

# HIV Prevention, Treatment, Care & Support - A Training Package for Community Volunteers

## *Module* 3



## TREATMENT PREPAREDNESS

# Acknowledgements

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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
- Mrs Shungu Mttero-Munayati – National institute of Health Research – Consultant

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# Introduction

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Module Three: Treatment Preparedness aims to provide CBVs with the knowledge and skills to assist clients and the general community to prepare for comprehensive ART intervention through exploration of the following topics:

- What is Treatment Preparedness?
- Treatment Preparedness for the Individual
- Treatment Preparedness for the Community

Materials to be used in this module:

1. Module Three: Treatment Preparedness (this module)
2. Participant's Handbook
3. Facilitator's Guide
4. Evaluation Tools Manual

Training time for this module is approximately 11 hours

Facilitators should consider participant knowledge on the topics covered in this module when designing their training schedule. More time may need to be allocated to role-play exercises if Treatment Preparedness is a new topic to the participants.

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. Answer important questions clients might have about treatment preparedness.  
**Session One; Tool 5**
2. Demonstrate the ability to use the 5As when using the Preparing PLWHA for ART Checklist during home visits. **Session Two; Tool 7**
3. Conduct a community awareness meeting on the importance of community preparedness for ART interventions. **Session Three; Tool 5**
4. Organise Peer Support and Group Education Sessions for clients in the community.  
**Session Three; Tool 7**

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# 1 Session One: What is Treatment Preparedness?

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**Purpose:** The purpose of Session One is to provide CBVs with an understanding of what treatment preparedness is, who is involved in treatment preparedness and the role of CBVs in the care of PLWHA.

**Objectives:**

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

1. Demonstrate an awareness of the positives of engaging PLWHA in treatment preparedness and dangers of not assisting PLWHA to prepare for ART intervention.
2. Demonstrate knowledge on the importance of linking HIV positive clients to resources and health facilities in your community, especially when on ART.
3. Describe ways that CBVs can assist in ensuring good care for PLWHA in their community.
4. Demonstrate knowledge on the role of CBVs in ART in your community.
5. Answer important questions clients might have about treatment preparedness.

**Duration:** 3 hours

**Recommended Materials:** flipchart, markers

**Recommended Preparation:**

- It is recommended that training for Module One and Two be conducted prior to Module Three.
- If training has been conducted on Module One, compile community mapping information on referral services for PLWHA in your community from Session Two, Tool 4.
- Make copies of Handout 3-1 '9 Principles of Good Care for PLWHA' for distribution in Tool 3.



<b>Objective</b>	<b>Content</b>	<b>Time</b>	<b>Methodology</b>
Demonstrate an awareness of the positives of engaging PLWHA in treatment preparedness and dangers of not assisting PLWHA to prepare for ART intervention.	1. What is Treatment Preparedness?	30 minutes	Mini Lecture  Tool One (A): Group Activity
	2. When does treatment preparedness begin?	10 minutes	Mini lecture
Demonstrate knowledge on the importance of linking HIV positive clients to resources and health facilities in your community, especially when on ART.	3. Who is involved in treatment preparedness?	30 minutes	Tool Two (K): Group Activity
Describe ways that CBVs can assist in ensuring good care for PLWHA in their community.	4. Understanding General Principles of Good Care	30 minutes	Tool Three (K): Group Activity
Demonstrate knowledge on the role of CBVs in ART in your community.	5. The role of CBVs in ART	1 hour	Tool Four (K): Group Activity
Answer important questions clients might have about treatment preparedness.			Tool Five (ST): Role Play

# 1. What is Treatment Preparedness? (30 minutes with Tool 1)

**Treatment preparedness** is the process of preparing PLWHA and their surrounding community to initiate, or start, ART and related therapies. The aim of treatment preparedness is to ensure that PLWHA have all the support necessary to take their medications, such as ARVs and TB medications as prescribed by the clinical team at the health facility.

**Treatment preparedness has three main components:**

1. **Treatment Literacy** involves clients having the skills and knowledge necessary to manage HIV infection through ART. Treatment literacy is important because the more people know about their disease and how to manage it, the better they can manage and overcome possible problems. Aspects of treatment literacy were covered in Module Two, and will be reviewed in the next session.
2. **Advocacy** involves influencing all those responsible for ensuring that the needs of PLWHA are met prior to starting ART. At the personal level, advocacy involves ensuring that PLWHA are empowered with the knowledge and skills to be at the centre of their own care. PLWHA should be at the centre of important decisions such as starting treatment, managing side effects and designing a treatment plan that works for them.
3. **Community Mobilisation** involves ensuring a supportive environment for PLWHA before they start ART. Community mobilisation involves ensuring access to important services (health services, support groups, etc.), efforts to reduce stigma and discrimination and policies and procedures are in place, to provide ARV medications in a sustainable, affordable manner for PLWHA.

**Aspects of treatment preparedness include:**

- Educating PLWHA about HIV, AIDS and ART
- Assessing whether PLWHA are ready and willing to begin ART
- Preparing PLWHA for adherence to ART before treatment begins
- Identifying any barriers to ART PLWHA may face and helping to overcome these obstacles
- Mobilising community support for ART intervention.

Facilitators Note: Facilitators should emphasise that not all PLWHA need To be on ART.



## Tool 1: Importance of treatment Preparedness

This exercise is to familiarise participants with concepts related to treatment preparedness and encourage independent exploration of its importance in ART.

As a group, discuss why Treatment Preparedness is a key part of ART interventions by filling in the chart below.

Make a list similar to the one below on a flipchart:

**Positives of Treatment Preparedness**

**Dangers of Not Engaging Treatment Preparedness**

Ask CBVs to brainstorm on points for each specific to their community.

## 2. When Does Treatment Preparedness Begin? (5 minutes)

Treatment preparedness should be an ongoing process for both individuals and the larger community.

**Community Preparedness** involves creating awareness about HIV and AIDS and treatment that is available for PLWHA. Therefore, this type of treatment preparedness is ongoing.

**Individual preparedness** for ART should begin from the time a person is diagnosed with HIV as part of pre and post test counselling.

### a) Requirements to initiate ART

WHO uses Seven Requirements that must be met to begin ART in clients with no complications, or health issues that would require delaying ART. While CBVs are not involved in each of the seven requirements, they are useful to review because they illustrate that the initiation of ART is not a simple decision and involves many aspects related to the health, knowledge and support available to PLWHA and their families.

### Seven Requirements to Initiate ART:

**1. HIV positive written documentation** - ART can only be started in clients with a written document showing they are HIV positive.

**2. Medical eligibility** - Not all PLWHA need to be on ART. If ART is started too early, clients will only experience side effects and no benefit to overall health.

**3. Client fits criteria to be started on ART used in your country** - As discussed in Session One of Module Two, different countries can use different criteria for starting ART. Before starting ART, PLWHA must meet these criteria.

**4. Any Opportunistic Infection has been Treated or Stabilised** - In some situations, clients experiencing certain types of illness should not begin ART because illness may interfere with ART preparation, or the danger of drug interactions between ARVs and those being taken to treat OIs, or problems with adherence that can result from having too many pills to take at the same time (also called pill burden).

**5. Client is ready for ARV therapy** - This requirement concerns the many aspects of preparing clients for ART that will be discussed in this module. CBVs play a very important role in helping clients prepare for ART

**6. Supportive Clinical Team Prepared for Long-Term Care** - Providing ART requires many different care providers to work together including, doctors, nurses, counsellors, CBVs and community members.

**7. Reliable Drug Supply** - Once clients start ART, they should take ARVs for life. If drugs are out of stock this will prevent clients taking their ARVs regularly, and can cause resistance, allowing HIV to change in the body and stop ARV drugs from being effective.



### 3. Who is involved in Treatment Preparedness? (30 minutes with Tool 2)

Treatment preparedness involves not only PLWHA but also everyone that can help or support the success of ART interventions.

People that are often involved in treatment preparedness include:

- Individuals starting ART for the first time, “Treatment Inexperienced”
- Individuals who have used ARVs in the past, “Treatment Experienced”
- Community Based Volunteers (CBVs)
- Families of PLWHA
- People involved in health care (doctors, nurses, community health workers)
- Community leaders and the community at large.



#### **Tool 2: Mapping Resources in Your Community Involved in Treatment Preparedness**



**Facilitator's Note:** In Session Two of Module One, participants were asked to map community resources involved in HIV, AIDS and ART. If participants have completed training in Module One, refer to this community map and ask participants to identify resources on this map that will be important in preparing PLWHA for ART. If participants have not completed training in Module One, draw a map of your community on a flipchart and ask participants to identify important services involved in treatment preparedness on that map.

### 4. Understanding General Principles of Good Care

#### (30 minutes with Tool 3)

As a CBV, it is important to understand the general principles of good care; this represents “CBV preparedness” for assisting with the smooth roll out of HIV services in your community.

The care of PLWHA involves many different aspects. Every person has a different role to play in the care and support of PLWHA, including the role PLWHA themselves must play.

The following general principles of good care for PLWHA have been developed to help CBVs understand what caring includes:

### General principles of Good Care for PLWHA include:

- 1) Developing a treatment partnership with PLWHA
- 2) Focusing on the concerns and priorities of PLWHA
- 3) Supporting PLWHA to care for themselves as far as possible
- 4) Organising follow-up for PLWHA with hospitals, clinics and support groups
- 5) **Meaningful Involvement of People Living with HIV and AIDS (MIPA)** means recognising the important contribution PLWHA can make in response to the fight against HIV and AIDS and creating a space within society for the involvement and active participation of PLWHA in responses to the epidemic, such as ART intervention
- 6) Linking PLWHA to community-based resources and support staff
- 7) Using written information (where possible) to document, monitor and remind PLWHA of how and when to take ARVs
- 8) Working as a team with other carers, organisations, clinics and hospitals
- 9) Assuring care continues at the same level for PLWHA over time (**Continuity of Care**).

### Tool 3: General Principles of Good Care



**Facilitator's Note:** Distribute the '9 Principles of Good Care' Handout 3-1. Before conducting this activity, encourage CBVs to ask any questions they might have about any of the general principles they may not understand.

Divide participants into three groups. Provide each group with three of the principles of good care for PLWHA.

#### Group One:

1. Treatment Partnerships
2. Concerns and Priorities of PLWHA
3. Support Self-Care

#### Group Two:

1. Organise follow-up
2. MIPA
3. Linking to Resources

#### Group Three:

1. Document, monitor and remind of treatment
2. Work as a team
3. Continuity of care

Provide each group with a flipchart and marker and ask each group to list ways in which they feel CBVs can help support PLWHA to achieve each of the principles of good care to which they have been assigned.

Have each group present their answers. Ask remaining participants to offer any additional ways they feel CBVs can contribute to each principle.

## 5. The Role of CBVs in ART (1 hour)

As discussed in 'Introduction to Training', the role of CBVs in HIV prevention, treatment, care and support consists of many things. Each module in the training package is designed to help prepare CBVs to care for PLWHA to the best of their abilities.

### a) The Role of CBVs in supporting ART

Supporting ART intervention involves the team work of many people, including PLWHA, and can not be done by one person alone. CBVs have a special role in ART interventions as they are in close contact with PLWHA who may be beginning or continuing ART.

CBVs can help support ART by assisting PLWHA with:

- Treatment preparedness
- Treatment adherence (preparation, initiation, monitoring and support)
- Supportive care (counselling, nutrition advice and/or palliative care).

### b) What CBVs are NOT responsible for in ART (1 hour with Tool 4 and 5)

As mentioned, ART intervention requires a team approach. The clinical team at the health facility is responsible for preparing the client, treatment support and family for ART initiation. The role of the CBV is extremely important in continuing the work started at the facility and to continue to prepare the client to adhere to ART, and to monitor adherence once ART is started, including referral to the health facility if side effects occur.

**When it comes to ART, CBVs are NOT expected to:**

- Conduct medical tests
- Determine who 'qualifies' for ART and establish when the client is ready to start
- Develop a client's ARV treatment regimen
- Change a client's ARV regimen



## Tool 4: CBVs and Support

The purpose of this activity will be to help CBVs understand and shape their role in ART. Create a list of 'what support means' on a flipchart similar to the one below.

### What Support Means

- Educating PLWHA and others on HIV, AIDS and ART
- Helping prepare PLWHA and the community for ART intervention
- Helping PLWHA to adhere to ART
- Providing psychosocial support (counselling) to PLWHA
- Advising PLWHA on the importance of nutrition
- Caring for carers, including family, other CBVs and yourself, Palliative care for PLWHA and their families
- Support clients to report regularly to the clinical team at the local health facility and access other services in the community.

### What Support Does NOT Mean

- Doing things for PLWHA that they are capable of doing themselves
- Conducting medical tests or replacing the role of the clinical team at the health facility
- Knowing EVERYTHING when it comes to HIV, AIDS and ART (it is OK to not know all the answers, use others for support)
- Determining who should receive ART, And who should not
- Deciding what ARV medications PLWHA should take or how they should be taken
- Neglecting your own needs for those of the people you assist

This exercise is meant to emphasise that support for PLWHA is not sole responsibility of CBVs. Rather, the role of CBVs is to assist PLWHA to obtain the knowledge and services they need to live positively. ART intervention is one aspect of living positively that PLWHA need support with.

CBVs should be encouraged to discuss any fears or worries they have about supporting ART interventions during this activity.



## Tool 5: Describing Treatment Preparedness to Clients

By now, participants should have a good understanding of what treatment preparedness is and the role of CBVs in assisting clients to prepare for ART.

Divide participants into pairs. Ask each pair to role-play providing a client with information on treatment preparedness who asks the following questions:

- *What is treatment preparedness?*
- *What could happen if I don't prepare for treatment?*
- *When should I start preparing for ART?*
- *Who can help me prepare for ART?*
- *As my home-based care provider, what is your role in helping me prepare for ART?*

**Facilitator's Note:** As you observe role-plays, ensure participants provide the following information in each of their role plays. The checklist below should also be used to assess this core skill at the end of training for this module.

1. *What is treatment preparedness?*

- ☐ Treatment preparedness is the process of preparing PLWHA and their surrounding community to initiate, or start, ART. The aim of treatment preparedness is to ensure that PLWHA have all the support necessary to take their ARV medications correctly and over the long term (called **adherence**).

2. *What could happen if I don't prepare for treatment?*

- ☐ Participants should review answers generated from Tool Two, 'Dangers of not engaging in Treatment Preparedness'.

**Facilitator's Note:** Facilitator's may want to record the answers generated in Tool Two in the notes of this Module for reference when assessing this core skill.

3. *When should I start preparing for ART?*

- ☐ PLWHA should start preparing for ART *before* starting treatment.

4. *Who can help me prepare for ART?*

- ☐ CBVs should review the list of services available in the community identified during the community mapping exercise in Tool 2.

**Facilitator's Note:** Facilitator's should encourage participants to record the community map of services so that they can share the map with their clients during home visits.

5. *As my home-based care provider, what is your role in helping me prepare for ART?*

- ☐ Participants should review important elements of 'What support means' and 'What support does not mean', developed in Tool 4 with their clients.

# 2 Session Two: Treatment Preparedness for the Individual

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**Purpose:** The purpose of Session Two is to provide CBVs with the knowledge and skills required to prepare PLWHA for ART.

**Objectives:**

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

1. Describe the importance of PLWHA being at the centre of their own care to clients during a home visit.
2. Demonstrate the ability to use the 5 A's when using the Preparing PLWHA for ART Checklist during home visits.

**Duration:** 3 hours 45 minutes

Due to the number of role plays and group activities, it is recommended that an entire morning or afternoon be set aside for completing Session Two.

**Required Materials:** Flipchart, markers.

**Recommended Preparation:**

- Make copies of Handout 3-2 'PLWHA at the Centre of their Own Care' for distribution in Tool 1.
- Make Copies of Handout 3-3 'Preparing PLWHA for ART Checklist' for distribution at the beginning of the section two.
- Make copies of Handout 3-4 'The 5 A's' for distribution to participants in Section 2 a).



Objective	Content	Time	Methodology
Demonstrate the ability to describe the importance of PLWHA being at the centre of their own care to clients during a home visit.	1. Ensuring PLWHA are at the Centre of their Own Care	30 minutes	Mini Lecture  Tool One: PART A (K): Group Discussion PART B (ST): Role-Play
	2. How can PLWHA be prepared for ART?	30 minutes	Mini lecture
Demonstrate the ability to use the 5 A's when using the Preparing PLWHA for ART Checklist during home visits	3. Using the Checklist to Prepare PLWHA for ART	2 hours 45 minutes	Tool Two (ST): Group Role Play *Introduction to ART  Tool Three (ST): Group Role Play *Health and ART  Tool Four (ST): Group Role Play *ARV Medications  Tool Five (K): Group Discussion *Adherence  Tool Six (ST): Group Discussion *Client Self-Management  Tool Seven (ST): PART A: Group Discussion  PART B: Role-Play

# 1. Ensuring PLWHA Are At the Centre of Their Own Care

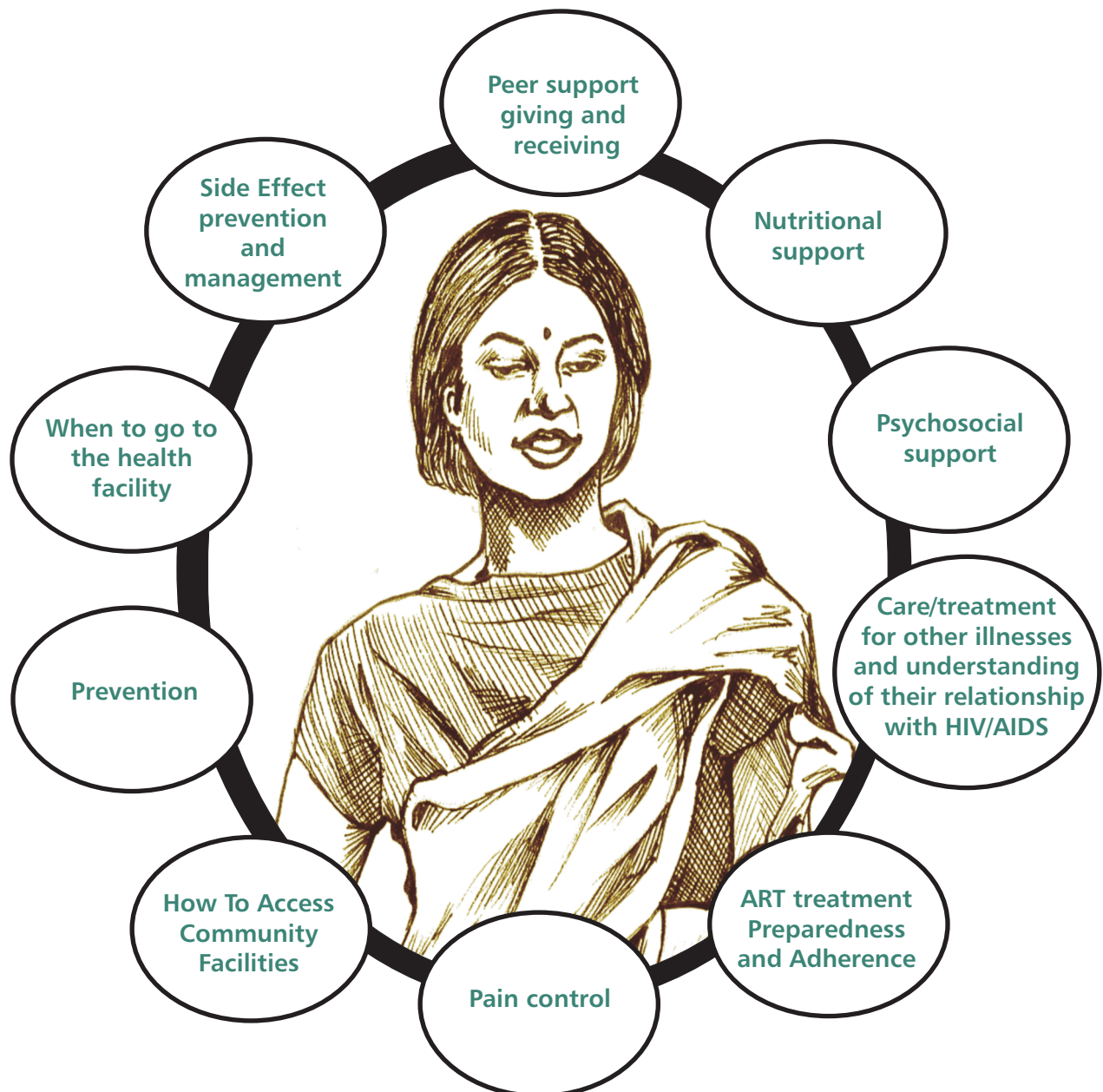
## (30 minutes with Tool 1)

Helping to ensure PLWHA are at the centre of their own care represents the first step in helping a client to prepare for ART. Ensuring PLWHA are at the centre of their own care applies to clients in all stages of illness, and includes:

- Clients in the early stages of HIV who do not require ART
- Clients preparing for ART
- Clients on ART
- Clients who are in the later stages of illness

Practical ways that CBVs can assist PLWHA to be at the centre of their own care are addressed in section 3 f) Client Self-Management

### PLWHA At The Centre Of Their Own Care:





## Tool 1: PLWHA at the Centre of the Own Care

PART A: Distribute copies of Handout 3-2: PLWHA at the Centre of their Own Care and review the handout as a group.

Engage participants in a discussion of how this diagram relates to the importance of treatment preparedness.

**Facilitator's Note:** If not addressed by participants, facilitators should emphasise that in order for clients to take ARVs successfully for their entire lives, clients must be provided with the skills to manage ALL aspects of HIV disease, and not just ART. This means that clients will need to be provided with skills and knowledge in nutritional management, pain relief and symptom management of HIV, in addition to being prepared to take control over their ART treatment.

PART B: Divide participants into pairs and have each pair conduct a role play of how they would explain the importance of PLWHA being at the centre of their to a client during a home visit using Handout 3-2.

## 2. How can PLWHA be prepared for ART? (30 minutes)

In collaboration with the clinical team at the health facility, CBVs can have a very important role in preparing clients for ART. All efforts, at the facility and in the community, should be coordinated.

Preparing for ART involves helping PLWHA understand and accept what Antiretroviral Therapy is, the benefits of taking ART and steps they can take to ensure that ART is successful.

Each of the points discussed in this session involve important ways CBVs can help PLWHA to prepare for ART. It is important to understand that ART preparation cannot be done at one time. It should be conducted over a number of visits before starting ARV therapy.

Distribute copies of the 'Preparing PLWHA for ART Checklist' from Handout 3-3 and encourage CBVs to make note of each item on the checklist as you review the remainder of the session.

# Preparing PLWHA for ART - A Checklist for CBVs

Name of CBV.....

Name of client.....

Topic for Discussion	1st Session	2nd Session	3rd Session
<b>Developing a Relationship with Your patient</b>			
Discussion of confidentiality			
Developing clear communication			
<b>Introduction to ART</b>			
Explaining ART			
Goals and Benefits of ART			
Who needs to take ARVs			
Key ART Contacts in Your Community			
<b>Important Aspects of Health Related to ART</b>			
Overall Health			
How HIV and AIDS Affect the Body			
CD4 Count			
Viral Load			
<b>What is an ART Regimen?</b>			
First-line regimen			
Resistance			
Second-line regimen			
Side-Effects of ARV Drugs			
Mild Side Effects			
Major Side Effects			
<b>Importance of Taking Medication Properly</b>			
Define Adherence and what Adherence involves			
<b>Identify Possible Barriers to Adherence</b> <ul style="list-style-type: none"> <li>- Communication problems</li> <li>- Knowledge and understanding about HIV and AIDS</li> <li>- Attitudes and beliefs</li> <li>- Lack of social support</li> <li>- Mental health or psychological well-being</li> <li>- Regimen complexity</li> <li>- Difficult life conditions</li> <li>- System barriers</li> </ul>			



**Discuss and agree upon strategies to be used for increasing adherence:-**

- Treatment preparation
- Pill boxes
- Electronic devices
- Buddy system
- Medication diaries-
- Support groups
- Pill charts

**Overview Client Self Management**

Provide handout to PLWHA and discuss each point

## a) Using the 5 A's in Treatment Preparedness

Distribute a copies of the 5 A's Handout 3-4 and review as a group.

<b>The 5 A's: Assess, Advise, Agree, Assist, Arrange</b>	
<b>ASSESS</b>	<p>Questions asked to clients about their health, family, situation or history</p> <p>Questions such as:</p> <ul style="list-style-type: none"> <li>• <i>"What would you like to talk about today?"</i></li> <li>• <i>"What concerns or questions do you have about preparing for ART?"</i></li> <li>• <i>"What do you already know about the importance of preparing for ART?"</i></li> </ul>
<b>ADVISE</b>	<p>Providing clients with information about their illness, positive living, prevention, treatment preparedness, adherence, nutrition...etc.</p> <p>*Advise DOES NOT mean "telling clients what to do", but providing clients with information they will need to make informed choices.</p> <p>Questions such as:</p> <ul style="list-style-type: none"> <li>• <i>"I have some information about...would you like to hear it?"</i></li> </ul>
<b>AGREE</b>	<p>Agreeing with clients about options discussed. Helping the client to decide what they want to do by discussing the possible advantages and disadvantages of each option. Helping to ensure clients are at the centre of their own care and have control over decisions made about their health and treatment.</p> <p>Questions such as:</p> <ul style="list-style-type: none"> <li>• <i>"Among the options we've discussed today, what would you like to do?"</i></li> </ul>
<b>ASSIST</b>	<p>Discussing with clients how to manage difficulties and predict possible barriers to following their plan. Linking clients to support available in the community to help them overcome potential difficulties.</p> <p>Questions such as:</p> <ul style="list-style-type: none"> <li>• <i>"What problems might arise when you try and follow this plan?"</i></li> </ul>
<b>ARRANGE</b>	<p>Arranging your ne t meeting with clients, arranging referral to community based support options such as support groups and recording what happened during your visit (i.e., using the checklist to record topics discussed).Questions such as:</p> <ul style="list-style-type: none"> <li>• <i>"There are other things we should discuss about preparing for treatment, what day and time should I come to see you again?"</i></li> </ul>

**Facilitator's Note:** As you review each of the sections of the Preparation Checklist for PLWHA, be sure to ask participants how they can use the 5 A's to ensure they provide clients with the information and support they require.

### 3. Using the Checklist to Prepare PLWHA for ART

(2 hours 45 minutes)

#### a) Developing a Relationship with your client (15 minutes)

CBVs may already know their clients well and know the importance of a good relationship. Good relationships between clients and health providers are the first step of good chronic care.

Developing a relationship with your client involves:

- **Establishing trust:** Ensuring your client trusts you enough to discuss sensitive issues around his or her health and challenges he or she may face living with HIV or AIDS that may affect the way he or she adheres to ART
- **Assuring confidentiality:** It is important for PLWHA to feel that anything he or she tells a CBV during a meeting will be kept confidential, and not shared with others in the community. Confidentiality is especially important for a PLWHA who have not disclosed their HIV status to others, or in communities where there is stigma around HIV and AIDS
- **Ensuring mutual respect and non-judgemental attitudes:** Part of developing a good relationship with your client involves developing a mutual respect, and not making PLWHA feel as though they are being judged for their feelings or HIV status
- **Developing clear communication:** Communicating effectively is one of the most important ways CBVs can develop a good relationship with their clients. Clear communication involves understanding the knowledge level of your client and providing information in a way that PLWHA can both understand, and feel free to ask questions about.

#### b) Introduction to ART (30 minutes with Tool 2)

**Facilitator's Note:** As CBVs should have already received training on each of these topics, the purpose of review is not to spend a long time re-addressing content. Rather, facilitators should provide a brief lecture on the information below, with the majority of time spent in the group activity intended to demonstrate transfer of this information by participants to clients.

Just as CBVs have gone through Modules 1 & 2 to help them better understand issues surrounding HIV, AIDS and ART - preparing PLWHA for ART requires the same overview of topics. While this section includes repetition of topics already covered in previous modules, this will provide CBVs with an opportunity to practise educating their clients on these topics.

CBVs will need to be flexible when introducing PLWHA to ART, and adapt their knowledge to suit the level of knowledge of their client.

The following topics should be addressed when CBVs introduce ART to their clients:

Section 4 of the Flipchart for Client Education is a useful resource for introducing clients to ART. CBVs must be able to demonstrate the use of the flipchart while addressing the following key concepts:

## 1. Explaining ART to Clients

- Antiretroviral Therapy (ART) is a term used to describe giving ARV drugs in the correct way, with adherence support.
- PLWHA should be helped to understand what ART is, and what the goals of ART are as part of treatment preparation.

## 2. Goals and Benefits of ART

- CBVs should be well acquainted with the goals and benefits of ART from Module 2. If they require a refresher on each, return to Module 2; Session One: Introduction to ART and review as necessary.

## 3. Who needs to take ARVs?

- CBVs should educate clients that not all PLWHA need to take ARVs.

## 4. Medical Institutions, Key Staff and Support Groups PLWHA should be Familiar With

One of the most important roles for CBVs in introducing ART is providing clients with the contact information of people and institutions providing chronic HIV care including ART. CBVs must link clients with their HIV care team for ART to be successful.

Key contacts in your community might include:

- Medical Institutions (hospitals, clinics, HIV Testing and Counselling Services)
- Key Staff (Doctors, nurses, health workers and CBVs involved in ART)
- Support Groups (for PLWHA, for ART)



### Tool 2: Introduction to ART

Divide participants into pairs. Have each pair conduct a role play on how they would introduce clients to ART using the **Flipchart for Client Education Section 4p.4-1 to 4-5**.

**Facilitator's Note:** Facilitators should ensure that clients are using the flipchart tool properly when conducting their role plays. Participants should be encouraged to ask any questions, or review any information they will require to use this tool effectively. Refer back to Module 2: Treatment Literacy if necessary.

## c) Important Aspects of Health Related to ART (30 minutes with Tool 3)

This section explores aspects of client health that CBVs should support clients to explore with their clinical team. ART represents an exciting opportunity for PLWHA to take control over their health and live positively. Before they begin ART, PLWHA should understand aspects of their health that will become important when they begin taking ARV medications.

CBVs play an important role in helping PLWHA prepare for ART. CBVs can share their knowledge about HIV and AIDS to ensure that PLWHA are active participants in their own treatment and accept and understand all medical tests and terms used by their doctors when discussing their health.

### 1. Overall Health

Before starting ART, it is important for PLWHA to reflect upon their overall health and how it might affect the ARV drugs they take by consulting their clinical team. PLWHA should also be helped to consider any other aspects of their life that may affect the way ARVs are taken, and ultimately, the success of ART to fight HIV in their body.

Aspects of overall health PLWHA should reflect on include:

- **History of health and illness** - experience with HIV and OIs
  - **Specific conditions** they are currently experiencing that may affect ART (For example, Tuberculosis, STIs, pregnancy)
  - Their ability and acceptance of engaging in **safer sex** (both to avoid transmitting HIV and to avoid re-infection that may affect their health)
- Aspects of their lifestyle** that may affect their ability to take ART or for ART to be effective (drug or alcohol abuse, busy work schedule, disclosure of their HIV status).

### 2. How HIV and AIDS affect the body

In places where there is a lot of shame and secrecy surrounding HIV and AIDS, PLWHA may not seek out information on their own illness. While PLWHA may be feeling the effects of HIV and AIDS in their body, they may not have a good understanding of how HIV affects the body. Therefore they will not understand how ART works.

Review the following key points about HIV and AIDS from Module 1: Basic Facts on HIV and AIDS. If CBVs require a refresher on the facts, return to Module 1: Session One

- **HIV** is the virus that causes AIDS. It attacks the immune system the body's defence against disease
- HIV is part of a group of viruses, called **retroviruses** that combine with the genetic material of healthy cells in the human body
- The **immune system** is the body's defence system against diseases. White blood cells called **lymphocytes** play an important role in helping the body's immune system. **CD4** cells are a special type of lymphocyte.
- **AIDS** is the name given to a group of serious illnesses in PLWHA. These are illnesses that arise when PLWHA are no longer able to fight off infection because of lowered immunity.

### 3. CD4 Count

Because CD4 counts are used to determine both the stage of HIV a person is in, as well as how well ART is working, it is important for CBVs to review this information with their clients to prepare them for ART.

**CD4 cells** are a type of white blood cell in your body (called a lymphocyte or T4 cell) that fights infection. The more CD4 cells a person has, the healthier he or she is.

A CD4 count will tell a person living with HIV or AIDS:

- **How weak or strong his or her immune system is** (a high CD4 count means the immune system is strong)
- **Whether to start antiretroviral therapy.** PLWHA with CD4 counts below 200 should start ART if it is available, though this figure may change depending on country protocols.
- **Whether to change antiretroviral therapy.** If a person is on ART and the CD4 counts begin to drop, the ARVs he or she is taking may have stopped working. He or she may need to take different ARVs.

#### 4. Viral Load

**Viral Load** is essentially the amount of HIV in a person's blood.

A viral load test will tell a person living with HIV or AIDS:

- How much HIV he or she has in their system
- Whether antiretroviral therapy is working. ARVs act to decrease the amount of HIV in a person's system. So, if a person on ART has a low viral load, the medications are effective.



#### Tool 3: Health and ART

Divide participants into four groups. Have each group give a presentation on one of the four aspects of health related to ART again, with one group member acting as CBV, and another as the client):

**Group One:** Overall health

**Group Two:** How HIV and AIDS affect the body

**Group Three:** CD4 count

**Group Four:** Viral Load

During presentations, have other CBVs brainstorm additional questions clients may have on each topic. Write each question down and develop appropriate answers. Refer back to Module 2 if necessary.

#### d) ART Medications (30 minutes with Tool 4)

As discussed in Module 2: Treatment Literacy, understanding ARV medications can be quite difficult. It is important for PLWHA to have a basic knowledge of ARV drugs before beginning ART.

##### 1. ARV Medications

The specifics on their ARV regimen will be discussed in more detail as they begin receiving ART. CBVs can help at both stages by providing specific information on ARV regimens once a treatment plan has been made. Before this, however, it is important for CBVs to give PLWHA 'the basics' on ARVs and ART, that they will need to discuss their treatment options.



## 2. What is an ARV regimen?

The concept of first and second-line regimens of ARVs should be overviewed with PLWHA. While the specific regimen used will be determined by a doctor, understanding first and second-line regimens is important for understanding the importance of resistance in ART.

If CBVs require more information on ARV regimens, refer back to Module 2: Session Two: Basic Facts About ARVs.

Topics that CBVs should discuss with their clients:

- A **First-line regimen** is the name of a combination of ARV drugs used 'first' to treat HIV and AIDS. To prevent resistance, first-line regimens usually contain a combination of at least three antiretroviral drugs (commonly referred to as **Highly Active Antiretroviral Therapy** or **HAART**)
- **Resistance** refers to the ability of HIV to change its structure in ways that make ARV drugs less effective, or the ability of HIV to 'resist' the effects of ARVs
- A **Second-line regimen** of ARVs is prescribed to individuals when 'treatment failure' occurs with a First-line regimen, or if the side effects of first-line ARVs are too severe. A Second-line regimen is therefore a new or changed prescription of ARV medications.

## 3. Side Effects of ARV drugs

Before starting ART, PLWHA should understand and accept that ARV drugs will produce side effects. CBVs should review immune reconstitution syndrome (IRS) as well as the minor and major side effects of ARV drugs with their clients, to show that ART does come with some complications.

PLWHA should be encouraged to seek out information on the side-effects of their specific ARV regimen before treatment begins.

- Mild side effects of ARVs may include:
  - Sleeplessness
  - Upset stomach (nausea)
  - Diarrhoea
  - Drowsiness
  - Headache
  - Fatigue
  - Mild Rash
  - Confusion
  - Nightmares
  - Dizziness
- Major side effects of ARVs may include:
  - Severe headaches
  - Fat changes arms, legs, buttocks and cheeks become thin; breasts, belly, back of neck gain fat
  - Severe abdominal pain (pancreatitis)
  - Yellowing of the skin and pain of internal organs (liver toxicity or jaundice)
  - Severe rash
  - Severe fatigue or shortness of breath (lactic acidosis)
  - Fever



- Severe mental disturbance (confusion, psychosis, depression)
- Severe muscle pain or cramping (severe anaemia).

CBVs should encourage PLWHA to contact their doctor or community health worker in any instance where severe or 'major' side effects are felt and NOT to change the way they take medications on their own.

#### 4. Recording Side Effects

CBVs should review Handouts 2-4 Recording Side Effects, and 2-5 Side Effects diary with clients to assist them to correctly record any Side effects to ART experienced.



#### Tool 4: ARV Medications

Divide participants into three groups. Have each group give a presentation on one of the three aspects of ART medications (one as CBV, other as client).

Group One: ARV Medications

Group Two: ART Regimens (first-line regimen, resistance, second-line regimen)

Group Three: Side Effects of ART (mild side effects, major side effects)

During presentations, have other CBVs brainstorm additional questions clients may have on each topic. Write each question down and develop appropriate answers. Refer back to Module 2 if necessary.

#### e) ART Medications (30 minutes with Tool 4)

As discussed in Module 2: Treatment Literacy, understanding ARV medications can be quite difficult. It is important for PLWHA to have a basic knowledge of ARV drugs before beginning ART.

##### 1. ARV Medications

The specifics on their ARV regimen will be discussed in more detail as they begin receiving ART. CBVs can help at both stages by providing specific information on ARV regimens once a treatment plan has been made. Before this, however, it is important for CBVs to give PLWHA 'the basics' on ARVs and ART that they will need to discuss their treatment options.



- Knowing about interactions between ARVs and other types of medication. Other types of medication can change the way ARVs work in the body.

Barriers to adherence and the methods of measuring and enhancing adherence will be discussed in the next module. They do not need to be discussed in detail at this time, although CBVs should be familiar with these terms as they are on their preparatory Checklist.

It is important for CBVs to identify any barriers to adherence and agree on methods of enhancing adherence that PLWHA will use before starting treatment.

#### Barriers to Adherence:

- Communication problems
- Knowledge and Understanding About HIV and AIDS
- Attitudes and Beliefs
- Lack of social support
- Mental health or psychological well-being
- Regimen complexity
- Difficult life conditions
- System barriers.

#### Methods of Enhancing Adherence:

- Treatment Preparation
- Pill boxes
- Electronic Devices
- Buddy System
- Medication Diaries
- Support Groups
- Pill charts.

### Tool 5: Adherence



As the facilitator, give a presentation to the group on the definition of adherence and what adherence involves for PLWHA on ART.

During your presentations, ask CBVs to come up with questions clients may have on each topic. Write each question down and develop appropriate answers.

Remind participants that adherence will be discussed in greater detail in the next module. CBVs are encouraged to practice role-playing topics of adherence on their checklist with fellow CBVs after completing Module 4.

## f) Client Self-Management (1 hour with Tool 6 and 7)

Client self-management is a very important part of PLWHA being at the centre of their own care. Whenever talking about how clients can have his or her needs met and who can support him or her, CBVs should always try to leave the client in charge of his or her own care as much as possible. This is very important for adolescents and adults.

**Self-management** means the client is taking responsibility for his/her own health care.

Self management recognises that the client takes responsibility for the daily management of his or her condition including:

- Taking responsibility for taking their medication as prescribed (prophylaxis or ART) (**adherence**)
- Making positive choices about diet, exercise, and other lifestyle issues that protect or damage their health (**positive living**)
- Making choices about how to practice safer sex, use condoms, and prevent undesired pregnancies (**prevention**)

People that make up part of the client's care team (including CBVs) help clients to understand their options and the consequences of their decisions; but the **client** is the one who, on a daily basis, makes lifestyle choices and chooses to follow the plan of care. The **client** is responsible for doing what is recommended by the care team.

Clients need to be educated, motivated and supported in order to take care of themselves. This gives them a better sense of control and makes them feel better about their situation, and makes them more successful in caring for themselves.

Promoting self-management includes developing a good relationship between the care team and the client. This is called a **partnership**. The client should trust and believe in this partnership.

Self-management is particularly important when it comes to ART. We will learn about this in other modules such as Module 4 (Adherence), Module 6 (Positive Living and Nutrition) and Module 7 (Palliative Care).

## Tool 6: What CBVs Can Do to Promote Client Self Management

### PART A: The Role of CBVs in Client Self Management

Ask participants to think of ways that they can educate their clients in self-management.

List suggestions on a flipchart and add the following if not included:

- Inform clients about HIV and AIDS and progression of illness
- Encourage clients to ask questions
- Encourage clients to plan for meetings with health workers by writing down questions or topics they want to write about.
- Involve the client in all decisions about their health, including treatment, medications and referrals
- Encourage the client to choose a partner or friend to act as a treatment supporter
- Encourage the client to set realistic goals for themselves and revisit these goals at the following home visit
- Encourage the client to join peer support groups to share experiences with others.
- Encourage the client to talk about having HIV/AIDS
- Ask clients to request written records of agreement and information about drugs, illness or care to read at home
- Provide clients with information about who to contact at the health centre or clinic if problems arise between home visits

**Facilitator's Note:** Facilitators should end the discussion by confirming that CBVs should always try to leave the client in charge of his or her care as much as possible.

### PART B: How to Educate Clients in Self Management

CBVs will use the 'Taking Care of Yourself When You Are HIV+' Section of the **Flipchart for Client Education** as a communication aid with clients.

Explain that as CBVs, they will use the Flipchart to educate the client. In order to do so they will need to be very familiar with the content of the flipchart.

### g) Be involved in your own health

HIV is a lifelong disease. It is important for you to understand it, learn to feel comfortable about it and learn how to manage the problems that it might give you. It is very important that you are aware of the value of taking care of yourself. To a large extent, you are able to control and influence the path which your health takes.



**Your attitude towards your HIV status.** It might be difficult to be enthusiastic about your life when you have recently been diagnosed with HIV. Give yourself time to grieve. You might experience times when you feel angry, depressed, guilty or a range of other feelings. Allow yourself to feel these things. Eventually you might be able to let go of the negative feelings and be able to accept your HIV-positive status. Time will help this and you need to learn to wait.

With your experience and all the information given by the health worker, most often you can find



solutions to the problems you are experiencing. This will include seeking care for those problems that you cannot solve yourself. However, understanding your problems and what you need to do about them will need to come from you. In addition to this, every day you will need to make decisions about:

- Patterns of sexual behaviour and intimate relationships. There are some things which you need to keep in mind if you want to take care of yourself and others.
  - If you feel safe enough, it is important to try to talk to your sexual partner(s) about your HIV status.
  - You need to prevent sexual partners from being infected with HIV and other sexually transmitted infections.
  - You need to protect yourself and HIV positive sexual partners from being re-infected with HIV.
  - **FOR THIS**, use condoms during all your sexual encounters where there is a chance of bodily fluids (such as semen or vaginal fluids) being exchanged (entering another person's body).
  - If you have decided not to have children at the moment, take the necessary action to prevent pregnancy. Remember that some contraceptives interact negatively with ART. Check this with your health worker.
- Prevent and seek treatment for opportunistic infections
- Live positively and eat well
- Take your medicines as prescribed
- Use or abuse of drugs or alcohol. If you are on antiretroviral treatment or if you are sick with HIV/AIDS, drinking alcohol or using non-medicinal drugs can make you more ill.

ART does not go well with alcohol/drugs because:

- ~ They can make you feel more ill
- ~ It may affect the way ARVs work in the body
- ~ It could cause you to forget to take your ART on time.

You need to try to control your use of alcohol/drugs by:

- Seeking professional help
- Reducing how much alcohol/drugs you use
- Avoiding alcohol/drugs completely
- Rest and stress patterns. Your body needs time to rest and recover from the stress that it is experiencing.
  - If you are well and have energy, you can do some moderate exercise that is comfortable for you.
  - Try to get enough sleep at night.
  - Avoid smoking
  - Take good care of yourself.

### Talk to the health worker

You need to be in charge of your own health every time you visit the health worker. This will allow you to understand your condition, the information given and the solutions that the health worker will offer you much better.



If you do not understand something, ask questions. If you do not understand the answer, ask again. You can also ask a family member, a friend, a CBV or your treatment supporter (if you are on ART) to be with you to help you to remember what the health worker said.

It is normal to have fears and it is OK to show them. Sharing with your health worker will make you feel better and also will help you understand better. Understanding what is happening with you will allow you to be in control of your health.





## **Learn more about your health and your treatment**

Take this opportunity to learn more about your condition, the medicines you are taking, how you can best address problems you are having at home. Also ask about the resources and support that can be available for you and approach them when needed. The more information you have, the better prepared you will be to take care of yourself.

Ask your health care worker about the treatment available, if you need it, and how to get it.

Be sure to know what the risks of the treatment are, and what will happen if you do not take it.



## **Be careful if new symptoms appear**

You should also know how to handle new signs and symptoms that may appear.

You should remember what the health care worker and the caregiver have told you. It is important to know if you can manage the problem on your own or if you need to seek care from the health facility.



## **List all of the medicines you are taking**

Get to know the medicines you are taking. You can make a list or just memorise the shape and colour. If you have any doubt, ask your health care worker, your treatment supporter, your CBV or family.

Remember any problems you have experienced when taking certain medications.

Make sure your healthcare worker KNOWS about these problems with medications.

Ask your health care worker or CBV what you need to do in case the problems come again, whether you can do something at home or if you need to seek care.

You should take your medication with you when you go to see the health workers.



## **Understand the medicines you are taking**

Before you begin to take your medicines, be sure you know exactly HOW and WHEN to take them.

All medicines need to be taken as prescribed. ART, in particular, will lose its effect if not taken every day, twice a day.



## **Get the results of every test**

Ask for the results of every test or procedure you have taken. By keeping your own record of test results, you will have more information about your health.

When you get your results, always remember to ask what the results mean for your health and for your treatment.



## What to do if you are referred to the hospital

### Always ASK:

Why you are being referred. Knowing the reasons for referrals will help you to understand your problem better.

How quickly you will need to go to the hospital. Knowing how quickly you need to go will allow you to plan ahead, so you can tell your husband or wife, your friends or your caregiver.

If you will have to pay for treatment at the hospital, and how much it will cost you.

## Know your treatment plan *before* you leave the hospital



**Before you leave the hospital, ask the healthcare worker to explain what treatment you had and the new medicines you need to take, if any.**

### Tool 7: Using the 5 A's to Review the Checklist with Clients



**PART A:** As a group, review the 'Preparing PLWHA for ART Checklist'. Encourage participants to ask any questions they might have about the checklist or identify any topics they do not feel comfortable talking about. Remind participants that information regarding adherence barriers and adherence enhancing strategies will be covered in Module 4. Review information until participants are comfortable they can provide accurate information to their clients on each of the items on the checklist.

**Facilitator's Note:** It is very important that facilitators emphasise that preparing a client for ART can not be done in one home visit. If CBVs attempt to provide all the information covered on the checklist within one visit, clients are likely to feel overwhelmed. CBVs should take at least three home visits to cover all of the information provided. Information provided in each session should be ticked off, helping them to remember topics remaining for discussion in future home visits.

**PART B:** As a group, review the Preparing PLWHA for ART Checklist and brainstorm on how the 5 A's could be used to help clients with the following checklist topics:

- Introduction to ART
- Client Self-Management

Divide participants into pairs and provide them 10-15 minutes to practice role-playing providing this information to clients, using questions related to each of the 5 A's.

**Facilitator's Note:** In assessing this core skill at the end of the module, have participants provide a demonstration on how they would use the 5 A's to discuss the following checklist items above.

Facilitators should record questions related to these two topics developed during the brainstorm session to assist with measuring the participants' skill.

# 3 Session Three: Treatment Preparedness for the Community

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**Purpose:** The purpose of Session Three is to provide CBVs with the knowledge and skills to help prepare the community for comprehensive ART intervention.

**Objectives:**

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

1. Demonstrate an awareness of areas in need of strengthening to improve community preparedness for ART and how CBVs can help.
2. Use specific strategies for addressing stigma and discrimination against PLWHA in your community.
3. Involve traditional healers and leaders in your community in ART interventions.
4. Demonstrate an awareness of how PLWHA are currently involved in ART within the community and ways in which PLWHA can be further involved in community preparedness.
5. Conduct a community awareness meeting on the importance of community preparedness for ART interventions.
6. Organise Peer Support and Group Education Sessions for clients in the community.

**Duration:** 4 hours

**Required Materials:** Flipchart, markers.

**Recommended Preparation:**

- Make copies of Handout 3-6 'The Role of CBVs in Preparing their Community for ART' for distribution in section two.
- Invite one or two PLWHA in your community (who have openly disclosed and are comfortable speaking about their status) to participate in the session. Request these 'guest speakers' to lead the meaningful involvement of PLWHA discussion in Tool 4.

Objective	Content	Time	Methodology
Demonstrate an awareness of areas in need of strengthening to improve community preparedness for ART and how CBVs can help.	1. What is Community Preparedness?	1 hour	Mini Lecture  Tool One (PS): Group Brainstorm
Use specific strategies for addressing stigma and discrimination against PLWHA in your community.	2. The Role of CBVs in Community Preparedness	2 hours	Mini lecture  Tool Two (PS): Dramatisation and Group Brainstorm
Involve traditional healers and leaders in your community in ART interventions.			Mini Lecture  Tool Three (PS): Group Discussion
Demonstrate an awareness of how PLWHA are currently involved in ART within the community and ways in which PLWHA can be further involved in community preparedness.			Mini Lecture  Tool Four (PS): Group Discussion
Conduct a community awareness meeting on the importance of community preparedness for ART interventions.			Tool Five (ST): Group Role Play
Organise Peer Support and Group Education Sessions for clients in the community.	3. Peer Support and Group Education	1 hour	Tool Six (PS): Group Discussion and Role Play  Tool Seven (ST): Group Work

# 1. What is Community Preparedness? (1 hour)

## a) What does Community Preparedness for treatment mean? (20 minutes)

Community preparedness for treatment involves not only ARVs, but other medications, such as CTX, TB medications and others PLWHA may need in your community.

**Community Preparedness** involves providing support and breaking down barriers for successful interventions to ensure roll-out of treatment is successful. Before ART interventions begin, it is important that the community is educated on the benefits of ARVs, the importance of adhering to ART and the need for family and community support for ART to be successful.

Quick facts about community preparedness:

- The uptake and adherence of ART have been shown to improve when PLWHA and their families are helped to overcome obstacles in the community to accessing treatment, particularly stigma and discrimination
- Developing partnerships with communities helps PLWHA to understand ART and encourages efforts to improve their own health and accept treatment
- Community Home Based Care programmes, such as the involvement of CBVs, has been shown to improve community preparedness by involving PLWHA, their families and fellow community members to assist PLWHA
- Community preparedness involves understanding community beliefs around HIV, AIDS and ART, and working together to educate and inform
- Mobilising community resources and forming relationships between various stakeholders (health services, NGOs, CBOs, faith-based organisations and PLWHA groups) is a critical part of community preparedness
- Capacity building within the community through training (such as the ART training toolkit for CBVs) and improving existing community structures such as hospitals, clinics and VCT services, are all part of community preparedness.

## b) Who is Involved in Community Preparedness? (10 minutes)

As its name indicates, community preparedness involves all members of a community that have a role to play in the support and care of PLWHA.

Community Preparedness involves:

- Community groups (hospitals, clinics, support groups, NGOs, CBOs, churches)
- Community representatives (traditional leaders, civic leaders)
- Peers of PLWHA (friends, neighbours)
- Family of PLWHA (spouses, extended family)
- CBVs and others involved in home-based care and support
- PLWHA themselves
- Private and public sector

### c) Who is responsible for Community Preparedness? (30 minutes with Tool 1)

It is not one person's or group's responsibility to ensure community preparedness for the roll-out of ART. Rather, community preparedness involves a team effort.

Institutions and individuals responsible for community preparedness include:

- Government
- Hospitals and clinics
- NGOs, CBOs, FBOs
- Community leaders
- Family of PLWHA
- PLWHA
- Individual community members (including CBVs).



#### Tool 1: How Prepared is Your Community?

PART A: As a group, discuss how prepared your community is for comprehensive ART intervention. Create a table similar to the one below on a flipchart and brainstorm on the existing strengths and areas in need of improvement for your community to be prepared for ART intervention.

##### COMMUNITY STRENGTHS

- Local clinics providing ARVs
- Red Cross Involvement in the Community
- Support groups for PLWHA
- Training CBVs on ART interventions using this training package

##### AREAS FOR IMPROVEMENT

- Involvement of local leaders
- Community awareness of HIV, AIDS and ART
- Stigma and discrimination against PLWHA

PART B: Based on identified areas for improvement, as a group discuss specific ways that these areas can be improved and the role CBVs can play in improving community preparedness.



## 2. The role of CBVs in Community Preparedness (2 hours)

CBVs have an important role to play in community preparedness for ART interventions. As members of your community with special knowledge and skills on HIV, AIDS and ART, CBVs can increase awareness and acceptance of ART.

Distribute copies of Handout 3-5 'The Role of CBVs in Preparing their Community for ART' and ask participants to follow along as you provide information on each section. Ask CBVs to fill in any additional roles CBVs may have in preparing your community for comprehensive ART interventions.

### a) Ensuring that adequate information is available (10 minutes)

Providing accurate information about ART is one of the most important aspects of community preparedness that CBVs can assist with. Without information about what ARV treatment is, how ART will help PLWHA, how drugs are taken and the possible side effects of ARVs, it is possible for misconceptions about ART to be held by community members. Such misconceptions might create obstacles in the community for PLWHA to access treatment, or might cause ARVs to be taken improperly once treatment begins.

Ways that CBVs can help ensure that adequate information is available are:

- Knowing where people can access information they need about HIV, AIDS and ART (community resources)
- Acting as a sound source of information on HIV, AIDS and ART

### b) Addressing Stigma and Discrimination (30 minutes with Tool 2)

Stigma is one of the main reasons that people in the community might not make use of HIV Testing and Counselling services or access treatment for HIV and AIDS. Shame and secrecy work against ART interventions, because people hide the fact that they are taking ARVs if they have not disclosed their HIV status. Successful ART interventions depend on a culture of acceptance and openness that encourages PLWHA to seek out and adhere to treatment.

It is important for CBVs to understand the meaning of stigma and discrimination if they are going to help improve community preparedness.

**Stigma** involves negative **attitudes** toward people who are HIV positive or belong to a particular group, or who have different characteristics than others. PLWHA can be stigmatised through negative feelings by others or negative feelings of PLWHA towards themselves.

**Discrimination** is actually **treating other people differently** or unfairly because they are HIV positive or different from others.

Ways in which CBVs can address stigma in their community:

- Dispel myths about HIV and AIDS or ART interventions held by those in the community
- Encourage the use of HIV Testing and Counselling services and supportive disclosure
- Provide examples/act as an example of how PLWHA are important members of the community.

## Tool 2: Stigma in your Community

**Task One:** Divide participants into four groups. Have each group give a short dramatisation of a form of stigma or discrimination that is directed towards PLWHA in the community.

**Task Two:** After each group presents their dramatisation, make a master list of “Stigma and Discrimination to be Addressed” and discuss strategies for addressing each form of stigma or discrimination in the community.

### c) Involving Traditional Healers and Leaders

#### (20 minutes with Tool 3)

Traditional healers and leaders play an important role in the health-seeking behaviours of community members and the success of information programmes.

Traditional healers can include herbalists, spiritualists and witch doctors. It is important to include traditional healers in preparing a community for ART intervention.

Traditional leaders such as chiefs, village heads or headmen can also play an important role in the community acceptance of ART interventions and in dispelling myths and misconceptions about HIV, AIDS and ART.

Ways that CBVs can help involve traditional healers and leaders include:

- Encouraging partnerships between traditional healers and formal health services
- Educating traditional healers and leaders on HIV, AIDS and ART intervention
- Dispelling myths among traditional healers that might damage the acceptance of ART in the community
- Encouraging traditional leaders to help address stigma and discrimination in the community towards PLWHA





### **Tool 3: Traditional Leaders and Healers in your community.**

As a group, discuss how traditional healers and leaders play a role in your community. Identify any beliefs or customs used by traditional healers and leaders that could help or hinder ART interventions. Make a list of specific ways CBVs can help involve traditional healers and leaders in your community in ART interventions.

## **d) Meaningful Involvement of PLWHA (1 hour with Tool 4 and 5)**

The Meaningful Involvement of People Living with and Affected by HIV and AIDS (MIPA) is one of the most important aspects of preparing a community for ART. If PLWHA do not feel as though they have a voice in treatment and care decisions that affect them, the success of ART interventions will suffer.

PLWHA should be consulted at each step of planning and administering ART interventions. They are the community's best resource when it comes to finding out what areas of information on HIV, AIDS and ART might be lacking and pointing out obstacles to ART intervention.

CBVs can help involve PLWHA in community preparedness by:

- Emphasising that PLWHA are not passive “recipients” of treatment, but can make important contributions to the planning and execution of ART interventions
- Encouraging the involvement of PLWHA in community preparedness by telling others about HIV, AIDS and ART, addressing any stigma against PLWHA and encouraging testing and treatment
- Supporting the creation of support groups for PLWHA
- Being advocates for improved health services for PLWHA in the community.



### **Tool 4 : Meaningful Involvement of PLWHA**

Discuss as a group how PLWHA should be part of preparing the community for ART roll out. Specifically ask the PLWHA guest speakers to lead the discussion by answering the following questions:

1. How are PLWHA already involved in the community?
2. What are some ways that CBVs can involve PLWHA in preparing the Community for ART?



## Tool 5 : Conducting a Community Awareness Meeting

Now that CBVs have developed specific ways in which they can assist in preparing their community for comprehensive ART intervention, it is important that they demonstrate the ability to put this knowledge into practice.

Ask participants to provide a demonstration on how they would conduct a community awareness meeting to improve community preparedness for ART.

Important aspects participants should include in their presentation include:

Listing important individuals and organisations in your community that they need to attend the awareness meeting. For example, representatives from:

- o Local clinics
- o Traditional leaders and healers
- o Local government
- o NGOs, CBOs, FBOs involved in HIV and AIDS work

Addressing each of the aspects of community preparedness discussed in this session including:

- o Ensuring adequate information is available
- o Addressing stigma and discrimination
- o Involving traditional healers and leaders
- o Promoting the Meaningful Involvement of PLWHA

**Facilitator's Note:** In assessing this core skill at the end of the module, have individual participants describe how they would organise a community awareness meeting and the topics of discussion they would address at the meeting. Facilitators can use the points above to assess the competency of CBVs at this task

## 3. Peer Support and Group Education (1 hour)

### a). Peer support (30 minutes with Tool 6)

**Peer support is support for people by people in the same situation.**

- Peer support includes people who are facing the same challenges such as the client. These can be women living with HIV, partners of HIV+ people, or newly diagnosed people.
- Peer support can be between someone who is facing a challenge for the first time and someone who has already managed it. This means linking someone who is starting ART to someone else who has already started ART and is managing well.

### Benefits of Peer Support

- Reduces isolation
- Increases social support
- Reduces stigma
- Less intimidating source of support
- Helps to share experiences

- Helps people see that living with HIV is possible.
- Reduces reliance on health services
- Reduces the workload of the health workers
- Increases the quality of life for people living with HIV

While clients learn a lot from health workers, some things are better learned from those who have experienced the same problems and addressed the same barriers. Whether in the hospital, health centre or home community, clients find peer support to be a vital part of the care provided.

### **Promoting Peer Support:**

- Talking to clients regularly about peer support and encouraging them to access it
- Emphasising the benefits of peer support
- Acknowledging their fears
- Finding out what is available locally and knowing the details of the clubs/groups in that area
- Establishing peer support groups for: positive women, positive men, partners of people with HIV, people on ART
- Establishing post test clubs
- Running group education sessions
- Identifying individuals who are prepared to act as peer supporters

### **Why People Stop Using Peer Support:**

- Fear of confidentiality being broken
- Fear of meeting new people
- Fear of meeting other people with HIV
- Not knowing that peer support exists
- Being too busy to have peer support
- Not being able to get to the peer support meetings
- Not having transportation money
- Needing to care for children
- Not having partner support to attend
- Having to explain where they are going to others
- Having other commitments

### **Ways to Offer Peer Support:**

**Individual peer support:** If someone is newly diagnosed with HIV or is starting ART, it can be particularly helpful to link them to a person who has already come to terms with their situation and can share their experiences and give them encouragement.

**Social group:** Very often people living with HIV feel isolated and alone. Meeting other people living with HIV can reduce isolation and encourage them to live more fully. These groups can meet socially or focus on income generating activities. These groups are usually run for and by people living with HIV though they initially can be set up by a health worker.

**ART Support Groups:** People who are all starting ART or who are at a similar stage in taking ART (either preparing to begin ART, starting ART, having been on ART for more than 6 months, etc) may find it helpful to meet each other for mutual support. The role of the ART counsellor is to enable this to happen and to facilitate groups until they become self running.

**Post-test clubs:** These groups are for anyone who has been tested for HIV. Therefore, they do not require participants to identify their status when joining them. They often focus on promoting HIV information and education in the community, but they also provide a social environment for the members to meet each other and discuss any relevant issues.



## Tool 6: The Role of CBVs in Promoting Peer Support

Divide participants into four groups. Have each group develop a presentation on the following topics:

Group One: What are the benefits of peer support?

Group Two: How would you promote peer support?

Group Three: What might stop people from using peer support?

Group Four: How should CBVs offer information on peer support to their clients?

As each group presents, review information on each topic below to make sure that important concepts have been covered.

### **PART B: Providing Information to Clients**

Once all groups have presented and facilitators have provided key information below, ask participants to find a partner who they have not paired with yet during training. Have pairs role-play providing the information discussed in this activity as they should during a client education session.

## 4. Group Education (30 minutes with Tool 7)

A group education session is best described as an extended health centre visit where not only physical and medical needs are met, but educational, social and psychological concerns are dealt with in a group setting.

Group education sessions can help clients to make the most of scarce time in the health centre. CBVs should arrange for clients to make use of group appointments to:

- Educate clients about their conditions
- Develop peer support and expertise
- Promote self-management
- Conduct clinical follow-up
- Address difficulties

**Group education sessions should be established by the CBV and run by the health worker.**

**Ask:** Who should group appointments be for?

**Answer:** It is important to group clients with similar characteristics together. For example, linking HIV positive women, HIV positive teenagers, or people just starting ART, would all be appropriate groups.

**Ask:** What are the reasons for selecting appropriate groups?

**Answer:** Culturally, it would be very hard for a young HIV positive woman to speak openly with an older HIV positive man present. It is important to remember that women in general find it hard to speak with men, particularly about personal issues. It is also easier to share experiences with people in similar circumstances.





## **Tool 7: How to Organise a Peer Support or Group Education Session**

**Split** the participants into 2 groups.

**Ask Group 1:** What do you need to do to establish peer support in your area?

- Find out what is locally available so as not to duplicate services
- Consult with HIV positive people using the health services system
- Identify different strategies for peer support: either one-to-one support, support groups or post test clubs; and decide which of these strategies you wish to develop further
- Identify people who would be interested in working to develop peer support systems (both health workers and HIV positive people)
- Hold a meeting with health workers and HIV positive people so that you may discuss your plans
- When building peer support groups, it is important to carefully consider:
  - Venue and time
  - Costs and who will pay
  - Who the group is for
  - Who will lead the group
  - How confidentiality will be maintained
  - How the health worker will support the facilitators
  - The role of the health workers
  - How to promote the group in the wider community

**Ask Group 2:** What do you need to do to establish group education in your health centre?

- Consult with your clinical team/Red Cross and Red Crescent Society consult with HIV Positive people using the health services system
- Identify people who would be interested in working to develop peer support systems (both health workers and HIV positive people)
- Invite them to discuss plans:
- When establishing group education sessions, it is important to carefully consider:
  - Venue and time
  - Costs and who will pay
  - Who the group sessions will be for
  - How to choose people to be part of the group
  - What activities will happen in the sessions
  - What the role of the group members will be
  - What the role of the health worker will be
  - How to promote group education classes in the wider community

**Ask** each group to report back.



# References

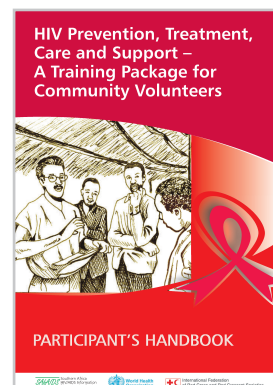
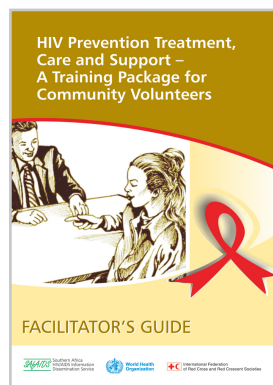
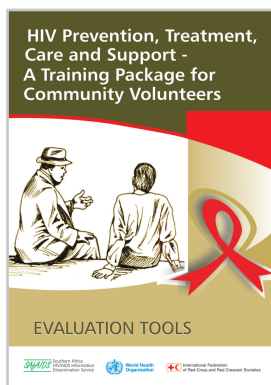
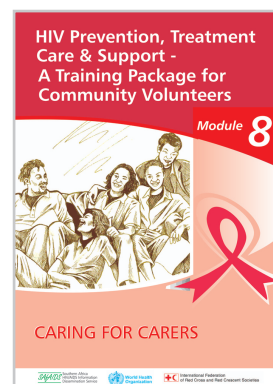
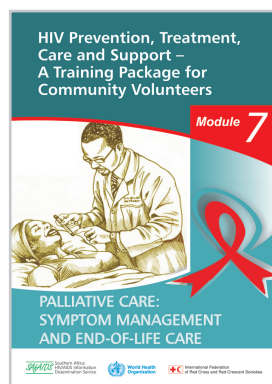
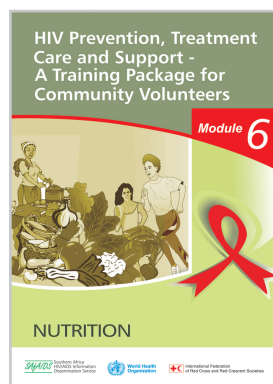
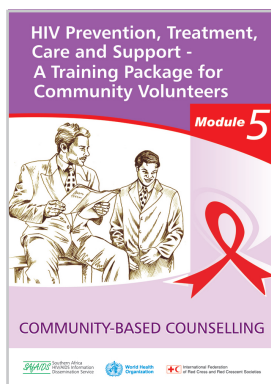
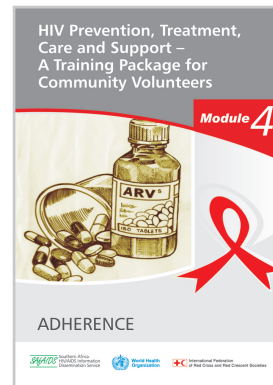
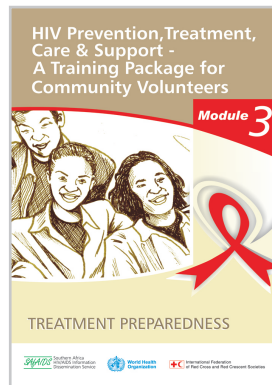
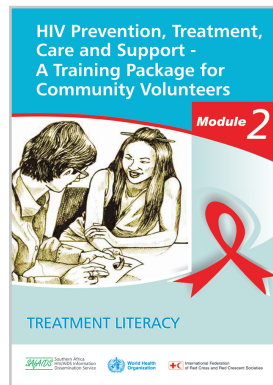
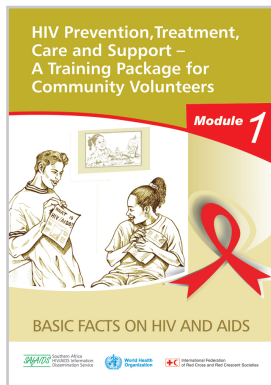
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My Notes

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