morphine into a clean cup. Using a syringe, draw up the correct amount of fluid for the prescribed dose (PLWHA and their families should be instructed on how to read the correct quantity)
- Drop the liquid from the syringe into the mouth
- Pour any remaining morphine in the cup back into the bottle
- Take doses every four hours during the day with a double dose at night.
- Give an extra, 'rescue dose' if pain comes back before the next dose.
- Do not suddenly stop giving the

client morphine.



### How to help manage side effects:

- **Nausea:** clients feel nausea during their first time to take morphine but this usually goes away after a few days
- **Constipation:** encourage the client to drink a lot of fluids, eat food rich in fibre (e.g. fruits, vegetables, porridge) and to take a tablespoon of vegetable oil before breakfast
- **Dry mouth:** give sips of water
- **Drowsiness:** clients will usually feel sleepy after taking morphine during the first few days and if this continues, inform the local health worker
- **Sweating or Muscle Jerks:** tell your CBV or local health worker.

### How to change dosages according to the level of pain:

- If the pain is getting worse, do not take it upon yourself to change the dose. Tell your local health worker who will help you to increase your dose.



## 5. Non-Medicinal Methods of Pain Control

### (30 minutes with Tool 5)

Non-medicinal methods of pain control involve ways to help clients cope with pain without, or in addition to, pain medications. Because everyone feels pain and deals with pain differently, the non-medicinal method that works for clients will be different with each client.

#### Non-medicinal ways that CBVs can help PLWHA with pain:

- **Emotional support** (listening to their clients worries, allowing him/her to discuss their pain, providing support and understanding)
- **Physical methods** (touch, ice or heat, deep breathing)
- **Cognitive methods** (distraction such as radio, music, relaxation techniques)
- **Prayer**
- **Massage**
- **Traditional practices**

#### Tool 5: Non-Medicinal Methods of Pain Relief



##### PART A: Non-Medicinal Methods of Pain Control In Your Community

Separate participants into two groups. Ask each group to list:

1. Non-medicinal methods of pain relief that CBVs feel they can assist clients with.
2. Identify any local customs or traditional practices that can be used to assist clients to cope with pain.

Discuss group answers and create a master list of non-medicinal methods of pain relief that are appropriate in your community, eliminating any inaccurate methods suggested or potentially harmful myths regarding pain relief.

##### PART B: Explaining the Importance of Non-Medicinal Pain Relief to Clients and Families.

Once the master list has been created, have participants role play how they would describe to clients and their families the importance of non-medicinal methods of pain relief. Ensure that each role play provides specific methods of non-medicinal pain relief using items from the list and dispelling potentially harmful myths.

## 6. Children and Pain

### Special considerations in assessing and controlling pain in children

- Children need adults to recognise and respond to their pain. They often do not complain.
- **Brief pain**—crying and distressed facial expression.
- **Persistent pain**—also look for behavioural signs of pain:
  - Irritability
  - not wanting to move
  - lack of interest
  - decreased ability to concentrate
  - sleeping problems
  - changes in how the child moves
  - restlessness
  - increased breathing rate or heart rate
- Differentiate pain from anxiety.
- Parents may under- or over-estimate pain in their child
- The child's judgment of pain control should be valued.
- Older child can grade pain by number of fingers or pointing on a ruler or faces (smiling or frowning):
- Never lie about painful procedures.
- Use cognitive methods to help relieve pain:
  - Age-appropriate active distraction.
  - Older child can concentrate on game, conversation or special story.
  - Music.
- Other non-drug methods:
  - Swaddling, carrying infant, warmth, breastfeeding, feeding.
  - Stroking, rocking, massage.
  - Avoid intramuscular injections in pain control.

### Special Considerations In Palliative Care - Children Pain Indications Dosing For Children

	<b>Paracetamol</b> Give Every 4 to 6 hours 100m tablet	<b>Codeine</b> Give Every 4 hours 30mg tablet	<b>Oral morphine</b> 0.15 - 0.3 mg/kg SEE P5 5mg/5ml
<b>2 months up to 4 months (4-&lt;6 kg)</b>		<b>1/4</b>	0.5 ml Dose Reduced In Infants < 6 Months)
<b>4 months up to 12 months (6-&lt;10 kg)</b>	<b>1</b>	<b>1/4</b>	<b>2ml</b>
<b>12 months up to 2 months (10-&lt;12 kg)</b>	<b>1 ½</b>	<b>½</b>	<b>3ml</b>
<b>2 years up to 3 years (12-&lt;14 kg)</b>	<b>2</b>	<b>½</b>	<b>4ml</b>
<b>3 years up to 5 years (14-&lt;19 kg)</b>	<b>½</b>	<b>3/4</b>	<b>5ml</b>
<b>6 years up to 8 years (19-29)</b>	<b>3</b>	<b>1</b>	<b>6ml</b>
<b>8 years up to 10 years (29-35 kg)</b>	<b>4</b>	<b>1</b>	<b>8ml</b>

# 3 Session Three: Preventing Discomfort Before It Begins

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**Purpose:** The purpose of Session Three is to provide participants with skills and knowledge on methods of preventive care for home-based clients.

**Objectives:**

By the end of this session, CBVs should be able to:

1. Demonstrate the ability to provide clients and their families with accurate information on Universal Precautions.
2. Provide clients and family care providers with the necessary knowledge and skills to provide preventive care

**Duration:** 3 hours 30 minutes

**Required Materials:** Flipchart, markers

**Recommended Preparation:**

- Make copies of Handout 7-4, Universal Precautions, for distribution in section one.
- Make copies of 'Exercises to Help Prevent Pain and Stiffness' and 'Moving the Bedridden Client' in Handout 7-5 and 7-6 to distribute to CBVs during Tool 8: Practical Demonstrations.

<b>Objective</b>	<b>Content</b>	<b>Time</b>	<b>Methodology</b>
Demonstrate the ability to provide clients and their families with accurate information on Universal Precautions.	1. Universal precautions	30 minutes	Mini Lecture  Tool One (ST): Group Role Play and Discussion  Tool Two (K): Group Discussion
Provide clients and family care providers with the necessary knowledge and skills to provide preventive care	2. Preventing discomfort Before It begins	3 hours	Mini Lectures  Tool Three (ST): Group Role Play *Mouth Care  Tool Four (ST): Role Play *Bed Sores  Tool Five: PART A (PS): Group Activity PART B (ST): Role Play *Bathing and Toileting  Tool Six (ST): Role Play *Bathing and Toileting  Tool Seven (K): Demonstration *ROM  Tool Eight (ST) Practical Demonstration *Exercises to Prevent Pain and Stiffness and Moving Bedridden Clients

Before discussing methods of care in the next two sessions, it is important that participants have a good understanding of what Universal precautions are and how they should be explained to clients and their families.

## 1. Universal Precautions (50 minutes)

### a) What are Universal Precautions? (30 minutes with Tool 1)

**Universal precautions** are simple infection control procedures that reduce the risk of transmitting **infectious agents** through exposure to blood, body fluids **and contaminated medical or other type of equipment** among clients, family members and health care workers. CBVs should take universal precautions with ALL care clients, whether you know if they are HIV positive or not. Universal precautions are meant to not only protect CBVs and family members, but also clients from unnecessary infection.

Distribute Handout 7-4, 'Universal Precautions' and review each precaution as a group.

Reassure the caregivers that there is an extremely low risk of getting HIV/AIDS through caring activities if the following universal precautions are taken:

- Wash hands with soap and water before and after caring
- Wear gloves when contacting blood or body fluids.
- Keep wounds covered (both those of the caregiver and the client).
- Clean up blood, feces, urine with ordinary household bleach.
- Clean cutlery, linen, bath, etc. with ordinary washing products.
- Keep clothing and sheets stained with blood, diarrhoea or other body fluids separate from other household laundry.
- Use a piece of plastic or paper, gloves or a big leaf to handle soiled items.
- Do not share toothbrushes, razors, needles or other sharp instruments that pierce the skin.
- Properly disinfect tools used for caring such as razors, needles and spit jars
- Wash your hands with soap and water after changing soiled bed sheets and clothing and after any contact with body fluids.

All caregivers should use universal precautions, while maintaining the dignity of clients. Universal precautions should not be used to make PLWHA feel bad (for example, wearing masks and gloves during caring activities where there is no chance of blood or fluid contact). Universal precautions are not needed with casual household contact, or when bathing if neither the client nor caregiver has wounds.





## Tool 1: Educating Clients and Families on Universal Precautions

It is important that CBVs are able to clearly explain the purpose of universal precautions and methods that should be used.

Divide participants into three groups:

1. Purpose of universal precautions.
2. Methods of taking universal precautions.
3. When universal precautions are not required.

Have each group give a presentation of key information that should be provided to clients and their families related to each topic.

**Facilitator's Note:** Ensure that presentations capture that universal precautions are not only meant to protect caregivers, but also to protect clients from infection. Participants should highlight that universal precautions should not be used as a tool for further stigmatizing PLWHA.

In testing this core skill, have participants provide a demonstration on how they would cover each point with their clients and family members.

## b) What should caregivers do if they think they have been exposed to HIV infection? (20 minutes with Tool 2)

As discussed in Module Two: Treatment Literacy, **Post-Exposure Prophylaxis** or **PEP** refers to a method of preventing the uptake of HIV after being exposed to transmission by blood or fluid contact with an HIV infected person or suspect by taking ARVs. For PEP ARVs should be taken within 72 hours from the time of exposure to HIV infection.

While PEP often refers to a specific medication taken by people who think they have been exposed to HIV, there are other precautions CBVs can take in cases of exposure before taking PEP drugs or if PEP is unavailable.

**Caregivers who think they have been exposed to HIV during caring activities should:**

- Immediately wash with soap and water any wound or skin site in contact with infected blood or fluid then wash out with saline or mild disinfectant
- Rinse eyes or exposed mucous membrane thoroughly with clear water or saline
- Report immediately to hospital or clinic in charge of PEP and follow local PEP protocol.

## Tool 2: Availability of PEP in Your Community



As a group discuss the availability of PEP in your setting.

**If available:** Discuss where CBVs can access PEP and any national protocols.

**If unavailable:** Discuss the importance of universal precautions in preventing exposure to HIV infection.

## 2. Preventing Discomfort Before It Begins (3 hours)

Now that we have discussed the universal precautions that caregivers and their clients can take to reduce the risk of infection during caring activities, we will now discuss real ways in which caregivers can help clients to prevent discomfort.

As stated in the last session, the main goal of palliative care is to provide support and care that makes life comfortable for clients through all stages of illness so they can live as fully and comfortably as possible. Preventing discomfort before it begins, or '**preventive care**,' is a major way in which CBVs can assist with the comfort and health of PLWHA.

**Facilitator's Note:** Facilitators should explain to participants that depending on which stage of illness a client is in, they may experience more, or none of the symptoms listed in this section. For example, PLWHA in the 'self-care' stage of palliative care on ART should not need assistance with bedsores. PLWHA in the 'assisted care' stage of palliative care, particularly requiring end-of-life care will need assistance with the preventive methods discussed. Facilitator's are encouraged to have participants identify which clients are likely to need the following care (i.e., those in end of life care), and which will not (i.e., those adhering to ART).

### a) Mouth Care (20 minutes with Tool 3)

**Mouth care** involves ensuring the proper cleaning of the mouth (teeth and gums) to prevent infection and decay.

**Ways in which CBVs can assist and instruct clients in mouth care:**

- Use a soft toothbrush to brush the teeth, tongue, roof of mouth (or palate) and gums in order to remove bits of food that could cause infection if left in the mouth
- Use diluted baking soda (called sodium bicarbonate) or toothpaste to brush teeth
- Rinse mouth with diluted salty water after eating and before bed (approximately 3-4 times daily)
- If the client has oral thrush in his/her mouth, do not try to remove the white coating, but refer the client to a local clinic for treatment.

#### Tool 3: Describing Mouth Care to Clients and their Families

Write each of the 4 methods of mouth care above on slips of paper. Ask for four volunteers to draw a slip of paper and provide a demonstration on how they would explain this aspect of mouth care to clients and family members with the facilitator acting as the client/family member.

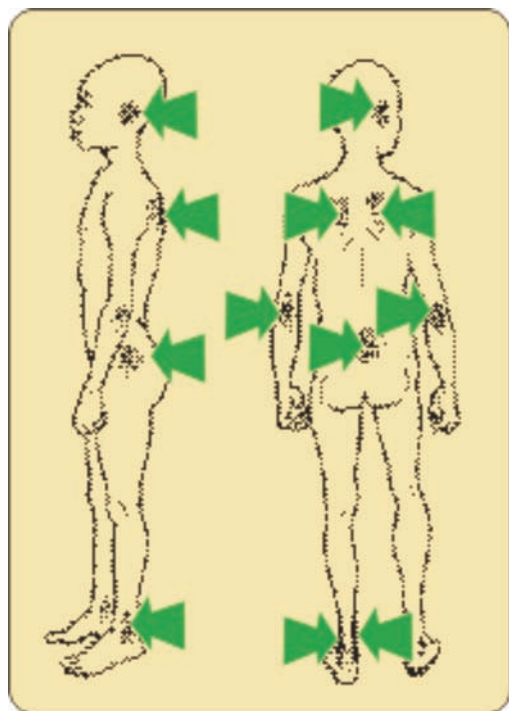
**Facilitator's Note:** Each presentation should ensure that CBVs encourage not only the client, but family members providing daily care to be present for the explanation.



## b) Bedsores (30 minutes with Tool 4)

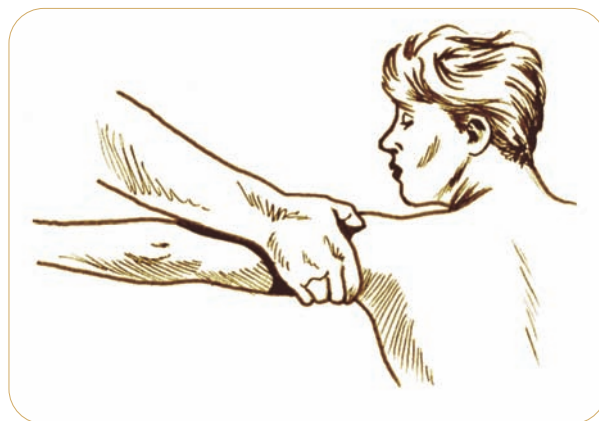
### Typical areas where bedsores are formed in bedridden clients:

**Bedsores**, or pressure sores, are wounds of the skin that can result from lying in one position for too long. Most frequently developed by bedridden clients, bedsores result from constant pressure on a particular part of the body. It is much better to prevent rather than treat bedsores.



### Ways in which caregivers can help prevent bedsores in bedridden clients:

- If the client can manage it, help him/her to sit up in a chair as often as possible
  - If moving a client, ALWAYS lift him/her up from the bed. Dragging a client to move him/her can break the skin and cause infection
  - Encourage clients to move themselves (turn over, sit up, shift pressure on legs, head, elbows and back) if they are able to
  - Help the client into a different position on the bed every one or two hours if possible. Use pillows or cushions to keep the bedridden client in this different position if he/her is unable to move himself/herself
  - Always teach a client's family how to move the client safely
  - Look for damaged skin on the back, shoulders and hips of bed ridden clients every day.
- If the skin looks a different colour, try to avoid the client placing pressure on these areas when he/she is lying down
  - Place extra soft materials such as soft cotton towels, pillows, newspapers, old sheets or blankets under the client.
  - If a client can be helped to exercise, He/she will be less likely to develop bedsores
  - Expose damaged skin to air and sunlight
  - Remove all weight (blankets) from damaged skin
  - Keep affected areas clean and dry
  - Keep the bed linen clean and dry.



### Tool 4: Teaching Client Families How to Prevent Bedsores

As CBVs will not be in client homes every day to assist bedridden clients to prevent bedsores, it is critical that CBVs provide this information to family members or others who provide the daily care for their clients.

Divide participants into pairs and have each pair role-play how they would describe methods to prevent bed sores to primary caregivers.

Ensure that each role-play includes each aspect of preventing bedsores described above. If it will assist participants to remember, encourage them to make a list of important points to carry with them to client households.



## c) Bathing and Toileting (40 minutes with Tool 5 and 6)

Losing the ability to bath or take yourself to the toilet can be very frustrating and stressful for people when they become sick. Bathing and helping people to the toilet that may not be able to do it themselves can be a very sensitive issue.

The dignity of clients who can no longer bath themselves should be respected at all times. Bathing is not only important for keeping away infection and illness but it makes people 'feel good about themselves'. CBVs should help ensure that daily carers have the appropriate information to ensure that their clients are as comfortable as possible during bathing and toileting activities.



### Tool 5 : Special Issues Around Bathing and Toileting

**PART A:** Provide each participant with a card and ask them to write down a special issue in your culture or community that may affect the ability of caregivers to conduct bathing and toileting activities.

Next ask participants to stick their cards on a wall and cluster answers according to major themes.

For example:

- **Gender issues** (male caregivers bathing female clients and vice versa)
- **Living Conditions** (availability of clean water, crowded households, or distance to facilities that may make regular bathing or toileting difficult)

Discuss each issue raised and brainstorm ways that each community specific problems could be dealt with that maximises the dignity and comfort of clients.

**PART B:** Divide participants into pairs and have them role-play discussing special issues around bathing and toileting in your community that could affect the dignity of clients.

**Facilitator's Note:** Participants playing the role of CBV should emphasise methods developed to overcome these challenges developed in Part A.

#### Ways in which caregivers can assist with bathing include:

- Helping to ensure as much privacy as possible for the client during bathing
- Only expose the area being bathed and keep the client warm (close windows to avoid drafts)
- After bathing, dry the skin of the client with a soft towel
- Take special care to dry under skin folds (i.e., armpits, between buttocks, behind knees and elbows)
- After drying skin, oil it with cream, body oil, lanolin or vegetable oil.

#### Ways in which caregivers can assist with toileting include:

- Use plastic sheets under bed linens to keep the bed dry if the client has lost the ability to control his/her urine or bowels
- Also, protect skin with petroleum jelly around private parts, back, hips, ankles and elbows if the client has lost the ability to control his/her urine or bowels
- Help the client support himself/herself over the bedpan or container used for going to the toilet to avoid wetting the bed or causing injury.



### Tool 6: Imparting Information on Bathing and Toileting

Divide participants into pairs. Have each pair role-play providing the clients primary caregiver (the client who provides daily care) with information on how to bath and assist clients with the toilet.

**Facilitator's Note:** Ensure that each role-play includes each aspect of information provided under the appropriate heading above. Encourage the participant playing the role of the primary caregiver to ask questions that might be raised by the primary caregiver.

## Tool 6: Imparting Information on Bathing and Toileting



Divide participants into pairs. Have each pair role-play providing the clients primary caregiver (the client who provides daily care) with information on how to bath and assist clients with the toilet.

**Facilitator's Note:** Ensure that each role-play includes each aspect of information provided under the appropriate heading above. Encourage the participant playing the role of the primary caregiver to ask questions that might be raised by the primary caregiver.

### d) Pain and Stiffness in Muscles and Joints (40 minutes with Tool 7)

When people are bedridden, they can begin to experience pain and stiffness in their muscles and joints. This can become very uncomfortable and limit the client's **range of motion (ROM)** and his/her ability to move their joints freely and without pain.

#### 7 key joints involved in Range of Motion

- |              |           |          |           |
|--------------|-----------|----------|-----------|
| 1) Wrists    | 2) Elbows | 3) Knees | 4) Ankles |
| 5) Shoulders | 6) Hips   | 7) Neck  |           |

#### Ways that caregivers can assist in the prevention of pain and stiffness in the muscles and joints

- Encourage clients who have some ability to move in order to conduct exercises themselves
- If your client is unable to move himself/herself, do range of motion exercises with him/her (and teach caregivers within the family how to conduct exercises):
  - Exercise limbs and joints on each side of the body at least once a day
  - Protect joints during exercise by holding the limb above and below it (for example, if exercising the shoulder, hold the arm and underneath the arm)
  - Bend, straighten and move joints as far as they will go without placing pressure on them. Be gentle and move slowly, allowing your client to guide you
  - Stretch joints by holding above and below the joint with firm steady pressure
  - Encourage your client to do each exercise as far as he/she is able to and assist him/her the rest of the way
  - Massage joints and muscles.



## Tool 7: Identifying 7 Key Joints in ROM

Ask for a volunteer from the group to stand at the front of the room.

Choose one volunteer at a time to go up to the front of the room and demonstrate the range of motion on one of each of the seven key joints involved in ROM.

As each CBV demonstrates a correct joint included in ROM, write the name of that joint(s) on a flipchart entitled, "7 Key Joints in ROM".

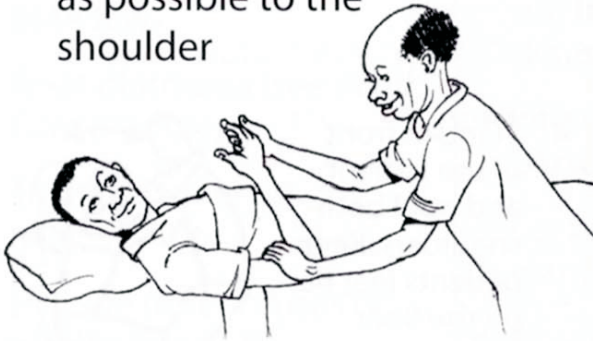
**Facilitator's Note:** CBVs should be encouraged to re-enact this exercise with clients and their daily carers during a home visit.

\*CBVs should be aware that stiffness in the neck can be a sign of serious illness (meningitis). If a client is experiencing a very stiff neck, he/she should be referred to a doctor immediately.

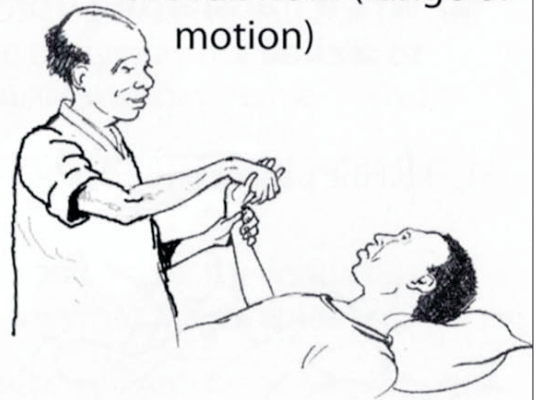


## Exercises to help prevent pain and stiffness

Exercise the elbow by gently bringing the hand as close as possible to the shoulder



Exercise the wrist doing the full ROM (range of motion)



Exercise the shoulder by lifting the arm up and bringing it behind the head and laterally as far as possible



Exercise the knee by lifting the thigh up and bringing it close to the chest and laterally as far as possible





## e) Moving Bedridden Clients (40 minutes with Tool 8)

### Instructions for CBVs and other caregivers to move bedridden clients:

Moving bedridden clients is an important way to prevent the formation of bedsores, and injury of clients who require assistance.

## Moving the Bedridden Patient

The following instructions are for a single caregiver. If the client is unconscious or unable to cooperate, it is better to have two people help with the moving.

### • When transferring from the bed to a chair:

1. Roll the client on one side



2. move the client to the side of the bed. Ask the client to bend legs and to prop on the same side elbow



3. Hold your hands on the client's pelvis, ask to raise him/her buttocks. Sit client on the edge of the bed with feet flat on the floor



4. Stand in front of the client and hold both shoulders. Keep client's feet flat on the floor



5. Help client raise bottom from the bed and rotate him/her towards the chair



6. Transfer from bed to chair. Hold client by shoulders and knees



*Remember that if you lose your balance, it is better to help the client fall gently rather than hurting yourself.*

## Tool 8: Practical Demonstrations and Skills Transfer



**PART ONE:** Distribute copies of 'Exercises to Help Prevent Pain and Stiffness' in Handout 7-5 and 'Moving the Bedridden Client' in Handout 7-6. Review each handout with participants.

**PART TWO:** Divide participants into groups of three for the following role play:  
 One group member as CBV;  
 One group member as client;  
 One group member as client's daily caregiver

Have each group role play how they would teach the daily caregivers of clients each skill through a demonstration. Ensure each group member has the opportunity to play the role of CBV and correct any methods that may hurt or injure the client.

# 4 Session Four: Management of Symptoms in PLWHA

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**Purpose:** The purpose of Session Four is to provide CBVs with knowledge and skills to help manage symptoms in PLWHA.

**Objectives:**

By the end of this session, CBVs should be able to:

1. Discuss how ART interventions might change symptoms experienced by clients living with HIV or AIDS.
2. Demonstrate to primary caregivers how to manage symptoms in clients by providing information on how caregivers can help, local remedies for symptom management and knowledge on when to contact a health professional.

**Duration:** 3 hours

**Required Materials:** Flipchart, markers.

**Recommended Preparation:**

- If they have not already received them through work in other modules, make copies of the 'Managing Symptoms in PLWHA' Handout 2-3. Distribute the handout in Tool 2 of this session and review together with CBVs.

Objective	Content	Time	Methodology
	1. What are the symptoms of HIV and AIDS?	15 minutes	Mini Lecture
Discuss how ART interventions might change symptoms experienced by clients living with HIV or AIDS	2. How will ART interventions change symptoms in PLWHA?	25 minutes	Mini Lecture  Too I One (K): Group Discussion
Demonstrate to primary caregivers how to manage symptoms in clients by providing information on how caregivers can help, local remedies for symptom management and knowledge on when to contact a health professional.	3. Management of Key Symptoms	2 hours 20 minutes	Mini Lectures  Tool Two (ST): Role Plays

## 1. What are the symptoms of HIV and AIDS? (15 minutes)

The symptoms of HIV and AIDS can be different for each client, depending on what stage of illness he/she is in, or what opportunistic infections he/she may have at any point in time. There are no 'symptoms of HIV and AIDS' that apply to all PLWHA, all of the time.

Because symptoms are never the same, and can change over time, CBVs should be aware of the various kinds of ailments PLWHA can suffer from and how to assist their clients in the relief of these symptoms.

### Signs and Symptoms of HIV and AIDS:

- General Weight Loss
- Nausea and Vomiting
- Mouth Ulcers or Pain Swallowing
- Dry Mouth
- Constipation
- Incontinence of Urine or Stool
- Rectal Tenderness
- Diarrhoea
- Anxiety and Worries
- Trouble Sleeping
- Confusion (dementia or delirium) Depression
- Itching
- Bedsores
- Cough or difficult breathing
- Fever
- Hiccups.



## 2. How will ART Interventions Change Symptoms in PLWHA? (25 minutes with Tool 1)

**Antiretroviral Therapy (ART)** will affect the symptoms of HIV and AIDS felt by PLWHA. Because ARVs will help to strengthen the immune system, PLWHA should experience fewer symptoms of HIV while on ARVs. OIs should reduce if PLWHA are adhering to their ART regimen, which means the symptoms of HIV and AIDS should also reduce.

As discussed in Modules 2 (Treatment Literacy), 3 (Treatment Preparation) and 4 (Adherence), taking ARVs will also produce side effects in PLWHA. CBVs should know how to help PLWHA cope with side effects of taking ARVs.

### Tool 1: ART and Managing Symptoms

As a group, discuss how ART intervention in your community may change some of the symptoms of HIV and AIDS experienced by clients.

Discuss how managing symptoms of HIV and AIDS are an important way that carers can provide good palliative care and improve the quality of life of PLWHA.



### 3. Management of Key Symptoms (2 hours 20 minutes)

Helping clients and their families with methods of managing symptoms is one of the best ways CBVs can help PLWHA and their families. The suggestions in this section are not only meant to help CBVs better care for PLWHA, but are for CBVs to share with the **primary caregivers** of their clients. Primary caregivers include the friends, family or neighbours that do most of the day-to-day caring for PLWHA.

CBVs will notice that many of the ways they can help their clients manage symptoms have been discussed in other modules. For information on communication skills when providing information to clients and family members refer to Module 5: Counselling. For information on how nutrition can help to manage symptoms, refer to Module 6: Nutrition. Highlight that over viewing these topics will help CBVs to remember each technique and take them a step further in becoming 'community experts' in the care of clients



#### Tool 2 : Managing Symptoms Handout.

**PART ONE:** If participants have not already received it through work done on Modules 2: Treatment Literacy or Module 6: Nutrition, distribute copies of the 'Symptom Management' Handout located in Handout 2-3. As you review each of the symptoms and ways that carers can help clients to manage each symptom, engage participants in a role play of how they will explain the methods to the primary caregivers of their clients.

**PART TWO:** As you review each section in the handout, have participants fill in the space provided for local remedies for each symptom if applicable.

**Facilitator's Note:** In the assessment of this core skill, choose 5 symptoms from this section and ask participants to demonstrate how they would explain each method of symptom management to clients and their primary caregivers.

It is important to note that when describing the methods of symptom management to primary caregivers, terms such as “the client” or “PLWHA” should be replaced with your client's name. The terms used in the handout are for CBVs because they can apply to a number of different clients, male and female. Through transfer of knowledge to the primary caregiver, CBVs should make this information more personal and focus on the individual and not “the client”.

#### a) Weight Loss (10 minutes)

When the body needs extra energy to fight infection and it is not receiving enough nutrients, it will use stored fat. If a person has used all his/her fat stores, the body will then use protein stores in the form of muscle to get energy.

Weight loss is a common problem with PLWHA and can happen without a person being aware of it. Because infections increase the body's need for energy, early treatment of infections is an important way to avoid weight loss in PLWHA.

#### Ways caregivers can help:

- Avoid cooking close to the client as the smell may make nausea worse
- Provide frequent, nutritious meals of food the client likes
- Make food appetising to the client

- Let the client choose the food he/she would like to eat from what is available
- Do not force-feed the client
- Understand and accept that as the client becomes more sick he/she will eat less.

**Consult a medical professional if:**

- You notice rapid weight loss in the client
- If the client consistently refuses to eat
- The client is not able to swallow
- Severe weight loss can mean a progression of HIV.

**b) Nausea and Vomiting (10 minutes)**

**Nausea** is feeling like you want to vomit and can occur in PLWHA due to infection, eating bad food, stress, not drinking enough water or side-effects of ARVs and other medications. Nausea also reduces appetite and can therefore reduce the food intake of PLWHA.

**Ways caregivers can help:**

- Sit up straight when eating and try not to lie down until one or two hours after eating
- Eat small and frequent meals
- Drink plenty of fluids after meals
- Ask someone else to cook for you as the smell of food cooking may make nausea worse
- Eat dry and lightly salty foods such as crackers, toast or popcorn to calm the stomach
- The smell of fresh orange or lemon peel may relieve nausea. Squeeze the peel or drink lemon juice in hot water.
- Avoid foods that make nausea worse such as fatty and sweet food, or alcohol.
- After vomiting, slowly drink half a glass of water, diluted soup or diluted fruit juice. Take sips every 15 minutes until the glass is finished.

**Facilitator's Note:** Remind participants that vomiting and nausea can be side effects of medications. CBVs should be aware of potential side effects to ARVs that clients are taking that may explain why clients feel nauseous.

**Local Remedies:**

- discuss

**Consult a medical professional if:**

- Vomiting lasts for more than one day
- The client has a dry tongue
- The client is passing little urine or has abdominal pain
- The client vomits after every meal
- The client vomits blood

**c) Lack of Appetite**

Not feeling hungry is one of the most common problems in PLWHA. Even though their bodies require more nutrients, PLWHA may always feel full. It is very important that PLWHA continue to eat, even if they do not feel hungry.

**Changes in Taste**

A common side effect of ARVs is a change in taste (either a loss of taste or abnormal taste in the mouth). Changes in taste can cause a lack of appetite.



#### **d) Dry Mouth (5 minutes)**

##### **Ways CBVs can help:**

- Give the client frequent sips of water
- Moisten his/her mouth frequently with water
- Give the client fruit such as pineapple, orange or passion fruit (or other locally available fruit) to suck on.

##### **Consult a medical professional if:**

- Dry mouth persists.

#### **e) Constipation (10 minutes)**

##### **Ways caregivers can help:**

- Encourage drinking fluids often
- Encourage eating high-fibre foods such as fruits, vegetables, porridge or other locally available foods
- Use local herbal treatments
- Take a teaspoon of vegetable oil before breakfast
- If stool is impacted, wearing gloves, gently put petroleum jelly or soapy water into the rectum. Encourage the client to do this for him/herself if they are able
- Encourage clients to take a stool softener.

##### **Consult a medical professional if:**

- No stool is passed in 5 days
- If the client is feeling pain.
- Constipation is accompanied by vomiting

#### **f) Incontinence of Urine (5 minutes)**

##### **Ways caregivers can help:**

- Change cloth pads regularly
- Keep the client dry
- Protect skin with petroleum jelly.

**Facilitator's Note:** Remember to conduct role-plays of imparting this information to primary caregivers of clients as indicated in Tool Two.

#### **g) Rectal Tenderness (5 minutes)**

##### **Ways caregivers can help:**

- After the client has passed stool, clean the anus with toilet paper or soft tissue paper
- Wash the anal area 3 times a day with soap and water
- Apply petroleum jelly around the anal area if the client feels pain when passing stool
- If the client is comfortable to do so, encourage him/her to sit in a basin of water with a pinch of salt twice daily.

**Facilitator's Note:** Remember to conduct role-plays of imparting this information to primary caregivers of clients as indicated in Tool Two.

#### **h) Mouth Ulcers or Pain on Swallowing (10 minutes)**

##### **Ways caregivers can help:**

##### **Treatment:**

- Maintain good mouth care by removing bits of food stuck in the mouth with a soft toothbrush, some cotton wool or gauze, or soft cloth soaked in salt water

- Brush the teeth, gums, roof of mouth (palate) and gums regularly to prevent build up of food debris
- Rinse the mouth with diluted salt water after eating and at bedtime
- If available, mix 2 tablets of aspirin in water and rinse out the mouth up to 4 times a day.

#### **Diet:**

- Eat a diet of soft foods such as yoghurt or other locally available foods to decrease discomfort while eating
- Textured foods and fluids may be swallowed more easily
- Avoid extremely hot, cold or spicy foods.

#### **Consult a medical professional if:**

- Client is suffering from mouth sores that will not heal
- If mouth sores are bleeding
- Client has white patches inside of their mouth (thrush)
- Client has difficulty swallowing.

### **i) Depression (5 minutes)**

#### **Ways caregivers can help:**

- Provide support to the client by listening, empathising and caring about his/her problems
- Do not leave the client alone if he/she is at risk of committing suicide.

#### **Consult a medical professional if:**

- The client is planning or has attempted suicide
- The client is abnormally sad, cannot sleep or has lost interest in living

### **j) Itching (10 minutes)**

#### **Ways caregivers can help:**

- Apply petroleum jelly, aqueous cream or petroleum jelly mixed with water to the itching part of the body
- Put one tablespoon of vegetable oil in 5 litres of water and wash the client's body
- After bathing, apply one teaspoon of chlorhexidine (antiseptic such as Dettol) to one litre of water and apply to itching area
- Use warm water for bathing.

#### **Consult a medical professional if:**

- The client develops painful blisters
- The client develops a spreading skin infection.

### **k) Bedsores (10 minutes)**

#### **Ways CBVs can help:**

- Prevent formation of bedsores using the preventative care methods discussed in Session Three
- Gently clean small sores with salty water and allow to dry
- If bedsores are not deep, leave them in the open air to dry
- If bedsores are painful, provide pain medications such as aspirin or paracetamol
- If bedsores are deep, clean every day with salty water, fill the bedsore with pure honey (or other appropriate local remedies) and cover with a clean, light dressing to encourage healing.

## Special considerations for skin care in children.

### **Skin care.**

- They are prone to rashes, some of which are itchy. Clean and cover moist areas with a dressing, or expose and apply GV solution if there are not too many flies around.
- Keep finger nails short and clean to help reduce scratched areas from getting infected.
- Give an antihistamine for sleep at night if sleep is disturbed by scratching.
- Sometimes an oil-based cream or a short course of a weak steroid cream is helpful.

### **Nappy area.**

- Diarrhoea may cause a nappy rash or sores near the anus.
- Encourage careful washing with soap and clean water, and the application of a protective ointment (eg vaseline).
- Avoid the constant use of plastic pants over nappies.
- Change wet pants or nappies often.

### **Consult a medical professional if:**

- The client's skin becomes discoloured
- The bedsores keep getting worse.

## **l) Cough or Difficult Breathing (10 minutes)**

### **Ways caregivers can help a 'simple cough' (not TB or bronchial):**

- Use locally available remedies to soothe and open up airways including putting lemon, honey or Eucalyptus leaves in boiling water and breathing in the steam
- Help the client sit in the most comfortable position that helps him/her breathe
- Use extra pillows or back support to help client sit up comfortably
- Open windows to allow fresh air into the room
- Fan the client with a newspaper or clean cloth
- Give the client water frequently as it helps loosen sputum

### **How to help clients collect and dispose of sputum:**

- Encourage client to collect sputum in a empty tin with ash for spitting and keep it covered
- When emptying or moving tin with sputum, handle it with care to avoid spreading infection
- Empty tin in a toilet or pit latrine and wash with detergent or bleach or clean the tin with boiled water.

### **Consult a medical professional:**

- If the client has a 'productive cough' (wet cough with sputum) for more than 2 weeks, that may be tuberculosis and the client should consult a doctor as soon as possible
- Arrange with health workers to send 3 sputum samples to be tested for TB.

**Facilitator's Note:** Remember to conduct role-plays of imparting this information to primary caregivers of clients as indicated in Tool Two.

## **m) Fever (10 minutes)**

### **Ways caregivers can help with a fever:**

- Encourage the client to drink plenty of fluid while they have a fever as they will lose a lot of water through sweating
- Wipe the client's body with a damp cloth or give them a cool bath to reduce the body temperature
- Encourage the client to wear only light clothes and not to use heavy blankets even if they feel cold

- Give the client aspirin, paracetamol or ibuprofen to help reduce the fever.

**Consult a medical professional if:**

- The client's fever does not improve or returns after treatment
- If the client has a cough, diarrhoea, severe pain, confusion, night sweats, stiff neck loses consciousness with their fever
- If the client is pregnant or has just given birth and has a fever.

**Facilitator's Note:** Conduct role-play of imparting this information to primary caregivers of clients as indicated in Tool One.

**n) Hiccups (5 minutes)**

**Ways caregivers can help hiccups:**

**1) Stimulating the throat:**

- Have the client quickly eat 2 heaped teaspoons of sugar
- Have the client drink cold water or eat crushed ice
- Rub the inside of the top of the mouth where it is soft with a clean cloth.

**2) Interrupting normal breathing:**

- Encourage the client to breathe into a paper bag or hold his/her breath (tell him/her to stop if they start feeling uncomfortable or dizzy)
- Help the client pull his/her knees to his/her chest and lean forward to compress the chest.

# 5 Session Five: End-of-Life Care

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**Purpose:** The purpose of Session Five is to discuss aspects of end-of-life care that will prepare CBVs to assist clients and their families with issues around death and dying.

**Objectives:**

By the end of this session, CBVs should be able to:

1. Demonstrate an ability to identify sensitive issues surrounding end of life care in their community and how to overcome these issues while respecting the wishes of clients.
2. Impart information to family members and/or primary caregivers on how they can help clients cope with feelings and emotions experienced during illness.
3. Discuss important aspects of preparing for the death of clients with family members.
4. Explain the signs of approaching death and signs of death to family members and/or primary caregivers of clients in an accurate and sensitive manner.
5. Assist bereaved family members to understand the possible emotional, physical and spiritual experiences after the death of a loved one through bereavement counselling.

**Duration:** 6 hours

This is a very demanding session on participants. Due to this, facilitators should reserve an entire day for the completion of session Five and begin training in the morning when participants are “fresh” to prevent overwhelming them.

**Required Materials:** Flipchart, markers.

**Recommended Preparation:**

- Obtain sample copies of local wills where possible and hand out to participants during Tool 6
- Make copies of Handout 7-7, Feelings and Emotions During Illness for distribution to participant at the beginning of section 2.
- Make copies of Handout 7-8, 'Rights of the Dying Client' for distribution to CBVs in Tool 7.
- Make copies of the table of possible experiences during grief Handout 7-9 for distribution in section 5.
- Copy out each of the case studies in Tool 3 for placement at skills stations.

Objective	Content	Time	Methodology
Demonstrate an ability to identify sensitive issues surrounding end of life care in their community and how to overcome these issues while respecting the wishes of clients.	1. What is End of Life Care?	40 minutes	Mini Lecture  Tool One (A): Self Reflection  Tool Two (K): Group Discussion
Impart information to family members and/or primary caregivers on how they can help clients cope with feelings and emotions experienced during illness	2. Feelings and Emotions of a Client During Illness	1 hour	Mini Lecture  Tool Three (ST): Group Role Play
Discuss important aspects of preparing for the death of clients with family members.	3. Preparing for Death	1 hour 30 minutes	Mini Lectures Tool Four (ST): Role Play Mini Lectures Tool Five (K): Group Discussion Tool Six (ST): PART A: Group Activity PART B: Role Play Tool Seven (ST): Role Play
Explain the signs of approaching death and signs of death to family members and/or primary caregivers of clients in an accurate and sensitive manner.	4. Signs of Death and Dying	1 hour 30 minutes	Tool Eight (ST): Matching Activity  Tool Nine (K): Group Discussion
Assist bereaved family members to understand the possible emotional, physical and spiritual experiences after the death of a loved one through bereavement counselling.	5. Bereavement Counselling	1 hour 30 minutes	Tool Ten (PS): Group Discussion  Tool Eleven (ST): Role Play  Tool Twelve (ST): Group Discussion and Role Play



# 1. What is End of Life Care? (40 minutes with Tool 1 and 2)

**End-of-Life Care** is helping a dying client and their family with the physical, emotional, social and spiritual support and comfort they need during the end stages of life. It involves ensuring the client's quality of life until the time of death.

## Tool 1: Helping Participants Express Emotions Surrounding End-of-Life



**PART A:** Divide participants into groups of three. All participants should sit in a small circle. Ask each participant to share their own feelings and attitudes surrounding end-of-life care. Participants can close their eyes or wear a blindfold if they feel it is easier to discuss their emotions this way.

Participants can reflect their own experiences of loss, memories and bereavement.

**Facilitator's Note:** During this exercise, facilitator's should not attempt to suppress the expression of emotions. Participants who express extreme coping difficulties should be referred to counselling.

This exercise has been done to demonstrate that each of us have personal experiences and emotions regarding end-of-life care. Participants should acknowledge how these emotions may affect the way they approach end-of-life care with clients.

End-of-life care centres on the belief that everyone has the right to be treated and to die with dignity. CBVs may find that the most important aspects of end-of-life care are different in each community or in each household they work in.

### Emotional and spiritual support involves:

- **Active listening**, counselling and support for the worries and wishes of dying clients
- **Spiritual support** of clients, allowing dying clients to discuss spiritual matters and helping them receive the spiritual support they are seeking
- **Understanding the process of anger and grief** in dying clients and their families
- **Not imposing your own beliefs** about death and dying onto clients, but allowing them to explore their own religious and spiritual wishes.

## Tool 2: End of Life Care in Your Community



Participants have had an opportunity to explore their own experiences and emotions surrounding end-of-life care through the activity in Tool One. Now, ask participants to discuss specific aspects of end of life care that may be important to clients in your community by answering the following questions:

1. What, if any, sensitive issues might CBVs be face with in end-of-life care in your community? (For example, religious beliefs, disclosure of HIV status, inheritance issues)
2. How do CBVs feel they should deal with these issues while respecting the wishes of their clients?

## 2. Feelings and Emotions of a Client during Illness (1 hour)

People who are sick and dying will respond to their illness in different ways. No one client will go through the same feelings and emotions as another.

For a CBV to effectively provide end-of-life care for clients, they must understand some of the feelings and emotions people experience throughout illness, particularly as they become seriously ill and acknowledge that they may be dying. Not all clients will experience each emotion, but it is important for CBVs to recognise these emotions if they are to respond effectively.

**Facilitator's Note:** The emotions of children can also be greatly affected by the illness of a parent or loved one. To review common emotional responses of children please refer to Session Four: Counselling Children Affected by HIV and AIDS of Module 5. If participants have already received training on this module, provide a reminder that in addition to clients, children may also need counselling support during illness and end-of-life care.

Distribute copies of Handout 7-7 Feelings and Emotions During Illness.

### a) Anticipatory Grief (5 minutes)

**Anticipatory Grief** involves grieving by both clients and their families that begins once they realise he/she has an incurable illness. Feelings associated with anticipatory grief may include anger, fear, anxiety, sadness or blame. These feelings are normal and are part of coming to terms with a situation, and preparing for the idea that illness may threaten their own life, or the life of a loved one.

### b) Depression (5 minutes)

**Depression** is a common term to describe feeling very sad or discouraged. Depression is a normal response to feeling sick or knowing that you are dying or that a loved one is very sick or dying.

Signs of depression that clients and their families may show include:

- Being short-tempered or irritable
- Losing interest in daily activities
- Sleep disturbances such as being unable to fall asleep or waking very early in the morning
- Withdrawing from friends and family
- Feelings of worthlessness
- Loss of appetite or weight loss
- Thinking about death constantly
- Crying easily
- Worrying a great deal or feeling very nervous about things that did not bother you before.



### **Ways caregivers can help PLWHA and their families with depression:**

- Do not tell people “you will be fine” or use other false sympathies to try and cheer them up, but allow the client to speak about their sadness and encourage him/her to talk about their feelings
- Do not try and stop clients or their families from crying. Tears can represent a positive way of coming to terms with the reality of illness and relieve stress.
- If clients are speaking of or planning suicide, refer them to a health professional immediately.

### **c) Anger (5 minutes)**

Clients may feel angry when they know they are going to die. HIV makes anger very complicated, as PLWHA may be very angry towards the person they think they contracted HIV from.

When people are angry they often 'take it out' on those that are in a caring or supportive role. This means that PLWHA could release their anger on their family, friends or CBVs.

### **Ways that caregivers can help clients cope with feelings of anger:**

- Encourage clients to express their anger safely (e.g. through exercise, by writing a journal, hitting a pillow)
- Do not take expressions of anger towards yourself personally
- Try to remain calm if clients or their family members become angry with you, do not get angry back, but speak to them in a calm and reassuring manner.

### **d) Fear (5 minutes)**

The thought of being sick or dying raises fear in most people. The types of fear felt by clients can include fear of physical symptoms, fear of losing control over their lives and their bodies, and fear of death.

People who are dying may experience the following fears:

- Fear of pain, choking, or suffocating
- Fear of not knowing what will happen when they die
- Fear of dying alone, without loved ones
- Fear of losing their bodily functions
- Fear of what will happen to the body and soul after death
- Fear of what will happen to their family members left behind
- Fear of what will happen to their possessions after they die.

### **Ways that caregivers can help people cope with fear:**

- Encourage clients to talk about their fears
- Help link clients to people or groups who can provide them with support (family, friends, support groups for PLWHA, churches, medical facilities)
- Encourage clients to talk with their families about what they would like to happen after their death (burial and funeral arrangements, inheritance and custody issues)
- Help provide clients with spiritual support they desire (do not push your own beliefs upon clients)
- Allow clients to speak about fears they have in their own time, do not force topics that client's may not feel comfortable speaking about.

## e) Losses (40 minutes with Tool 3)

Clients may become concerned with the losses involved from death or illness.

### Common losses that PLWHA may feel are:

- Loss of job or income
- Loss of looks (for example, from weight loss)
- Loss of good health (the ability to play sport, be active, have a healthy sex life)
- Loss of love (fear of rejection)
- Loss of their position in the family (as mother, father or husband)
- Loss of position in the community (as a community or church leader, teacher...etc)
- Loss of control of life (not being involved in choices made about their health)
- Loss of the future (not being able to have children, watch children or grandchildren grow).



### Ways caregivers can help with feelings of loss:

- Acknowledge the importance of losses
- Help ensure that clients are allowed to remain in control of decisions that affect them and their family
- Help the client to explore alternative sources of income if he/she is no longer able to work
- Encourage the entire family to join together and discuss future plans with the client.

## Tool 3: Feelings and Emotions During Illness



Divide participants into five groups. Create separate skills stations in five different areas of the room, placing a copy of one of the five case studies below at each station.

**Facilitator's Note:** A 'skills station' is an area where each group will spend no more than 10 minutes conducting a role play in which they address the problem described in the case study. Each group begins at one of the five stations, and rotates until all groups have completed each role play. The role of the facilitator is to walk around the room and provide assistance in how each group could improve their role play to better help a client deal with each situation, based on information provided in the 'ways caregivers can help' handout for each emotion.

### Case Study One: Anticipatory Grief

Your client has just learned that she is HIV positive. She is very angry and says that this illness will prevent her from seeing her children grow up. How do you help her?

### Case Study Two: Depression

The wife of your client has not been well during your past few home visits. She admits to you that she is feeling very concerned about her husband's failing health and that she has not been able to sleep or eat the past week. How do you help her?

#### Case Study Three: Anger

You have just visited your client, who is becoming increasingly ill. During your visit he was very angry and criticised the way you were performing your duties. His children later tell you that he has been yelling at them more than usual. How do you help your client?

#### Case Study Four: Fear

Your client is very sick, and has begun speaking about how he worries that his family will take his home away from his wife and children when he dies. He also mentions that he is afraid of becoming a burden to his family. How do you help him?

#### Case Study Five: Losses

Your client is a mother of three children and begins to cry during a home visit that she feels as she is losing everything she has worked for to give her family. She wants to continue to provide, but her health is not well and she does not know how she will continue to work and earn income while she is sick. How do you support her?

**Facilitator's Note:** In assessing this core skill, facilitator's should choose one case study and use the 'how caregivers can help' handout to determine participant knowledge.

### 3. Preparing for Death (1 hour 30 minutes)

Preparing for death is often an uncomfortable topic for CBVs, their client and their client's family. CBVs have an important role to play in helping their clients prepare for death. Often, if death is not discussed or prepared for, the families of the deceased can experience great emotional, financial and spiritual distress.

It is important for CBVs to help their clients and their families to accept that death is a normal and natural process, and that the death of clients living with HIV or AIDS should not be a topic of shame or secrecy.

None of us want to die with 'unfinished business'. We want to take care of our families after our death, to let our loved ones know how we feel about them and to die feeling safe within our own spiritual beliefs.

#### Ways that caregivers can help an adult client to prepare for death:

- Discuss issues such as wills, child custody, funeral costs
- Help the client know they are loved and will be remembered (memory boxes)
- Encourage clients to talk about death
- Help the client with feelings of guilt or regret.
- Providing physical contact with the sick client, such as holding hands.
- Continuing to provide the client with pain killers. Make sure pain is controlled even if the sick client is unconscious.
- Treat fever
- Control symptoms to relieve suffering with diarrhoea medicine or antibiotics
- Continue with TB treatment to avoid spreading the disease to family members
- Moisten lips, mouth and eyes of the sick client
- Keep the sick client clean and dry
- Give skin care and turn the sick client every 2 hours or more frequently
- Eating little is OK when near death
- Call a religious leader if the sick client asks



## Ways that caregivers can prepare children for their own death or the death of a loved one:

- Be willing to talk and answer questions
- Help the child feel loved and not alone
- Ensure that family members are around to play when the child is able
- Remember that children from about 18 months to 5 years can have “magical thinking”. They may fear they have somehow caused themselves or others to be ill by being naughty’.
- Allow children to express anger or fear and help the child to do so without harming themselves or anyone else
- Acknowledge that a child's most natural reaction to the idea of death may be denial.
- Allow the child to express fears and ask questions when they are ready.
- Allow children to discuss how they would like themselves or their family member to be remembered.



### Tool 4: Helping Families Prepare for Death

Divide participants into pairs. Have each pair conduct a role-play on how they would describe to family members of a client how they can help their loved one prepare for death in a manner that ensures the best comfort possible, including ways to help children in the household prepare for death.

## a) Memory Books and Memory Boxes (30 minutes with Tool 5)

**Memory books and boxes** are like a treasure chest of family photographs, letters, stories or documents that help describe the history of a family. Clients can create memory books or boxes for their children, family or friends as things they want to be remembered for, or to give advice and share feelings with people after they die.

Memory books and boxes are especially important for PLWHA with children. They encourage parents to tell their children important stories and create positive memories for the entire family to share later.

### Benefits of memory books and memory boxes:

- Help clients and their families come to terms with death
- Allow clients to communicate with their families about death and prepare children for the future.

### Ways that caregivers can help their clients with memory boxes:

- If the client does not read or write well, help them to write down stories or letters he/she would like to include in the memory box
- Involve the children of clients (with permission of parents) in helping to make the memory box.



### Tool 5: Creating a Memory Box

Discuss the use of Memory Books and Boxes as a good psychosocial tool for preparing for death. Discuss whether Memory Boxes would be a culturally accepted activity in your community. Discuss what people in your location might want to put in their memory box (any culturally specific items that have a lot of meaning).



## b) Preparing a Will (30 minutes with Tool 6)

Preparing a will is a very important part of preparing for death, particularly in cultures where matters of inheritance can cause conflict.

### Reasons why everyone should write a will:

- It helps prevent arguments among families about possessions and guardianship of children
- It prevents people from taking goods and belongings that don't belong to them after the death of the owner.
- It helps protect the partner and children by ensuring that they will benefit from whatever property the client owned.

### Tool 6: Will Writing In Your Community



**PART A:** CBVs are not expected to become 'experts' in helping clients to write wills. Identify resources in your community that CBVs could refer their clients to for assistance in will writing. Ask each participant to consider what they would want to include in their own will and to draft this according to samples provided. If samples are unavailable, simply ask CBVs to write down what their final wishes would be. Participants do not have to share their wills.

**PART B:** It is important that CBVs can explain to clients and family members the importance of everyone writing a will, and not just people suffering from illness. Divide participants into pairs and role-play discussing with clients and families the importance of preparing a will, including referral to services that can assist clients with will writing.

## c) Rights of the Dying Client (30 minutes with Tool 7)

All people have the right to live with dignity, particularly those who are dying. Reviewing the Rights of a Dying Client is a good way for CBVs and their clients to think about the rights of people who are dying.

### Tool 7: Rights of the Dying Person



**PART ONE:** Distribute Copies of 'The Rights of the Dying Person' located in Handout 7-8. Read together as a group and ask CBVs to list any other rights of people who are dying that may be specific to your community or culture.

**PART TWO:** Divide participants into pairs and role-play how CBVs would discuss the rights of the dying person with clients and/or client families

## **Rights of the Dying Person**

### **I have the right to....**

- Be treated as a living human being until I die
- Maintain a sense of hopefulness
- Be cared for by those who can maintain a sense of hopefulness
- Express my feelings and emotions about my approaching death in my own way
- Participate in decisions concerning my care
- Expect continuing medical and nursing attention even though I cannot be "cured"
- Choose whether or not to die alone
- Be free from pain
- Have my questions about my health and future answered honestly
- Have help from, and for, my family in accepting my death
- Die in peace with dignity
- Retain my 'individuality' and not be judged
- Discuss and enlarge my spiritual or religious experiences
- Expect that the sanctity of my body will be respected after death
- Be cared for by caring, sensitive and knowledgeable people who will attempt to understand my needs.

*Adapted from Island Hospice, Harare.*

## **4. Signs of Death and Dying (1 hour 10 minutes)**

CBVs must be aware of how to prepare family members for death and the signs of death and dying to help client families be prepared to react calmly and appropriately when and if their client passes away.

### **a) Signs of Approaching Death (10 minutes)**

It is important for CBVs to help primary caregivers and family members to understand that alone, some of the signs of imminent death could be associated with HIV related illness and do not mean a client is going to die. However, if a client has experienced a prolonged illness and many signs of approaching death are noticed at once, the client may be close to death.

#### **Signs of approaching death can include:**

- The client interacts less with others, sleeps more, is confused or goes into a coma
- The body slows down, the client loses appetite and does not feel thirsty
- The normal bowel movements and urination habits of the client are reduced
- The breathing of the client changes, becomes irregular or rattles
- The client's blood flow changes, arms and legs become cold and greyish or purple and heart rate and blood pressure fall.

## b) Signs of Death (30 minutes with Tool 8)

### Signs of death include:

- Breathing stops completely
- Heart beat and pulse stop
- The client does not respond to shaking or shouting
- The client's eyes are fixed in one direction (eye lids can be open or closed)
- The client's skin turns to a different colour than normal

### Tool 8: Signs of Death and Dying



As it is unlikely that CBVs will always be in a client's home at the moment of death, CBVs should provide information regarding the signs of death and dying to family members and primary caregivers of their clients.

Write each of the signs of approaching death and signs of dying on slips of paper. Create two separate flipcharts, one listed "Signs of Approaching Death" and the other, "Signs of Death". Ask for volunteers to draw a slip of paper and indicate whether this is a sign of approaching death or a sign of death by affixing their item under the appropriate flipchart heading. Finally, participants should give a presentation on how they would explain this item to family members or primary caregivers of their client in an accurate and sensitive manner.

## c) What to do and what not to do at the time of death (20 minutes with Tool 9)

As a CBV, it is very likely that a client's family will look to you for guidance on what to do at the time of death.

## At the time of death.....

DO	DO NOT
– Encourage family members to stay with the deceased as long as they need to or want to	– Tell family members what they should and should not do
– Encourage family members to hold the Deceased's hand and say goodbye	– Panic when strong emotions are expressed
– Refer to the deceased by his or her name and NOT as "the body"	– Tell grieving family members how they feel. Every experience with illness and death is different.
– Give as much detail as possible to family who were not present at the time of death	– Talk about your own experience with death. That makes people feel like their feelings are not important
– Involve children and explain to them what is happening	– Make grieving family or friends feel like you are in a hurry.
– Be comfortable with the expression of feelings (crying, shouting, wailing)	– Tell a grieving person he/she will "get over it"
– Encourage repetition of the story of illness and death by family and friends	– Lie to children or other family members about the death in an attempt to protect them
– Ensure the presence of religious persons requested by the client	– Try to stop a grieving family member or friend from crying.
– Take time, go slowly	– Rush family members out of the room of the deceased

**Adapted from SAT Counselling Guidelines on Palliative Care and Bereavement, 2001**

### Tool 9: Do's and Don'ts in Your Community



Engage participants in a discussion surrounding the 'dos and don'ts' at the time of death in your community. Ask specific questions such as:

1. Were there any do's or don'ts not listed that would be important in your community?
2. What influence do things like traditional practices, culture, gender and religion play in how people are treated at the time of death?

## 5. Bereavement Counselling (1 hour 30 minutes)

### a) What is Bereavement Counselling? (5 minutes)

**Bereavement** refers to the loss of something of value and grief associated with that loss. Bereavement counselling most commonly refers to assisting friends and family members cope with the death of a loved one.

### b) How Can CBVs Help a Grieving Family? (20 minutes with Tool 10)

Helping people during bereavement is as simple as *being there* for those who are grieving, allowing them to express their emotions and work through their grief.

#### Ways that CBVs can help friends and family of clients during bereavement:

- Encourage family members to **share their feelings** with one another.
- **Listen** more than you talk
- Encourage family members to **avoid making important decisions** immediately after the death of a loved one, such as moving their home, changing their job or leaving the community
- Encourage families to **perform traditional rituals** that help them remember their loved one such as memorials
- Support family members to **speak openly** about the deceased, about memories, qualities of that client they loved and why he/she will be missed
- Encourage family members to **continue to acknowledge special dates** in that client's life such as birthdays and wedding anniversaries.



#### Tool 10: Bereavement in Your Community



As a group, discuss any special ways that CBVs can help friends and families with bereavement in their community.

For example,

1. Are there any special local customs or rituals done after a person dies?
2. Are there any traditional customs CBVs think may interfere with the bereavement process (for example, not speaking of a person after his/her death, people discouraged to show grief). How can CBVs support these customs and still help friends and family grieve?

### c) Possible Experiences during Bereavement (15 minutes)

Just like the experience of illness, ways people cope with stress and many other topics of discussion in this training package, the way in which people experience grief and go through bereavement are different for everyone.

#### **Important things for CBVs to remember about bereavement are:**

- There is no specific time when people begin and end grieving
- Some people experience what is called “shock” after the death of a loved one and only feel the pain of losing their loved one some time after the death. Shock can last from a few weeks to several months
- The pain of losing a loved one usually gets worse after several months when the shock wears off
- After a long illness, some people may experience a sense of relief that the stress of illness is over. This does not mean that they do not love the client who has died and is a normal part of the grieving process.

The following table lists some of the possible experiences people will go through during bereavement. Distribute Handout 7-9 and review the table with participants.



# POSSIBLE EXPERIENCES DURING BEREAVEMENT

	IMMEDIATE	LATER (several months)	LONG TERM
EMOTIONS	<ul style="list-style-type: none"> <li>• Numbness</li> <li>• Emptiness</li> <li>• Disbelief of death</li> <li>• Fear of being alone</li> <li>• Need to talk about the event and the lost loved one</li> </ul>	<ul style="list-style-type: none"> <li>• Anger</li> <li>• Guilt</li> <li>• Sadness</li> <li>• Depression</li> <li>• Worry and anxiety</li> <li>• Feeling like they are losing their mind "going crazy"</li> </ul>	<ul style="list-style-type: none"> <li>• Some guilt and sadness</li> <li>• Adjustment to life without their loved one</li> <li>• New relationships</li> <li>• Need for independence</li> <li>• Begin to feel "normal" again</li> </ul>
PHYSICAL	<ul style="list-style-type: none"> <li>• Crying/wailing</li> <li>• Cannot eat or sleep</li> <li>• Signs of shock</li> <li>• Aches and pains</li> <li>• Collapse, breathlessness, exhaustion or headaches</li> </ul>	<ul style="list-style-type: none"> <li>• Nightmares</li> <li>• Restlessness</li> <li>• Withdrawal from family and friends</li> <li>• Experience symptoms of person who has died</li> <li>• Forgetfulness</li> </ul>	<ul style="list-style-type: none"> <li>• Fewer bad dreams</li> <li>• Appetite and sleep return to normal</li> <li>• Physical symptoms fade</li> </ul>
SPIRITUAL	<ul style="list-style-type: none"> <li>• Blame God for 'taking' the person they love</li> <li>• Questioning</li> <li>• Feeling that life lacks meaning</li> <li>• Feel like they want to be 'taken' as well</li> </ul>	<ul style="list-style-type: none"> <li>• Question beliefs</li> <li>• Feel confused about their spirituality</li> <li>• Feel that life lacks purpose</li> <li>• Want to make contact with their deceased loved one</li> </ul>	<ul style="list-style-type: none"> <li>• Readjustment of Spiritual beliefs</li> <li>• Feel new direction in life and spirituality</li> <li>• May accept death as part of life</li> </ul>
TASKS	<ul style="list-style-type: none"> <li>• Accept the reality of the loss</li> </ul>	<ul style="list-style-type: none"> <li>• Work through feelings of grief and loss</li> </ul>	<ul style="list-style-type: none"> <li>• Adjust to life without the deceased</li> <li>• Find an appropriate place for the memories of the deceased to carry with them In the future</li> </ul>

**Table Source: SAT Counselling Guidelines on Palliative Care, p.14**

## d) Supporting Children After the Death of a Loved One (30 minutes with Tool 11)

If a child's parent or sibling has died, caregivers and remaining family members can help to support children by:

- Giving children time to think about the death. Allow children to ask questions, but also accept their silences. It may be useful to look at photos or discuss memories of the person who has died.
- Accept that the child may engage in searching behaviour, such as physically looking for the person who has died. This is an opportunity to accompany the child and gently reconfirm the reality of the death.
- Allow children to express anger and fears surrounding the death.
- Provide simple and honest repetitions about facts that have happened without rejecting the child's feelings. For example, "I know it's hard to believe that your mother has died, but her body was weak and tired and could not carry on".
- Be prepared to discuss questions related to the child's faith or cultural beliefs. For example, children may ask questions such as "Why has God taken my brother away?" Reassure the child that death or illness is not a punishment from God, spirits or another person.
- Help make the loss real for the child. For example, allow children to participate in rituals, such as wakes and funerals.
- Never impose expectations on the child such as saying "You will feel much better in a few months time" or "It is time to get on with your life".
- Avoid the child being unnecessarily separated from other loved ones, and address any fears the child might have about the future of the family.

### Tool 11: Experiences During Bereavement



Divide participants into pairs. Have each pair role play how they would discuss issues of bereavement with family members after the death of a loved one. Role-plays should focus on:

- Re-assuring grieving family members that their emotional, physical or spiritual responses are a normal and acceptable reaction to losing a loved one.
- The needs of children in the home.

**Facilitator's Note:** In assessing this core skill, facilitator's should use the bullet points above to determine the ability of participants to perform this task.

## e) How HIV and AIDS Impact Bereavement (20 minutes with Tool 12)

The death of a loved one to AIDS related illness can affect the way loved ones experience grief.

**Ways in which HIV and AIDS can impact bereavement and how CBVs can help:**

**1) The physical state of a client dying of AIDS-related illness may remain in the mind of loved ones for a very long time. The weight loss or experience of infections or diseases of the skin in people suffering from AIDS-related illness may frighten loved ones.**

CBVs should encourage loved ones to describe what they saw when the client was dying and what they found the most painful part of watching their loved one die.

**2) If there is stigma related to HIV and AIDS in your community, there may be secrecy surrounding why and how your client has died. This means that loved ones may feel an additional emotion of shame with their grief.**

CBVs should encourage loved ones to join support groups or speak to people they feel they can be honest with about the deceased client's condition. Loved ones should be reassured that dying of AIDS related illness is nothing shameful.

If loved ones do not feel they can be truthful about the cause of death, do not force them or pressure them. Help them to prepare a way of explaining the death of their loved one to others, particularly children, who may face uncomfortable questions from others.

**3) If they have not been tested, watching a loved one die to AIDS-related illness may create fears of HIV infection.**

CBVs should encourage use of VCT services and educate families about HIV testing so they can make an 'informed' decision about knowing their status.

Allow family to speak about their fears of dying. Educate family on positive living and ART intervention, so they understand that HIV and AIDS do not have to mean illness or death, but is becoming an increasingly manageable chronic illness.

**4) Issues related to how well the client who has died was cared for are often examined by loved ones who lose a family to any illness. Caregivers often feel that 'they could have, should have 'done more' after a loved one or client has died.**

Caregivers should understand that this is a normal feeling that may occur in families and themselves. Allow people to reflect on the caring process, but reassure them that they should not feel guilt or blame.

## **Tool 12** How HIV and AIDS May Affect the Grieving Process



**PART A:** Engage participants in a discussion of additional ways in which HIV and AIDS may affect the way in which loved ones feel grief in your community. Encourage CBVs to talk about how they might, or have, experienced grief for a client who has died.

**PART B:** Divide participants into pairs. Have each pair conduct a role play on how they would discuss the impact of HIV and AIDS on bereavement with a family member or other caregiver.

**Facilitator's Note:** Facilitators should raise the issue of confidentiality during role plays if their client did not disclose their status, or the family does not want the community to be aware of the cause of death

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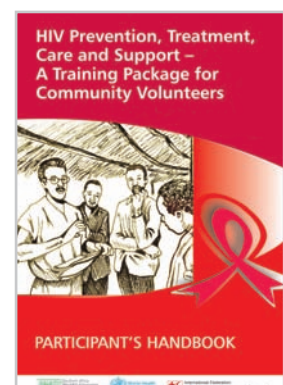
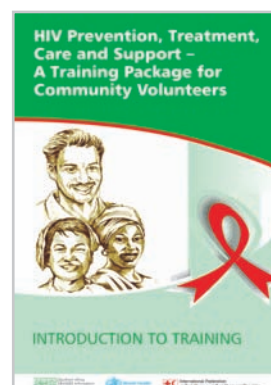
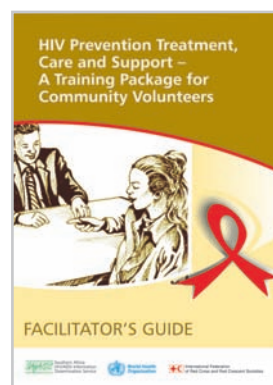
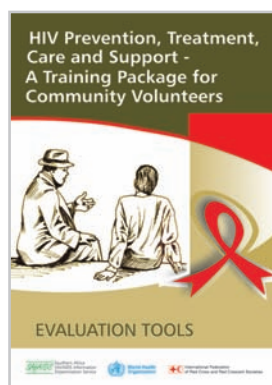
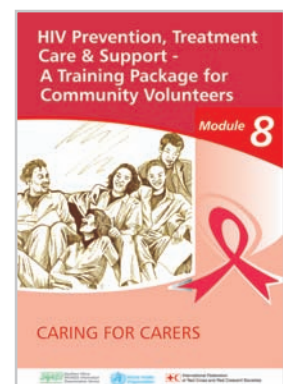
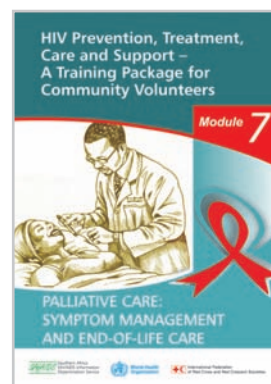
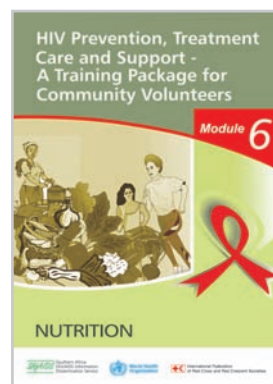
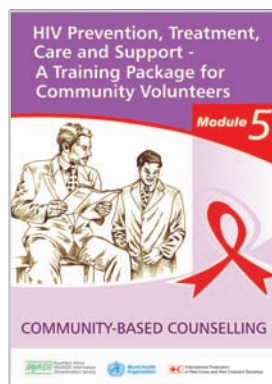
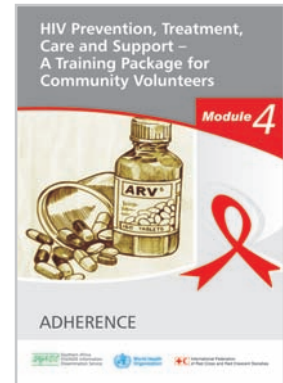
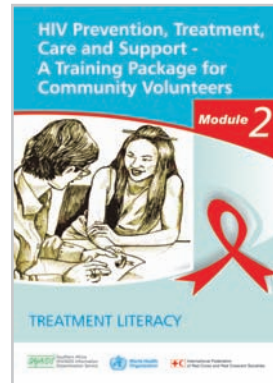
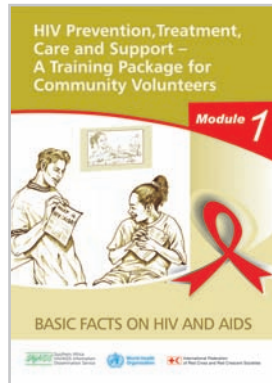
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