

# TRAINING OF LAC COUNSELLORS HANDBOOK FOR TRAINEES

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**Care, Support & Treatment Division**

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**Ministry of Health and Family Welfare**

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# List of Abbreviations

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AIDS	Acquired Immune Deficiency Syndrome
ANC	Ante-Natal Care
ARS	Acute Retroviral Syndrome
ART	Anti-Retroviral Treatment
ARTC	Anti-Retroviral Treatment Centre
ARV	Anti-Retroviral
ATT	Anti-Tuberculosis Treatment
AZT	Zidovudine
BCG	Bacille Calmette Guerin – vaccine against TB
CBO	Community Based Organisation
CCC	Community Care Centre
CD4	White blood cell which is part of immune system
CLHIV	Children Living with HIV
CPT	Co-trimoxazole prophylaxis treatment
COE	Centre of Excellence
CST	Care, Support and Treatment
DLN	District Level Network
DMC	Designated Microscopy Centre
DOTS	Directly Observed Treatment Short Course
d4T	Stavudine
EFV	Efavirenz
FDC	Fixed-Dose Combination
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ICTC	Integrated Counselling and Testing Centre
IDU-TI	Targetted Intervention Project - Injecting Drug Users
INH	Isoniazid prophylaxis
LAC	Link ART Centre
LFU	Lost-to-Follow-up
LPV	Lopinavir/Ritonavir

MO	Medical Officer
NACO	National AIDS Control Organisation
NGO	Non-Governmental Organisation
NRTI	Nucleoside Reverse Transcriptase Inhibitor
NNRTI	Non-Nucleoside Reverse Transcriptase Inhibitor
NVP	Nevirapine
OI	Opportunistic Infection
ORS	Oral Rehydration Solution.
PCP	Pneumocystis Carinii Pneumonia
PI	Protease inhibitors
PLHIV	People Living with HIV
RNTCP	Revised National Tuberculosis Control Programme
SACEP	State AIDS Clinical Expert Panel
SACS	State AIDS Control Society
STI	Sexually Transmitted Infection
TDF	Tenofovir
TB	Tuberculosis
VAS	Visual Analogue Scale
ZDV	Zidovudine
3TC	Lamivudine

# Understanding the Link ART Centre

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At the end of this unit, participants will be able to

- Describe the activities of the Link ART Centre and their relevance to the National AIDS Control Programme
- Distinguish between the Link ART Centre and the LAC Plus

This chapter will first explain why there is a need for Link ART Centres (LAC) and what these LACs do. Next it will describe the services of the LAC Plus.

## Background

Once a person has started antiretroviral treatment (ART) he/she has to take the medicines for life. Most research studies on adherence to ART show that patients are adherent when they agree to the recommendations of a healthcare provider and ‘take the prescribed medications in a timely manner.’ But their willingness to adhere is also limited by economic burden and transportation costs.

Free Antiretroviral treatment has been available to People Living with HIV/AIDS (PLHIV) from 2004 through the National AIDS Control Programme’s Care, Support and Treatment (CST) services. This takes care of one kind of limiting factor – financial cost of the medicine. But most ART centres are situated at medical colleges, tertiary hospitals and district hospitals.

A situational analysis was undertaken of 27 ART centres in 14 states and Union Territories covering 1366 clients (Sogarwal and Bachani, 2009). Out of 1007 persons who reported being

currently employed, nearly half (48.6%) were agricultural, unskilled workers, industrial or factory workers. While almost one-third (29.6%) had to travel less than 20 kms to reach the ART centre, for a little over one-third (35.6%) the distance from home to ART centre was at least 100 kms. More than three-quarters (76.3%) rely on a bus or train to reach the ART centre. Further, though free treatment is available in all ART centres, clients reported incurring expenditure related to transportation to and from the ART centre as well as refreshments during the wait period. While 86% visited the ART centre regularly, the reasons for not visiting, among the 14% who were not consistent, included long distances and financial reasons.

From these findings it is clear that several patients have to travel long distances to reach their designated ART centre. This may lead to missed monthly visits, particularly when the patient is travelling or is otherwise feeling healthy. Such monthly visits may also require the patient to stay in the city which may lead to further expense. Another discouraging factor they may face is inconvenience with the rush and long waiting hours in the ART centre.

To reduce these difficulties faced by clients on ART, the National AIDS Control Organization (NACO) initiated the Link ART Centre Programme in 2008. These LACs function at convenient Integrated Counselling and Testing Centres (ICTCs) at district/ sub-district level. LACs serve as authorized drug distribution centres closer to the client than the ART centre. They are linked to Nodal ART centres. Their goal is to help clients to stay adherent to treatment and to ensure the integration of ART services with the primary health care system. In 2012, the role of some LACs was also expanded and they were designated as "LAC Plus." LAC Plus centres are select ICTCs which also undertake Pre-ART Management – that is management of patients who are not eligible for ART. The goal of NACP IV is to scale up to 1200 LACs by 2017.



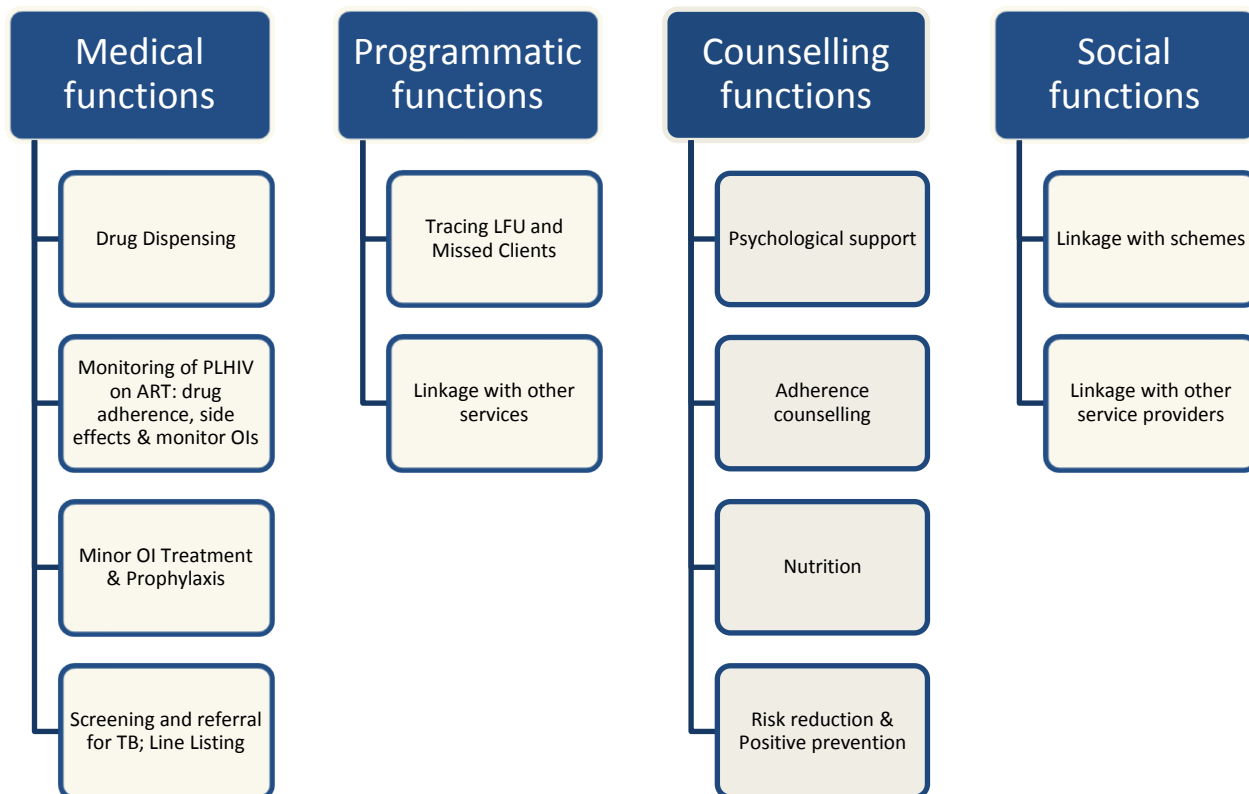
# **Objectives of the Link ART Centre**

1. To reduce the travel cost and travel time of PLHIV in accessing ART services.
2. To increase the access of the PLHIV to HIV care.
3. To improve the drug adherence of patients on ART.
4. To bridge the gap between Counseling & Testing services (ICTC) and Care, Support & Treatment (CST) services
5. To integrate HIV Care, Support and Treatment services with the primary/ secondary health care system.
6. To build the capacity of the health care providers at the primary/secondary health care level for CST services for sustainability of services.

The objectives can be identified as directed towards client and towards the national programme on Care, Support and Treatment.

# **Functions of the Link ART Centre**

The members of the Link ART Centre team are counsellors, doctors, staff nurses and a pharmacist. They serve the following functions at the LAC as per the Operational Guidelines for Link ART Centres and LAC Plus (2012):



### Medical Functions:

- LAC is responsible for providing ARV drugs to stable patients on ART who have been linked out from the nodal ART centre. The drugs will be sourced from that ART centre.

**LAC or LAC Plus shall not modify/ initiate ART regimens at any time.**



- Monitoring of PLHIV on ART: LACs will monitor PLHIV who have been linked out from the ART Centre in terms of drug adherence, side-effects of drugs and Opportunistic Infections (OIs). The LAC is responsible for patient follow-up to maintain optimum drug adherence, prevent and trace Missed and Lost-to-Follow-up (LFU) cases of both pre-ART and ART categories. The LAC has to refer the patient back to the ART centre in case of a major OI, serious side effects of drugs and pregnancy.

- LAC will identify and treat minor OIs. It may provide in-patient care for OIs depending on the hospital facilities. However after the patient has stabilized, he/ she must be referred back to the ART centre for re-evaluation.
- All PLHIV will be screened for tuberculosis (TB) at every visit. All patients with symptoms of TB will be referred to the nearest RNTCP unit for diagnosis and treatment of TB. In case the patient is diagnosed as having TB, she/he must be referred back to the nodal ART centre so that the ART regimen can be altered before TB treatment is started. LAC will do line-listing of HIV-TB co infected cases. Intensified case finding for TB will be undertaken by the LAC as per guidelines

### **Programmatic Functions**

- Tracing LFU and Missed Clients (Pre-ART & on ART): LAC will maintain a Daily-Due list of PLHIV on ART and a CD4 due list of PLHIV who are registered in pre-ART care. The staff nurse and the counsellor will be responsible for tracing Missed and LFU cases through the telephone or through outreach. They may use the services of the District Level Network (DLN), Link Workers and outreach workers for such tracing.
- Linkage with other services: The LAC will maintain links with RNTCP, STI, DLN, NGOs, CBOs and other services.

### **Counselling Functions:**

- LAC will provide psychological support to PLHIV.
- LAC will provide counseling for adherence to ARV drugs.
- LAC will counsel and educate PLHIV on proper nutrition.
- LAC will counsel on risk reduction and positive prevention.

### **Social Functions:**

- LAC will provide information about various social welfare schemes available for PLHIVs and facilitate their access to available resources provided by government agencies and NGOs.
- LACs will facilitate linkage with other service providers such as educational help for children, income generation schemes, etc.

# Functions of the LAC Plus

An LAC is designated as an LAC Plus when persons whose positive status is detected at nearby ICTCs can come for ART registration to that centre. This centre will therefore have both patients who are on ART as well as patients who are not yet eligible for ART.

In addition to the general functions of an LAC, an LAC Plus must also do the following:

## Pre-ART Care:

HIV-positive clients in the catchment area of the LAC may opt to get registered for pre-ART care and baseline investigations at the nearest LAC Plus if the nearest ART Centre is more distant.

For such PLHIV registered at an LAC Plus.

- The LAC Plus will collect their sample for the CD4 count at the LAC itself on a pre-designated day and send it to the nodal ART centre for processing.
- The LAC Plus will follow the PLHIV throughout the period of Pre-ART care (that is the person's CD4 count is not low enough to merit ART. The centre will follow the person every 6 months for the semi-annual CD4 test. The centre will treat minor OIs and provide in-patient care.
- The LAC Plus will refer the PLHIV to the nodal ART Centre when they become eligible for ART, or if they develop a major OI which requires specialized treatment.

## Tracing Pre-ART Missed or LFU cases:

The LAC Plus will maintain a CD4 due list. Cases that miss an appointment or who are lost to follow up are traced by the nurse or the counsellor. The protocol is the same as the ART tracing. But the counselling will differ.

## References:

Sogarwal, R. & Bachani, D. (2009). Assessment of ART centres in India: Client perspectives. *Journal of the Indian Medical Association*, 107 (5), 276-280.

National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India (2012). *Operational guidelines for Link ART centres and LAC Plus*. New Delhi, India: Author.

National AIDS Control Organisation, Department of AIDS Control, Ministry of Health and Family Welfare, Government of India (December 2009). *Assessment of Link ART centres in India: client and provider perspectives*. New Delhi, India: Author.

# Comparing LAC and LAC Plus



## Exercise

Write Yes if the LAC or the LAC Plus does this activity

Activity	LAC	LAC Plus
Dispensing ARV drugs		
Monitoring PLHIV who are on ART		
Counselling on adherence		
Counselling on nutrition, risk reduction and positive prevention		
Treatment of minor OIs		
Treatment of major OIs		
Identification of side effects of ARVs		
Tracing of Missed cases and LFU		
Screening for TB symptoms on every visit		
Social support to PLHIV		
Back-referral to ART Centre		
Registration of PLHIV into pre-ART care		
Pre-ART management including CD4 test		
Initiation of ART		

# Counselling at the Link ART Centre

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At the end of this unit, participants will be able to

- State the needs of clients visiting the LAC
- Compare counselling at the LAC with counselling at the ICTC
- Describe the stages of counselling in relation to work at the LAC

## Role of counsellor at the LAC

In addition to their existing tasks of the ICTC, the counsellor in a Link ART centre must, through ongoing counselling:

- Address issues of stigma and discrimination and rights of the PLHIV.
- Address issues related to ARV treatment such as adherence and side-effects.
- Provide emotional, social, and psychological support to patients and/or direct the patient to suitable organizations.
- Repeatedly emphasize positive living, prevention and condom use. Here they may also have to dispense condoms.
- Complete the required reporting formats.



## Exercise

Write 3 differences between counselling for the ICTC and counselling for the LAC.

ICTC	LAC

### *Positive Prevention*

Positive prevention refers to prevention efforts by those who are HIV-positive. It includes:

1. Capacity of People Living with HIV to protect their own health. This involves their actions to prevent HIV super-infection (that is re-infection with another strain of HIV leading to an increased viral load), Sexually Transmitted Infection (STIs) and Opportunistic Infections (OIs).
2. Prevention of HIV transmission to others.

PLHIV can practice positive prevention through:

- Safer sex practices (also prevents STI)
- Safe injection practices
- Healthy lifestyle including a proper diet, exercise and adequate rest to prevent OIs
- Seek medical care at the onset of OI symptoms

While providing counselling for positive prevention, counsellors should respect the rights and needs of people living with HIV to enjoy sexual relationships, have reproductive choices and live a full and healthy life. They should also assist PLHIVs to access the services they require to treat their OIs (i.e., LAC, ART or CCC), to treat their STIs (i.e., STI clinic) and to reduce the harm caused by their behaviours (i.e., IDU-TI). Finally, a non-judgmental and non-discriminatory attitude is a key requirement of positive prevention services.

# Stages of Counselling

Though the tasks of a Link ART counsellor are new to you, you already have some experience of counselling. So perhaps you might wonder how working with a client accessing LAC services is different. There are 2 basic differences.

The first most obvious difference is that earlier you were more focused on testing and related issues if you were an ICTC counsellor. Whereas for the LAC client, your counselling will centre on adherence to ART, and on psycho-social support related to living with a chronic illness. However, what will still be common are the prevention messages you give the client.

You will still discuss Positive Prevention:

- Prevention of Opportunistic Infections to the PLHIV
- Prevention of re-infection by another strain of HIV
- Prevention of transmission to sexual partners, and from an infected woman to any child she might bear from this point forward

The second difference is slightly less obvious. Most of the ICTC clients you have met are probably “therapy virgins” or “therapy naïve”– that is, they have no prior experience of any kind of counselling. But the LAC client has already experienced at least two counselling interactions. They carry with them into the current counselling relationship, expectations that have been built up from these earlier two interactions. If the earlier counsellors were rushed or rude, they may expect all counsellors to be the same. If their previous counsellor was patient, they will expect patience. So one of the first things you should explore is the client’s previous experiences.

The third obvious, but relatively unimportant, difference is the time factor. ICTC interactions are usually time-limited and brief. In LAC interactions, you have an opportunity to explore the client’s situation in a more relaxed manner. You have the scope to pace out the different topics you wish to address in the client’s life

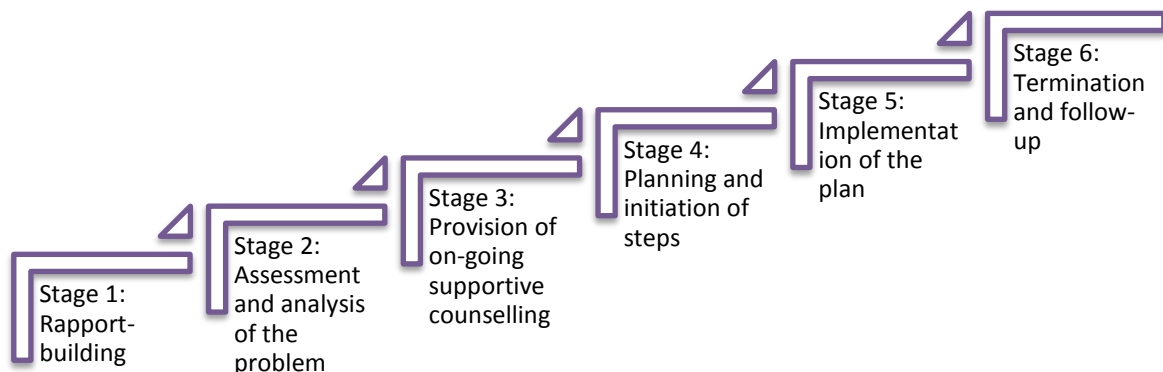
No matter whether you are seeing ICTC clients or LAC clients, the counselling process will follow the same stages: Rapport-building, Assessment and analysis of the problem, Provision of ongoing supportive counselling, Planning and initiation of steps, Implementation of the plan, Termination and follow-up. You should be familiar with these concepts from your induction training. Presented below is a review of the stages along with some brief insights about their application to the LAC process.



What you should note is that most ICTC counsellors practise a form of brief therapy or counselling – that is they are expected to go through all six stages of the counselling process in the course of one day through two brief sessions of not more than 15-20 minutes (They may take more time in the case of a person with a positive test result).

However, working with an LAC client presents the possibility of a much longer-term engagement. You will see the patient for at least 5 sessions before referring them back for their six-monthly check-up at the Nodal ART Centre. This should set you thinking about what is the best way to work with individual clients - namely you can take up different topic in different sessions.

Also, as you are likely to follow up the same client over a period of years, you should be alert to changes in the person’s life which may affect their adjustment. For instance, one LAC counsellor reported that an adolescent client had recently completed school and entered college. A life change like this would immediately trigger questions like: “Do you have to take your ART at a different time now? Do you feel comfortable carrying your pills with you (or taking your pills in front of your new friends)? If you have a new boyfriend/ girlfriend, what will you tell them about your condition? Do we need to change the day on which you come to pick up your medicine refill?”



## **Stage 1: Rapport-building**

Rapport-building refers to the act of forming a working relationship with the client and gaining their trust. This stage is facilitated by a warm, welcoming atmosphere with adequate privacy, good seating arrangement, and establishing eye contact with the client. NACO's Induction Training materials describe the following sub-processes as part of rapport-building.

- Assuring confidentiality and discussing the limits of confidentiality
- Allowing ventilation
- Allowing expression of feelings
- Exploring the problem(s), asking the client to discuss their problem
- Clarifying the client's expectations of counselling
- Describing what the counsellor can offer and the method of working
- Statement from the counsellor about their commitment to work with the client

To this it is also important to add the discussion of their relationship with their previous counsellors. This will give you some idea of their expectations. You may even at this point clarify the scope of counselling.

## **Stage 2: Assessment and analysis of the problem**

Though the main issue is dispensing of ART to the client and related adherence, the counsellor should at this stage go beyond information presented in the Green Book and White Card. The client may have concerns related to family. Also the LAC/ ICTC is much closer to their home than the nodal ART Centre. So they may be worried about their status becoming public. It is good to check the PLHIV's comprehension of adherence and other issues. This will be discussed in a following chapter.

## **Stage 3: Provision of on-going supportive counselling**

This stage is one which was likely to be missing from the brief kind of ICTC counselling you have managed before. You must note that even though a PLHIV has been linked out to your centre because they are stable on ART for 6 months, he/ she still needs your support. An obvious way of providing support is with regard to maintaining adherence. But you may also find yourself discussing other issues such as client's need for a therapy holiday (break from treatment), desire to have a child now that he/she is feeling better, etc. For this you must help with the following processes

- Continuing expression of thoughts and feelings
- Identifying options
- Identifying existing coping skills
- Developing further coping skills
- Evaluating options and their implications
- Enabling behaviour change
- Supporting and sustaining work on the client's problems
- Monitoring progress towards identified goals
- Altering plans as required
- Providing referral as appropriate

As regards the last point, a PLHIV may require referrals to the CCC or back to the ART Centre. Those who are doing well should be encouraged to go to work. The patient records provide you a good mechanism to track physical progress. But you must also make a note of psycho-social progress. You may have to encourage the patient to develop new behaviours.

#### **Stage 4: Planning and initiation of steps**

An important dimension of this process model is that it clearly focuses on behaviour change. The next two steps deal with this behaviour change. You may want to inculcate in your client new behaviours such as open communication with their spouse or giving up addictions like smoking and excess alcohol use. But an important goal in counselling is to strengthen the behaviour which he/she has already developed at the ART Centre – that of adhering to the medicine.

- Motivating the client for behaviour change
- Setting attainable goals
- Planning to achieve goals
- Planning and initiating is done by
  - identifying the options,
  - identifying existing coping skills, and
  - developing further coping skills
- Evaluating options and implications to enable behaviour change

#### **Stage 5: Implementation of the plan**

- Selecting a plan of action

- Sequencing the intervention activities
- Ways of implementation
- Putting the plan into action
- Reinforcing and monitoring behaviour change
- Being supportive while the client performs the new behaviour

## **Stage 6: Termination and follow-up**

This model of counselling focuses on successful behaviour change and termination of the relationship when the behaviour has been successfully incorporated into the life of the client. At the LAC, the counselling relationship is more likely to terminate if a patient is not doing well on the ART and has to be referred back to the nodal ART centre. Unfortunately, our progress in medicine has not yet brought us to a stage where the PLHIV may be declared HIV-free or in remission.

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### **Questions to LAC counsellors:**

- ✓ What are some of the new behaviours that an LAC client may have to develop?
  - ✓ What changes would you have to make to accommodate an LAC client?
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## **Understanding the Profile of LAC clients**

In 2009, NACO undertook a study on Link ART Centres in 4 states: Gujarat (high-prevalence), Maharashtra (high-prevalence), Rajasthan (low-prevalence) and Uttar Pradesh (low-prevalence). This section carries some of the study findings that are most relevant to HIV counsellors at LACs.

### **Travel and Access Time**

One critical feature of the LAC concept is that it reduces time to access services. This study looked at travel and service access time for patients. Understandably, clients in the high-prevalence states of Maharashtra and Gujarat spent less time commuting to the LAC in comparison to clients in Rajasthan and UP. This was because some LACs in high prevalence states have been established in sub-district facilities.

Two key points should be noted: Even though most clients reported a lower travel time, at least one out of every 10 clients surveyed came from distances of 80 kms or more to access the LAC. Secondly, even in the low-prevalence states, distance for travelling was cut down in many instances because some LACs were located in districts different from where the ART centre was located. (However, this would have implications for how the LAC team keeps in touch with the nodal ART centre.)

Most clients report being able to access the service they require in a reasonable time: About 87% report completing registration procedures within 30 minutes and more than 95% report waiting less than 30 minutes to meet the counsellor and collect their drugs. Overall 50% of the LAC service recipients reported that their actual waiting time for registration and counselling is 10 minutes.

## **Adherence**

PLHIVs who avail their ART through LACs tend to be very regular in following up: In the study 97% were prompt in their monthly attendance at the centre. The small number of clients who were irregular mentioned the following excuses: Long distance (9 out of 12), financial reasons (5 out of 12) and adverse reactions to ARV drugs (2 out of 12).

## **Views on Counselling**

When asked what services they avail, three-fourths (76.6%) of the respondents reported using counselling services. Moreover, about half were dispensed drugs by the counsellor. These figures highlight how central the role of the counsellor is to the functioning of the LAC. Most study participants also indicated that the counsellor at the LAC always listened to their problems.

However, the scope of counselling imparted by the counsellors was limited to regular intake of ARV drugs. Less than 1% of clients were able to recall the counsellor discussing other issues related to secondary prevention such as use of a condom and personal hygiene. Further, 12% of LAC patients reported that their last counselling session was not undertaken privately but in the presence of other patients. This shows that there is much room for improvement in counselling.

## Cost to patient

Though the LAC is, in theory, supposed to reduce the cost to the patient, PLHIVs still incur costs (Please see the table for the costs mentioned by the study participants.). So it would be wrong to assume that treatment is free.

	<i>Minimum Expenditure (Rs)</i>	<i>Maximum Expenditure (Rs)</i>
<i>Transportation</i>	3	700
<i>Registration</i>	2	260
<i>Other drugs from outside</i>	15	900
<i>Laboratory tests</i>	40	1500
<i>Other</i>	5	500
<i>Loss of wages</i>	10	390

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### Questions to LAC counsellors:

- ✓ Do the findings of the study match what you have observed in your practice?
  - ✓ What expectations do you think clients have when they come to the LAC?
  - ✓ How can you as a counsellor deliver a quality service?
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### References:

Sogarwal, R. & Bachani, D. (2009). Assessment of ART centres in India: Client perspectives. *Journal of the Indian Medical Association*, 107 (5), 276-280.

National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India (2012). *Operational guidelines for Link ART centres and LAC Plus*. New Delhi, India: Author.

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# Basics of Antiretroviral Therapy

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At the end of this unit, participants will be able to

- Describe the progression of HIV infection to AIDS and the WHO clinical staging
- Explain about ART, its benefits, side-effects and limitations
- Describe the effects of ARV drugs in relation to the HIV life cycle in the body
- Identify the reasons for treatment failure and need of 'switch' and 'substitution' of treatment
- Assess and evaluate these issues jointly with clients

LAC counsellors have an important role to play in addressing issues related with ART treatment. As an LAC counsellor you counsel clients who have been receiving ART for more than six months. During counselling sessions you may need to explain the details of treatment, the side-effects of ARV drugs and the limitations of ART. This is despite the fact that clients may have already heard this information from the ARTC team. You also have to play a very important role in helping clients to adhere to their treatment by assisting them to identify possible challenges and solutions to managing treatment as successfully as possible and in maintaining quality of life. Therefore, you need to review what you know about HIV/AIDS and ART.

# Stages of progression of HIV to AIDS

Understanding how HIV progresses to AIDS helps in understanding the importance of timely treatment for PLHIV.

**HIV** is the short form for Human Immunodeficiency Virus. It breaks down the body's defence against infection and disease (the immune system) by destroying specific white blood cells (CD4 cells).

**CD4 cells** are a type of white blood cells that make up the main fighting force of the immune system. When HIV actively multiplies, it infects and kills CD4 cells, the immune system becomes weak or compromised, the body loses its ability to fight illness and the person becomes more prone to infections that he/she can fight normally. As time passes, the person develops diseases that lead to death, including opportunistic infections and some types of cancer.

The **CD4 Count** is the number of the CD4 cells in the blood. It reflects whether the immune system is strong or not. So as the CD4 cell count falls, the risk of infections increases.

**AIDS** is the advanced stage of HIV infection and stands for

**A:** Acquired - not inherited, but something one gets

**I:** Immune - refers to the immune system (how the body fights infections)

**D:** Deficiency – the inability to protect against illness

**S:** Syndrome - a group of signs and symptoms of an infection

People living with HIV will go through the following stages of disease progression: Primary HIV Infection, Clinically Asymptomatic Stage, Symptomatic HIV infection and AIDS

## Primary HIV Infection

A few weeks after HIV enters the body, the body starts to respond to the virus. The immune system recognizes HIV as an **antigen** (any foreign substance that causes the immune system to produce antibodies to neutralize it) and this causes flu-like symptoms. The short flu-like sickness which is also called Primary HIV Infection or Acute Retroviral Syndrome (ARS) lasts for a few weeks. During this stage **HIV viral load** (Amount of HIV in the blood) is high. Therefore, the infected person is highly infectious and can easily transmit the virus to others.



At this stage the person is HIV-infected but looks and feels healthy. None of the physical signs or symptoms that indicate HIV infection are present. People Living with HIV may develop antibodies in the blood anywhere from 4 weeks to 3 months. The time period between infection with HIV and detection of antibodies for HIV in the blood is called the **window period**.

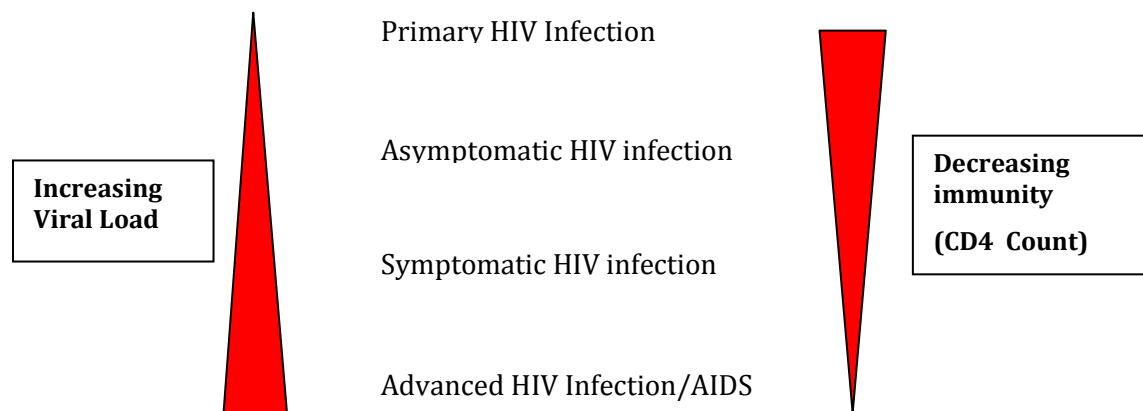
### **Clinically Asymptomatic Stage**

This period is free from major symptoms, although the person may have swollen glands. The level of HIV in the blood drops to very low levels but the person remains infectious. HIV antibodies are detectable in the blood and so antibody tests will show a positive result.

The duration of the asymptomatic phase varies greatly from person to person. Some adults may develop symptoms of HIV as quickly as a few months after getting infected with HIV. Others may take up to 15 years to develop symptoms. Healthy, positive living can make this stage last long.

### **Symptomatic HIV infection**

Over time HIV multiplies in the body. The immune system weakens and the CD4 count decreases during this phase. The person develops physical signs of HIV and reports symptoms related to HIV. Skin, nail and mouth infections develop. The PLHIV starts to lose weight. How HIV progresses depends on the type of virus and specific physical conditions of the PLHIV, including general health, nutritional status and immune status. Nutritious food, healthy living habits and precautions to protect against infections may help the individual to remain healthy during this stage. The counsellor should convey this information to clients.



**Figure Showing Progression of the HIV infection.**

## **AIDS**

As HIV infection progresses, the CD4 count continues to fall. The person's immune system becomes very weak. He/she is vulnerable to diseases that they could normally fight off. These diseases are called **opportunistic infections** (OIs) because they take advantage of the weak immune system to cause disease. Together the different opportunistic infections, create the condition known as AIDS. The person loses weight and may get infected with serious infections like TB and Pneumonia.

*Remember: HIV can be transmitted in all these stages.*

In the Indian set up where medical facilities in the ART centres such as CD4 machines are sometimes poorly equipped, it is not always possible to use CD4 and viral load test results to determine the right time to begin antiretroviral treatment. The World Health Organisation (WHO) has therefore developed a staging system for HIV disease based on clinical symptoms, which may be used to guide medical decision making. Clinical stages are categorized as 1 through 4, progressing from primary HIV infection to advanced HIV/AIDS (Please see Box below). These stages are defined by specific clinical conditions or symptoms.

*HIV/AIDS has no cure at present. But with proper treatment, the person can live a long productive life. ART started at the right time can delay disease progression and death. ART acts by decreasing the viral load which further leads to increase in the CD4 count.*

But when started very late in the disease process, ART may not be able to control how the disease progresses. This may happen because at the late stage in disease progression, CD4 cells are so badly affected by HIV that the body becomes unable to fight back, allowing the opportunistic infections to become life-threatening. Any increase in the CD4 count by ART at this point is not effective in fighting the opportunistic infections. Thus it becomes necessary for all HIV-infected persons to enroll at an ART Centre as early as possible and to keep in regular touch with the ARTC team and later with your team at the LAC. For those counsellors working at centres designated as LAC Plus, you have the additional task of Pre-ART Care. This includes ensuring regular drawing of blood every 6 months for the CD4 check which determines when a client needs to begin ART.

# Anti Retroviral Therapy

Anti Retroviral Therapy (ART) includes drugs which act at various stages of the HIV life cycle in the human body. These drugs act by interrupting the process of virus multiplication and hence reduce the number of CD4 cells that are destroyed. They delay the progression of HIV disease.

## Goals of ARV Therapy

Currently available ARV drugs cannot eradicate HIV infection from the human body. This is because a pool of latently HIV-infected CD4 cells (Virus is present in the cells but remains inactive) is established during the earliest stages of acute HIV infection. The goals of ARV therapy are as follows:

### Clinical goal

This refers to prolonging life and improving its quality by preventing, controlling and treating opportunistic infections.

### Virological goal

This refers to the greatest possible reduction in the viral load for as long as possible.

### Immunological goal

This refers to the immune reconstitution - improvement in the CD4 count.

### Therapeutic goal

This refers to optimizing treatment so as to limit drug toxicity and facilitating adherence. This will help in achieving the clinical, virological and immunological goals.

### Reduction of HIV transmission to other individuals:

Reduction of HIV transmission to other persons is achieved by suppressing the viral load in the infected person.

Important terms:

**ART**- Antiretroviral Therapy      **HAART**- Highly Active Antiretroviral Therapy

**ARVs**- Anti Retrovirals      **Triple Therapy**- Treatment combination of 3 drugs

*These terms are all used interchangeably!*

## *WHO Clinical Staging of HIV/AIDS for Adults and Adolescents:*

### *Clinical Stage 1*

- Asymptomatic
- Persistent generalised lymphadenopathy

### *Clinical Stage 2*

- Unexplained moderate weight loss (<10% of presumed or measured body weight)<sup>1</sup>
- Recurrent respiratory tract infections (sinusitis, tonsillitis, otitis media, pharyngitis)
- Herpes zoster
- Angular cheilitis
- Recurrent oral ulceration
- Papular pruritic eruptions
- Seborrhoeic dermatitis
- Fungal nail infections

### *Clinical Stage 3*

- Unexplained<sup>2</sup> severe weight loss (>10% of presumed or measured body weight )
- Unexplained chronic diarrhoea for longer than one month
- Unexplained persistent fever (above 37.5oC intermittent or constant for longer than one month)
- Persistent oral candidiasis
- Oral hairy leukoplakia
- Pulmonary tuberculosis
- Severe bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia,)
- Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
- Unexplained anaemia (<8 g/dl ), neutropenia (<0.5 x 10<sup>9</sup> /L) and or chronic thrombocytopenia (<50 X 10<sup>9</sup> /L) <sup>3</sup>

### *Clinical Stage 4*

- HIV wasting syndrome
- Pneumocystis carinii pneumonia
- Recurrent severe bacterial pneumonia
- Chronic herpes simplex infection (oro-labial, genital or anorectal of more than one month's duration or visceral at any site)
- Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)
- Extrapulmonary tuberculosis
- Kaposi's sarcoma
- Cytomegalovirus infection (retinitis or infection of other organs)
- Central nervous system toxoplasmosis
- HIV encephalopathy
- Extrapulmonary cryptococcosis including meningitis
- Disseminated non-tuberculous mycobacteria infection
- Progressive multifocal leukoencephalopathy
- Chronic cryptosporidiosis
- Chronic isosporiasis
- Disseminated mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
- Recurrent septicaemia (including non-typhoidal salmonella)
- Lymphoma (cerebral or B cell non-Hodgkin)
- Invasive cervical carcinoma
- Atypical disseminated leishmaniasis
- Symptomatic HIV associated nephropathy or Symptomatic HIV associated cardiomyopathy

<sup>1</sup>Assessment of body weight in pregnant woman needs to consider expected weight gain of pregnancy.

<sup>2</sup>Unexplained refers to where the condition is not explained by other conditions.

<sup>3</sup>Some additional specific conditions can also be included in regional classifications (e.g. reactivation of American trypanosomiasis (meningoencephalitis and/or myocarditis) in Americas region, Penicilliosis in Asia).

## *How to Explain HIV Infection to Clients*

### *How our body fights illness*

Each of us has a shield that protects us from getting sick. We call this our body defence, or immunity. It helps us to fight diseases.

We can imagine that our shield or body defence, is made up of pieces of metal. These are our CD4 cells.

We keep our shield strong by taking care of our health (i.e. good nutrition, how we manage stress, maintaining fitness, etc.)

Even when HIV positive, we start out feeling very strong, feeling well.

This is because we still have many metal pieces on our shield, and few HIV arrows which attack them.

Therefore, being HIV positive does not mean that you will feel sick. Until your body shield suffers great damage you can function normally as any person who is HIV negative.

### *How HIV attacks our body*

HIV hurts the body by making tears and holes in the shield - by chipping away the metal pieces.

The more our shield gets broken or damaged, the easier it is for illnesses like TB and other infections to pass through and become more severe.

These illnesses are called opportunistic infections.

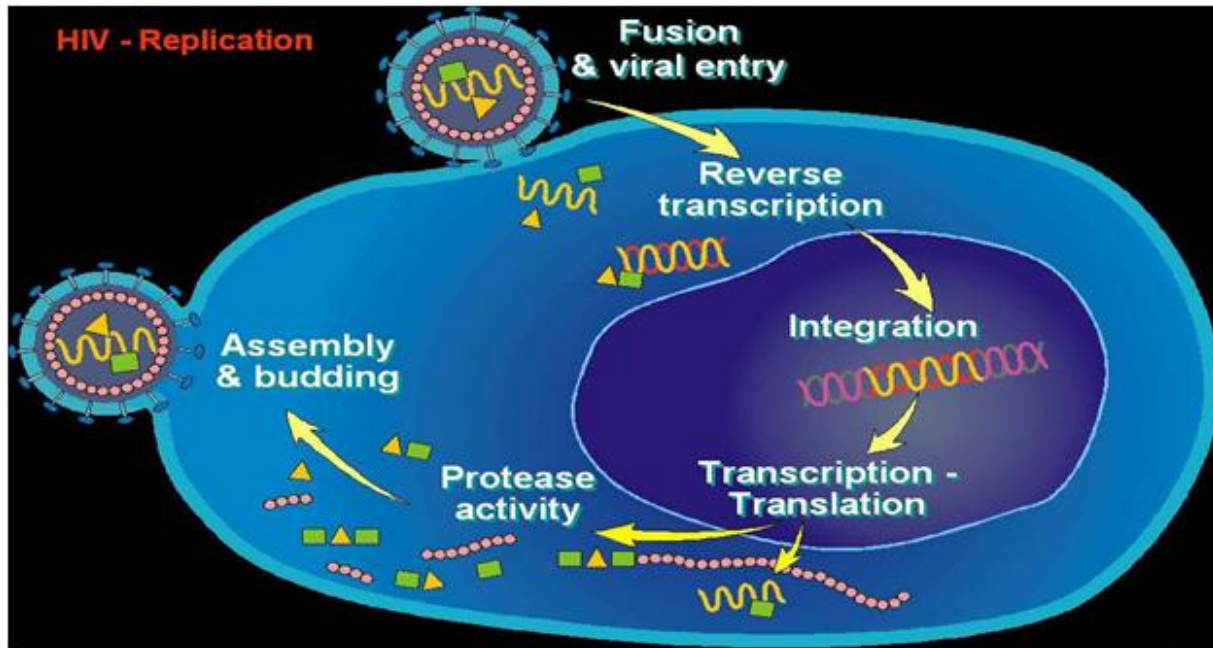
At first, when HIV arrows begin to strike the shield, the shield still holds together and can look normal on the outside.

Over time, this changes. More HIV arrows are produced which destroy more metal pieces of the shield. We may feel weaker and have different illnesses. Developing AIDS means there are many HIV arrows in our bodies and almost no shield to defend us.

## HIV Life Cycle

To understand how ART acts in the body, you must first learn about the life-cycle of HIV as it infects the immune system. Earlier we have seen how HIV disease progresses at the body level. But the next section deals with the action at the level of the cell.

- When HIV enters the blood stream of the person it specifically targets the CD4 cells of the immune system. It binds to the CD4 receptors on the surface of the CD4 cell (**Fusion**).
- After attaching to the CD4 cell, HIV injects its genetic material – the viral RNA - into the cytoplasm of the host CD4 cell. This is depicted in the accompanying figure.
- Then the single-strand RNA of the virus is converted to double-stranded DNA using the enzyme **reverse transcriptase**. The process of formation of DNA from RNA is called '**Reverse Transcription**'.
- The double-stranded viral DNA then enters the nucleus of the host cell and integrates with the DNA of the host nucleus, using the enzyme **integrase**. This is known as '**Integration**'.
- As the host cell replicates, multiple copies of viral RNA are produced from the integrated DNA and are released into the cytoplasm of the host cell. The process of formation of the RNA from DNA is called '**Transcription**'.



- The viral RNA is decoded into polypeptides (protein chains) and **protease**. The decoding of the RNA to form protein chains is called **Translation**. The enzyme protease cuts the polypeptide chains into functional HIV protein units.

- The functional HIV protein units are assembled and the new HIV viruses bud from the cell surface.

The infected CD4 cells produce many new copies of the virus, and then die. The new copies of HIV then attack new CD4 cells. These freshly attacked CD4 cells also produce new copies of HIV and then die. As this goes on, more CD4 cells are destroyed, more new copies of HIV are made and an increasing number of new CD4 cells get infected.

### **Action Points for Antiretroviral Drugs**

There are three big groups of antiretroviral drugs available at present:

- Nucleoside Reverse Transcriptase Inhibitors (NRTIs)
- Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)
- Protease inhibitors (PIs)

These available drugs target the virus mainly by inhibiting the enzymes Reverse Transcriptase (RT inhibitors), Integrase (NNRTI) and Protease (protease inhibitors), and preventing fusion of the virus with CD4 cells (fusion inhibitors). Newer classes of drugs are also emerging.

The flow chart on the following page shows how these ARV drugs interfere with the HIV life cycle in the human body.

The important point is that protease inhibitors and NRTI/NNRTI work at different steps in the process that HIV goes through when it makes new copies of itself inside cells.

The list of drugs available under the NACP in India is presented in the next table.

<i>Nucleoside reverse transcriptase inhibitors (NRTIs)</i>	<i>Non-nucleoside reverse transcriptase inhibitors (NNRTIs)</i>	<i>Protease inhibitors (PIs)</i>
Zidovudine (AZT/ZDV) Stavudine (d4t) Lamivudine (3TC) Abacavir (ABC) <u>Nucleotide (NtRTI)</u> Tenofovir (TDF)	Nevirapine (NVP) Efavirenz (EFV)	Lopinavir/Ritonavir (LPV) Atazanavir/ Ritonavir (ATV)

# HIV Cycle

# Drug Action

As the virus enters the bloodstream, the virus binds to the surface of the CD4 cells.

**Fusion Inhibitors (NNRTI)** block the binding of HIV to CD4 cell.

The viral genetic material (RNA) is injected into the CD4 cell.

The RNA material is converted to DNA, using the enzyme **Reverse Transcriptase**

**Nucleoside and Non- Nucleoside inhibitors (NRTI and NNRTI)** inhibit this enzyme, thus blocking the process of conversion of viral RNA to DNA.

The viral DNA enters the nucleus of the CD4 cell and integrates with CD4 DNA, using the enzyme **Integrase**.

**Integrase inhibitors (NNRTI)** inhibit the integrase enzyme thus blocking the process of integration of viral DNA to CD4 DNA.

The intergrated DNA is decoded to form multiple copies of the viral RNA. These are released in the cytoplasm of the CD4 cell.

These multiple viral RNA copies are translated to form the chains of proteins.

The enzyme **Protease** cleaves these protein chains into functional HIV protein units.

**Protease inhibitors (PI)** inhibit the enzyme protease. They block the step of cleavage of the polypeptide chains to make functional HIV units.

The functional HIV proteins are assembled and the HIV virons bud from the cell surface.



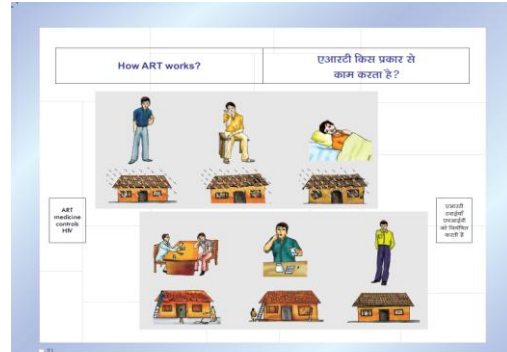
### *How to Explain to the Client How ART Works*

- ART reduces the supply of HIV arrows. This gives your body time to build/mend the metal pieces and this will strengthen your shield to stop the HIV arrows.
- It does not cure HIV. It slows down the growth of HIV in the body.
- When on ART, you will get less sick and feel better for longer periods of time.

#### *Points to remember:*

As an LAC counsellor you have to make sure that the client is adhering to the treatment. Explain to the client the importance of adherence. Discuss the following points: ART tablets only work for 12 hours. You can imagine that ART works in two shifts, a day shift and a night shift. If you don't take your tablets regularly, the tablets are not able to destroy the HIV arrows. So you need to take your pill every morning and evening as prescribed by your doctor. If you forget to take your tablets every day or if you stop, the HIV arrows will come back even stronger.

Use the ART Adherence Flip Chart to demonstrate the right use and importance of the ART to the clients.



#### **Questions to LAC counsellors:**

- ✓ What are some of the common questions that clients ask about antiretroviral treatment?
- ✓ Would you be able to draw the processes involved in the life-cycle of HIV?
- ✓ How would you explain the need for regular treatment to a child client?

## When to start the ART

When started on time, ART can delay disease progression and death in a PLHIV. But when started very late in the disease process, medications may not be able to control the disease progression. This happens because at late stages the increase in the CD4 count by ART is not effective in combatting the opportunistic infections. The clients that you will encounter have been stable on ART for at least six months. But as a counsellor you still need to know this information. Further some of you may also be involved in Pre-ART care.

NACO has laid down the guidelines for the initiation of ART based on the WHO clinical staging and the CD4 count. When CD4 count is not available the doctor uses the WHO clinical staging to guide treatment and follow-up.

The optimum time to start ART is before the patient becomes unwell or presents with the first Opportunistic Infection.

### *Initiation of ART based on CD4 count and WHO clinical staging*

	<i>Clinical Stage 1</i>	<i>Clinical Stage 2</i>	<i>Clinical Stage 3</i>	<i>Clinical Stage 4</i>
<i>Regular Clients</i>	Treat if CD4 is less than 350	Treat if CD4 is less than 350	Treat irrespective of CD4 count	Treat irrespective of CD4 count
<i>Clients with Tuberculosis</i>	Start after 2 weeks of initiation of Anti-tuberculosis treatment (ATT) irrespective of CD4 count	Start after 2 weeks of initiation of ATT irrespective of CD4 count	Start after 2 weeks of initiation of ATT irrespective of CD4 count	Start after 2 weeks of initiation of ATT irrespective of CD4 count
<i>Pregnant Women</i>	Treat if CD4 is less than 350	Treat if CD4 is less than 350	Treat irrespective of CD4 count	Treat irrespective of CD4 count

## National First-Line ART Formulations and Regimens for Adults and Children

The first-line regimen is a combination of drugs that will be used in a patient who has never taken ARV drugs before. The most common first-line regimen consists of two NRTIs and one NNRTI forming a triple-drug combination. The following tables show the national first-line and alternate first-line ART regimens for adults and children that are available at ART centres.

These formulations are available at the centres in fixed-dose combinations (FDCs). For instance, there are three-drug combination tablets containing Stavudine 30 mg plus Lamivudine 150 mg plus

Nevirapine 200 mg and those containing Zidovudine 300mg plus Lamivudine 150mg plus Nevirapine 200mg. These FDCs are preferred because they are easy to use, have distribution advantages, improve adherence to treatment and thus reduce the development of drug resistance.

*National first-line and alternate first-line ART regimens for adults*

<i>National ART regimen</i>	<i>Regimens</i>
<i>Regimen I</i>	Zidovudine + Lamivudine+ Nevirapine
<i>Regimen I (a)</i>	Tenofovir + Lamivudine+ Nevirapine
<i>Regimen II</i>	Zidovudine + Lamivudine + Efavirenz
<i>Regimen II (a)</i>	Tenofovir + Lamivudine + Efavirenz
<i>Regimen III</i>	Zidovudine + Lamivudine + Atazanavir/Ritonavir
<i>Regimen III (a)</i>	Zidovudine + Lamivudine + Lopinavir/Ritonavir
<i>Regimen IV</i>	Tenofovir + Lamivudine + Atazanavir/Ritonavir
<i>Regimen IV (a)</i>	Tenofovir + Lamivudine + Lopinavir/Ritonavir

Source: Office Memorandum titled Revised Guidelines on Initiation of ART in Adults and Adolescents dated January 24, 2013.

**An LAC counsellor is likely to see people who are on Regimens I, IA, II and IIA.**

*National first-line and alternate first-line ART regimens for children*

<i>National ART regimen</i>	<i>Regimens</i>
<i>Regimen PI</i>	Zidovudine + Lamivudine + Nevirapine
<i>Regimen PI (a)</i>	Stavudine + Lamivudine + Nevirapine
<i>Regimen P II</i>	Zidovudine + Lamivudine + Efavirenz
<i>Regimen P II (a)</i>	Stavudine + Lamivudine + Efavirenz

Source: NACO (2008) Draft Guidelines for National Roll-Out of Second-line ART

**Why PLHIVs have to use a combination of 3 antiretroviral drugs**

**It takes a lot of force to stop HIV**

One drug, by itself, can slow down the high rate of infection of the cells by HIV. Two drugs can slow it down more, and three drugs together have a very powerful effect.

### **ARV drugs from different drug groups attack the virus in different ways**

The different anti-HIV drugs attack HIV at different steps of its lifecycle. Hitting two targets increases the chance of stopping the production of HIV and protecting new cells from infection.

### **Combinations of anti-HIV drugs may overcome or delay resistance**

**Resistance** is the ability of HIV to change its structure in ways that make ARV drugs less effective. HIV has to make only a single, small change to resist the effects of some drugs. For other drugs, HIV has to make several changes. When one drug is given by itself, sooner or later HIV in the body makes the necessary changes to resist that drug. When two drugs are given together, it takes longer for HIV to make the changes necessary for resistance. When three drugs are given together, it takes even longer.

When resistance develops to a first-line regimen, it ceases to be effective. The doctor then change to an alternate first-line regimen or to a second-line regimen. The most common reason for treatment failure is poor adherence, especially early in the initiation phase when viral loads are high.

## **Understanding treatment failure**

You may observe that the health status of some PLHIVs deteriorates day by day because their medicines are no longer working. This is called treatment failure.

### **Types of Treatment Failure**

There are three types of treatment failure: virologic failure, immunologic failure and clinical failure..

#### **Virologic failure**

This happens when anti-HIV medications can no longer reduce the amount of virus in the blood. While taking medications, the viral load does not drop or it repeatedly rises again after having dropped.

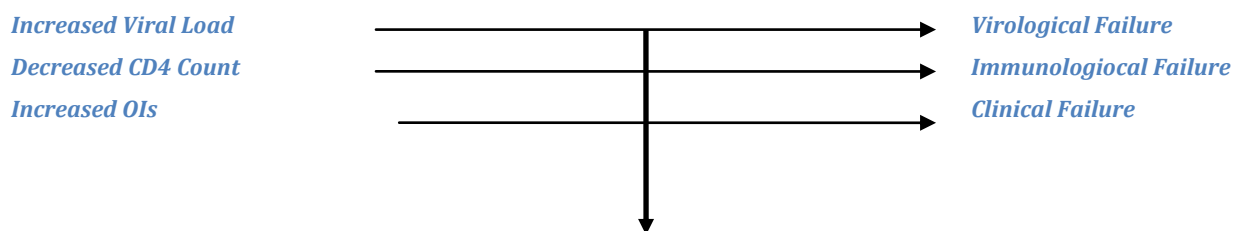
#### **Immunologic failure**

This happens when the immune system does not respond to anti-HIV medications. While taking medications, the CD4 count does not rise or it drops.

## Clinical failure

Clinical failure occurs when a person has symptoms of HIV disease despite taking anti-HIV medications.

The three types of treatment failure may occur alone or together. In general, virologic failure occurs first, followed by immunologic failure, and then clinical progression. They may happen months to years apart. An LAC counsellor may be able to identify signs of treatment failure and refer the client to a physician in a timely manner so that necessary changes in treatment may be made.



### *Indication of Treatment Failure.*

Clinical Failure <sup>i</sup>	New or recurrent WHO stage 4 condition, after at least 6 months of ART. <sup>ii,iii</sup>
Immunological Failure <sup>iv</sup>	Fall of CD4 count to pre-therapy baseline (or below) 50% fall from the on treatment peak value (if known) Persistent CD4 levels below 100 cells/mm <sup>3</sup> <sup>v</sup>
Virological Failure	Plasma viral load > 5,000 copies/ml <sup>vi</sup>

#### Notes:

- i. Current event must be differentiated from IRIS.
- ii. Certain WHO clinical stage 3 conditions (eg. pulmonary TB, severe bacterial infections) may indicate treatment failure and thus required second-line therapy to be considered.
- iii. Some WHO clinical stage 4 conditions (lymph node TB, uncomplicated TB pleural disease, oesophageal candidiasis, recurrent bacterial pneumonia) may not indicate treatment failure and thus second –line therapy need not be considered.
- iv. Without any concomitant infection causing transient CD4 cell count decrease.
- v. Some experts consider persistent CD4 counts of below 50/mm<sup>3</sup> after 12 months of ART to be more appropriate.
- vi. The optimal viral load value at which ARV drugs should be switched has not been defined. However, values of more than 5,000 copies/ml have been associated with subsequent clinical progression and an appreciable decline in the CD4 cell count.

Source: NACO (2008) Draft Guidelines for National Roll-Out of Second-line ART

## **Factors contributing to treatment failure**

### **Lack of treatment adherence**

Not taking medications as prescribed is one of the main reasons for treatment failure. The explanation below will help in more understanding.

When we take the drug orally, (that is by mouth) it is absorbed from the gastro-intestinal tract into the blood. The drug then passes through the liver and is distributed to the tissue, and in the end it is excreted from the body. When the drugs come into the blood they need to reach a level (or concentration) that is high enough in order to be effective against the virus. This will happen only if the correct number of pills is taken and no doses are missed or taken late.

When we do not take the drugs correctly, the level of drugs in the blood is not enough to suppress viral replication. This, in turn, leads to increased viral replication which further leads to increased viral load and increased mutant viruses. After some time, the body will contain more and more resistant viruses. The result will be that the drugs lose their effect and HIV will take over the body. This results in treatment failure.

*Good adherence is the key to maintaining the first line ART for longer duration.*

### **Suboptimal ARV regimen**

Use of a single ARV drug or a two-drug ARV combination may provide temporary benefit but will ultimately fail because they do not adequately suppress viral load for a sustained period of time.

### **Suboptimal drug level**

This is because of lower than optimal dose of medication, drug interaction and malabsorption (due to intestinal parasites, nausea and vomiting).

### **Side-effects and drug toxicity**

These are common reasons for temporary treatment discontinuation.

### **High cost and drug stock-outs**

These are indirect causes.

It is important for a PLHIV to understand that regular intake of medication or high adherence leads to decrease in the viral load, increase in the CD4 cell counts and success in treatment. As a LAC counsellor you should emphasize the need for taking every dose, every day, and correctly with respect to time intervals and dietary instructions. Help client to identify the barriers in adherence and monitor whether the client is taking the drugs at right time or not. The subsequent chapters will give you more guidelines.

### *How to explain to the Client the Relation between Adherence and ART Success*

Think of your body as a pot with a tap. When you take ART regularly, the body has enough medicine to fight the virus. After about 12 hours, however, the level of medicine decreases. This happens because medication only stays in our bodies for a short time. The medicines are excreted from our body like a bottle that has a leak in the bottom.

Thus, if we don't take medicines on time, the optimum amount of medicine in the blood will not be maintained and HIV will get an opportunity to oppose the effect of the medicine. The virus that has overpowered the medicines then reproduces in the body. Even when a person returns to the medicine on time, the drugs are not able to kill the virus. So the medicine no longer works against the virus, and HIV takes over the body. The only way to keep HIV from increasing is to take the medicine at the same time every day.

Therefore, you have to continuously take the medicine to stay healthy for a long time (usually every 12 hours, but it depends on the medicine and recommended dose).

## **Substitution vs Switch**

When the treatment is not found to be effective against the virus then a change of ARVs is prescribed. Change of ARVs prescribed could be a substitution: a drug within a regimen or it can be a switch of the entire ART regimen:

- Single-drug replacement of individual ARV drugs (usually within the same class) refers to **SUBSTITUTION** of individual drugs. This does not indicate a second-line regimen is being used.

- Failure refers to the loss of antiviral efficacy. It requires a **SWITCH** of the entire regimen from first to second-line. It is identified by clinical and/or immunological and confirmed by virological testing.

Identifying the cause of failure is important before deciding to modify the ART regimen.

<i>Reasons to consider ARV drug substitution</i>	<i>Reasons to consider ARV regimen Switch</i>
Intolerance Drug toxicity Occurrence of active TB Pregnancy	ARV treatment failure

**Substituting within a First-line Antiretroviral drug Regimen:**

A drug may need substitution to improve adherence, manage side-effects/ toxicities and/or reduce the cost of the regimen. The most common example of substitution to avoid long-term toxicity is substituting from d4T to TDF.

**Switch to Second-line**

Second-line ART is the next regimen used in sequence immediately after first-line therapy has failed. Usually, the second-line regimen consists of two NRTI and a Protease inhibitor.



### **Eligibility for enrollment into second-line treatment:**

- Free treatment and free viral load testing for all those below poverty line, widows and children.
- Patient under treatment in government ART centres continuously for at least two years, irrespective of income status. This will undergo changes as NACO implements a 2010 Supreme Court ruling to offer this treatment even to patients who have not undergone treatment at government ART centres. But the implementation will be undertaken in a phased manner.

The limitations of the Second-line treatment are that there are more pills, perhaps some food restrictions, and sometimes more side-effects. Also, the second-line regimen costs around Rs 30,000 per year per patient which is 6 times costlier than first-line treatment whose cost is only Rs 5000 per year. Moreover, second-line treatment is available only as per above mentioned eligibility criteria so it is very important that adherence to First-line drugs is maintained.

Even second-line regimen can fail, if not taken correctly. At present there is no third-line treatment available under NACP III. Thus, consequences of low adherence are serious for the individual, for public health and for the optimal use of limited health-care resources. Reinforcement and monitoring of treatment adherence by counsellors really helps.

## **Benefits, Side-effects & Limitations of ART**

### **Benefits of ART:**

ART is beneficial because:

- It prolongs life
- It improves quality of life
- It decreases occurrences of OIs
- Businesses can stay intact
- Households can stay intact
- There are less orphans
- HIV transmission is lowered
- It reduces mother-to-child transmission of HIV
- There is decreased stigma surrounding HIV infection since treatment is now available

- Less money is spent on OI treatment and on palliative care.



## Side-effects of ARV drugs

### What are side-effects?

Side-effects are unwanted effects of a drug. Medications are prescribed for a specific purpose, such as to control HIV. Anything else the drug does is a side-effect. Some side-effects are mild, such as a slight headache. Others, like liver damage, can be severe and, in rare cases, fatal. Some go on for just a few days or weeks, but others might continue as long as the patient is on medication, or even after it is stopped.

People with a higher number of side-effects will usually stop taking their drugs correctly because they are discouraged by the side-effects. If a PLHIV does not take the drugs properly, the treatment will not be successful. So if people are complaining about side-effects, you should take their complaints seriously. If not, they might start to 'forget' taking pills.

### Who gets side-effects?

Most people taking anti-HIV medications have some side-effects. In general, higher amounts of drugs cause more side-effects. Also, if the body processes drugs more slowly than normal, the patient may have more side-effects.

As an LAC counsellor, you should warn patients about the very common side-effects and suggest ways that they can be managed by the patient. It will help if you tell them what they can expect. This is called **anticipatory guidance**. You should also make it easy to get advice on managing other side-effects or any worries they have. Teach them how to use the Treatment Education Leaflets. Explain to the patient that many patients experience an adjustment period when starting a new therapy. This period usually lasts about four to six weeks when the body adapts to the new drug. Throughout this time, the patient may experience headache, nausea, muscle pain and occasional dizziness. These kinds of side-effects lessen or disappear as the body adjusts to medication. As the stable patients on ART for at least six months are linked out to LAC's it is unlikely that an LAC counselor will come across short term or medium term toxicities. Thus, LAC counsellors need to educate the clients about chronic toxicities.

### Basic Patient Education

- Normal side-effects for the treatment they are taking.
- When to get medical attention, i.e. before a side-effect goes on for too long, or has become severe.
- Some mild side-effects can be treated with home remedies or over-the-counter drugs.
- Patients should not stop taking any medications, or skip or reduce doses, without talking to the doctor. Doing so can allow the disease to progress, and might lower the effectiveness of some ARV drugs.

### *Treatment Education Leaflets*

(More examples given in the Annexures)

ADULT

**TREATMENT EDUCATION INFORMATION**

ZDV + 3TC + NVP

REGIMEN – I

ZDV + 3TC + NVP			
Zidovudine (300mg)	Lamivudine (150mg)	Nevirapine (200mg)	
Day 1–14		Day 15 onwards	
Morning	1 tablet	Zidovudine+Lamivudine+ Nevirapine	1 tablet
Evening	1 tablet	Zidovudine+Lamivudine+ Nevirapine	1 tablet

**REMEMBER THAT**

- If you miss doses (even 2 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working.)
- No doses should be missed as it is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
- If you stop you will become ill within months or year.
- Drugs **MUST NOT** be shared with family and friends.
- If you find it difficult taking your pills twice daily, DISCUSS with health workers. ASK for support from your Treatment supporter, family or friends.

**Remember: Adherence is under your control**

Note: The color, shape and size of ARV drugs may be different due to different supplier each year.

ADULT

**TREATMENT EDUCATION INFORMATION**

TDF + 3TC + EFV

REGIMEN – IIIa

TDF + 3TC + EFV		
Tenofovir (300mg)	Lamivudine (150mg)	Efavirenz (600mg)
Daily		
Morning	Tenofovir + Lamivudine	1 tablet
Evening	Efavirenz	1 tablet

**REMEMBER THAT**

- If you miss your drugs (even 2 dose in a month) **DRUG RESISTANCE** will develop.
- Drugs must be taken as prescribed and no doses should be missed.
- This is bad for you as these drugs will stop working.
- If you forget a dose, do not take a double dose.
- If you stop taking the ART, you will become ill within months.
- Do not share any of the drugs with your spouse, family or friends.
- If you find it difficult to take your pills, go back to the ART center and discuss this with the doctor and counselor. Ask for support from your treatment supporter, family, friends, NGO and positive network.

**Remember: Adherence is under your control**

Note: The color, shape and size of ARV drugs may be different due to different supplier each year.

## Types of side-effects

<i>ARV Drugs</i>	<i>Very common side-effects:</i>	<i>Potentially serious side-effects:</i>	<i>Side-effects occurring later during treatment :</i>
	Warn patients and suggest how to manage.	Warn patients and tell them to seek care.	Discuss with patients
<i>Zidovudine (AZT)</i>	<ul style="list-style-type: none"> <li>➤ Nausea</li> <li>➤ Diarrhoea</li> <li>➤ Headache</li> <li>➤ Fatigue</li> <li>➤ Anaemia</li> <li>➤ Skin pigmentation</li> </ul>	Seek Urgent care: Anaemia = pallor, fatigue, shortness of breath, muscle pain	
<i>Stavudine (d4T)</i>	<ul style="list-style-type: none"> <li>➤ Nausea</li> <li>➤ Diarrhoea</li> </ul>	Seek care urgently: Pancreatitis (infection in pancreas)/Lactic acidosis = Severe abdominal pain, Fatigue and shortness of breath, persistent nausea and vomiting Seek advice soon: Peripheral neuropathy= Tingling, numb or painful feet or legs or hands	Changes in fat distribution: Lipodystrophy= Arms, legs, buttocks, cheeks becomes THIN Breast, belly, back of neck becomes FAT.
<i>Lamivudine (3TC)</i>	<ul style="list-style-type: none"> <li>➤ Nausea</li> <li>➤ Diarrhoea</li> </ul>		
<i>Nevirapine (NVP)</i>	<ul style="list-style-type: none"> <li>➤ Nausea</li> <li>➤ Diarrhoea</li> <li>➤ Mild skin rash</li> </ul>	Seek care urgently: Yellow eyes Skin rash with involvement of mucosa and exfoliation Fever	
<i>Efavirenz (EFV)</i>	<ul style="list-style-type: none"> <li>➤ Nausea</li> <li>➤ Diarrhoea</li> <li>➤ Strange dreams</li> <li>➤ Difficulty sleeping</li> <li>➤ Memory problems</li> <li>➤ Headache</li> <li>➤ Dizziness</li> </ul>	Seek care urgently: Psychosis or mental confusion Skin rash	

## Patient Education Related to Side-effects

<i>Side-effect</i>	<i>What to do</i>	<i>Go to the Clinic if</i>
<i>Headache</i>	<ul style="list-style-type: none"> <li>➤ Rub the base of your head and temple with your thumbs gently. Rest in a quiet dark room with your eyes closed.</li> <li>➤ Place a cold cloth over your eyes and forehead</li> <li>➤ Avoid things with caffeine such as coffee, string tea and carbonated drinks.</li> <li>➤ Take 2 tablets of paracetamol every 4 hours with food.</li> </ul>	<ul style="list-style-type: none"> <li>➤ Your vision becomes blurry or unfocussed.</li> <li>➤ Aspirin or paracetamol does not stop pain.</li> <li>➤ You have frequent or very painful headaches.</li> </ul>
<i>Dry Mouth</i>	<ul style="list-style-type: none"> <li>➤ Rinse your mouth with clean, warm water and salt.</li> <li>➤ Avoid sweets.</li> <li>➤ Avoid things with caffeine such as coffee, string tea and carbonated drinks.</li> </ul>	<ul style="list-style-type: none"> <li>➤ You have white spots on your tongue or in your mouth.</li> <li>➤ You have trouble swallowing food.</li> </ul>
<i>Skin rashes</i>	<ul style="list-style-type: none"> <li>➤ Wash often with unscented soap and water.</li> <li>➤ Keep the skin clean and dry.</li> <li>➤ Use calamine lotion to soothe itching</li> <li>➤ Avoid the sun when you have a rash.</li> </ul>	<ul style="list-style-type: none"> <li>➤ If side-effects persist, visit your doctor.</li> </ul>
<i>Diarrhoea</i>	<ul style="list-style-type: none"> <li>➤ Eat small meals more frequently each day.</li> <li>➤ Eat easy-to-digest food such as bananas and rice.</li> <li>➤ Drink clean, boiled water.</li> <li>➤ Boil water for 20 minutes to make it safe.</li> <li>➤ Take ORS (Oral Rehydration Solution).</li> <li>➤ Avoid spicy or fried food.</li> </ul>	<ul style="list-style-type: none"> <li>➤ There is a blood in the stool.</li> <li>➤ You have diarrhoea more than 4 times a day.</li> <li>➤ You also have fever.</li> <li>➤ You are thirsty but cannot eat or drink properly.</li> </ul>
<i>Anaemia</i> (Signs that you have anaemia include pale palms and finger nails)	<ul style="list-style-type: none"> <li>➤ Eat fish, meat, chicken, legumes.</li> <li>➤ Eat spinach, asparagus and dark, leafy greens.</li> <li>➤ Take iron tablets as prescribed by a doctor.</li> </ul>	<ul style="list-style-type: none"> <li>➤ You have been tired for 3 to 4 weeks, and you are feeling more and more tired.</li> <li>➤ If your feet swell.</li> </ul>
<i>Feeling dizzy</i> (These side-effects may occur when taking Efavirenz. They usually go away after a few weeks.)	<ul style="list-style-type: none"> <li>➤ If you feel dizzy, sit down until the dizziness goes away.</li> <li>➤ Try not to lift anything heavy or move quickly.</li> <li>➤ Take Efavirenz right before you go to sleep.</li> </ul>	<ul style="list-style-type: none"> <li>➤ If the side-effects persist, visit your doctor.</li> </ul>
<i>Tingling feet and hands</i>	<ul style="list-style-type: none"> <li>➤ Wear loose-fitting shoes and socks</li> <li>➤ Keep feet uncovered in bed.</li> <li>➤ Walk a little, but not much.</li> <li>➤ Soak your feet in warm water/massage</li> </ul>	<ul style="list-style-type: none"> <li>➤ The tingling does not go away or gets worse.</li> <li>➤ The pain is preventing you from</li> </ul>

	<p>with a cloth soaked in warm water.</p> <ul style="list-style-type: none"> <li>➤ Try ibuprofen to reduce pain and swelling (you can take up to 400 mg every 8 hours with food. Do not take ibuprofen for more than two day without visiting the clinic.)</li> </ul>	being able to walk.
<i>Nausea and vomiting</i>	<ul style="list-style-type: none"> <li>➤ Ask your doctor if you can take drugs with food.</li> <li>➤ Eat lots of small meals rather than big meals.</li> <li>➤ Take sips of clean, boiled water, weak tea, or oral rehydration salts (ORS) until the vomiting stops.</li> <li>➤ Avoid spicy or fried foods.</li> </ul>	<ul style="list-style-type: none"> <li>➤ You also have fever.</li> <li>➤ You have sharp pains in stomach.</li> <li>➤ There is blood in the vomit.</li> <li>➤ Vomiting lasts more than a day.</li> <li>➤ You are very thirsty but cannot eat or drink properly.</li> </ul>
<i>Unusual or bad dreams</i>	<ul style="list-style-type: none"> <li>➤ Try to do something that makes you happy and calm right before you go to sleep.</li> <li>➤ Avoid alcohol and street drugs as these will make things worse.</li> <li>➤ Avoid food with a lot of fat.</li> </ul>	<ul style="list-style-type: none"> <li>➤ If you can't sleep for several nights.</li> </ul>
<i>Feelings of sadness or worry</i> (This is common with Efavirenz).	<ul style="list-style-type: none"> <li>➤ Talk about your feeling with others.</li> </ul>	<ul style="list-style-type: none"> <li>➤ You have serious, sad or very worrying thoughts.</li> <li>➤ You are thinking about killing yourself.</li> <li>➤ You are very aggressive or very scared.</li> </ul>

### *Remember*

*Although ART dramatically improves the health and life expectancy for PLHIV,*

*ART is not a cure for AIDS. HIV is never entirely eliminated from body.*

*ART is to be taken life-long. The virus can never be eradicated completely from the body, so ART has to be continued forever, even if the patient is asymptomatic.*

*HIV can still be transmitted to others, even when the PLHIV is healthy and taking his/her medication regularly. Thus safe sex should be practiced even if the patient is on ART.*

The reinforcement of the principles of adherence and limitations of ART treatment by the counsellor is of great help for the client. You should make sure that clients have the information sheets specific to the ART regimen that they are taking. During counselling sessions stress that people on ART need to continue to use condoms regularly and practice safe injecting drug use. Also,

remember that ART means hope. You should emphasize the positive aspects of the treatment while making sure that they know the most appropriate way to consume the drugs.

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**Questions to LAC counsellors:**

- ✓ What anticipatory guidance will you give to a pregnant woman who is about to begin ART?
  - ✓ Are you aware which ARV drug is contraindicated for anaemic women?
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# Opportunistic Infections and their Management

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At the end of this unit, participants will be able to

- Demonstrate knowledge of common Opportunistic Infections among PLHIVs, their signs and symptoms
- Demonstrate an understanding of the syndromic management of Opportunistic infections at home
- Counsel clients on how to prevent and manage common problems related to Opportunistic infections

People living with HIV have to worry about more than just HIV infection and death. Opportunistic Infections (OIs) and associated complications also cause a great deal of trouble.

However, marked progress has been made in improving the quality and duration of life of PLHIVs: In addition to advances in Antiretroviral Therapy (ART), there is better recognition of opportunistic disease processes, improved treatment of acute and chronic complications, and introduction of chemoprophylaxis against key OIs. Prophylaxis against specific OIs and timely introduction of ART is the most effective approach in preventing OIs. It should be offered to all HIV infected persons who qualify for such therapy.

During the client's monthly visits to the Link ART centre, counsellors have an opportunity to identify and recognize the characteristic symptom patterns of serious and common OIs. After identification they should refer clients for prompt and effective treatment. Also, providing appropriate preventive advice can play a great role in the prevention of OIs. This will in turn help in reducing OIs, decrease days of hospitalization and reduce mortality among PLHIVs.



# What are Opportunistic Infections (OIs)?

An opportunistic infection is a disease caused by micro-organisms such as bacteria, fungi, viruses or parasites that normally do not cause serious disease in healthy people. But in individuals whose immune system is impaired or compromised they do create illness. These are infections that take advantage of the weakened immune system.

Most OIs are caused by micro-organisms that are common and that may have lived in the body for many years. When the immune system is intact and functional, these micro-organisms are prevented from growing or spreading within the body and causing disease. However, if the immune system is damaged the micro-organisms are able to invade, reactivate and grow. Thus, Opportunistic Infections are infections that make a person sick given the "opportunity" of a damaged or weakened immune system.

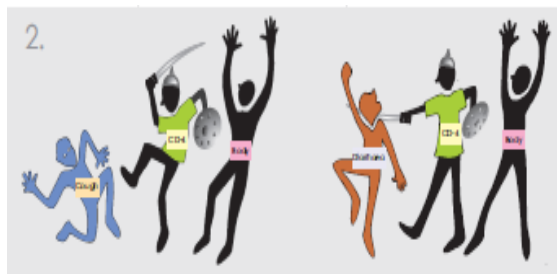
## *How to Explain how HIV leads to OIs*

Counsellors can use the pictures given in the ART Adherence Flipbook for explaining the mechanism of immune system breakdown to LAC clients.

- CD4 cells are white blood cells that act as soldiers of the body and form a shield (immune system) to protect the body from infection. Thus, CD4 is a friend of our body.



- Problems like common cold and tuberculosis try to attack our body, but CD4 cells fight them to defend the body.



# HIV/AIDS, Immune System and OIs

HIV infects the CD4 cells of the body's immune system, impairs their function and slowly kills them over time. This gradually weakens the immune system, and the body then loses its ability to fight disease. This is seen as a drop in the CD4 count. After the decrease in CD4 count and weakening of the immune system, organisms which are normally kept in check by an undamaged immune system begin to grow causing Opportunistic Infections such as Tuberculosis and Herpes.

- When HIV enters the body, it specifically starts attacking the CD4 cells.



- The CD4 cells cannot defend themselves effectively against HIV and their number gradually decreases. Over 5 to 10 years the CD4 cell count decreases to a low level. When CD4 cells - the soldiers that protect the body are very few - the body's shield (immune system), made up of CD4, becomes weak and it remains without defense.
- Now, bacteria and virus take advantage of the weak defenses and start attacking the body.



- In the end the body is so weak, that all diseases can attack easily. These diseases are called Opportunistic infections as they take advantage of the opportunity – the weakened immune system. This also explains why clients need to do a routine CD4 count.

The incidence of OIs among PLHIVs depends on:

- The weakness of their immune system – This is measured through the CD4 count.
- The presence of causative micro-organisms

Many OIs are seen in patients who are in WHO's clinical stage IV and are referred to as "AIDS-defining illnesses." AIDS is defined as the occurrence of life-threatening OIs, malignancies, neurological diseases and other specific illnesses in patients with HIV infection and CD4 counts less than 200 cells per cubic mm. (For more details, refer to the WHO clinical staging of HIV/AIDS for Adults in the section on Basics of ART.) These infections often result in hospitalization, disability, and time away from work. They are responsible for most of the deaths in persons with AIDS.

### *Remember*

*All of these illnesses and conditions can also be found in people with other problems of the immune system that are unrelated to HIV or AIDS such as aging people and people who have recently undergone major surgery. Therefore, being diagnosed with any of these illnesses or conditions, by themselves, does NOT specifically indicate HIV infection or AIDS.*

## **Common OIs and their Management**

The most common OIs among the patients with AIDS in India are Tuberculosis (65%), Oral and Oesophageal Candidiasis (57.5%), Cryptosporidiosis (36%), Herpes Zoster (14%), Pneumocystis Carinii Pneumonia or PCP (13%), Bacterial Pneumonia (9%), Cryptococcal Meningitis (9%) and Toxoplasmosis (3.8%)<sup>1</sup>. They are the main cause of illness and premature death among Indian PLHIVs. Fortunately, many of these OIs can be prevented by simple preventive measures such as eating properly cooked food, drinking boiled water, hand-washing after toilet use, avoiding

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<sup>1</sup> **Codes for the opportunistic infections which are entered in the Patient Treatment Card:** **TB** Tuberculosis, **C** Candidiasis, **D** Diarrhoea, **M** Cryptococcal Meningitis, **PCP** Pneumocystis Carinii Pneumonia, **CMV** Cytomegalovirus disease, **P** Penicilliosis, **Z** Herpes Zoster, **H** Genital Herpes, **T** Toxoplasmosis, **FTT** Failure to thrive, **ARI** Recurrent respiratory infection, **MAC** Mycobacterium Avium-intercellular Complex, **CMP** Cardiomyopathy, **AN** AIDS-Nephropathy, **MDL** Molluscum contagiosum, **PAR** Parotitis, **LIP** Lymphoid Interstitial Pneumonitis, **LAD** Lymphadenopathy, **HSM** Hepatosplenomegaly, **DEV** Delay in or missing developmental milestones, **Other** to be specified

situations with a high risk of infection, and appropriate and timely immunizations. Also, early recognition and management can make a measurable difference to one's health status.

Dealing with these OIs among the PLHIVs is an important part of a long-term plan for managing the HIV disease. One of the biggest challenges in managing OIs is early diagnosis - before the infection is able to take hold in different organs like the lungs, intestines and brain. Treatment will be more successful and will result in full recovery when OIs are detected and treated early.

For this reason, the LAC counsellor should encourage clients to immediately seek medical help for any new or unusual symptoms experienced by them. As an LAC counsellor, you should explain to the client that the symptoms are usually indications of underlying disease or conditions. The reason for their symptoms could be HIV itself, the OI micro-organisms or the side-effects of ART. None of these conditions can be diagnosed by symptoms alone. *Only* a doctor can diagnose these conditions based on clinical examination and the results of laboratory tests. Thus in case of any new or unusual symptoms, the client should immediately seek medical help. Here the counsellor can help PLHIVs to develop good treatment-seeking behaviours.

To fulfill this role, the counsellor should have basic understanding about common OIs, their prevention, treatment and their management at the LAC as well as at home. This section will help the LAC counsellor to build this understanding.

## **Tuberculosis (*Kshaya Rog*)**

Tuberculosis (TB) is a chronic (long-lasting), contagious (easily spread) disease that is caused by bacteria. In India, TB is the most common OI which affects nearly 65% of PLHIVs (that is 2 out of 3 patients). It is curable. But *untreated* TB can cause death. Most of us in the general population have been exposed to TB germs as tuberculosis is a very common condition and these germs are dormant in our body. If we are generally healthy, our immune system can prevent the bacteria from causing tuberculosis disease. However, in PLHIVs who have a weak immune system, these dormant bacteria become activated, multiply and produce TB disease.

Tuberculosis can affect the lungs (Pulmonary TB), causing cough and sputum production. The PLHIV with TB usually complains of:

- Chronic cough which is often worse just after waking and may have blood - cough of any duration should be a trigger to suspect TB among PLHIVs
- Loss of weight and general weakness
- Mild fever which may be continuous or may increase in the evenings

- Sweating at night
- Pain in the chest or upper back
- Loss of appetite

TB can also spread beyond the lungs (Extra Pulmonary TB) in the Advanced HIV stage:

- Lymph nodes - causing swelling and fever
- Intestines - causing pain in the abdomen, diarrhoea and fever
- Liver - causing jaundice and fever
- Brain - causing meningitis with symptoms of confusion
- Bones - most seriously in the spine

The LAC counsellor should check for these symptoms and, if present, should immediately refer the client to the General OPD medical officer. The counsellor should also explain to the client that he/she may have TB and may need to visit the DMC (Designated Microscopy Centre) for testing of TB.

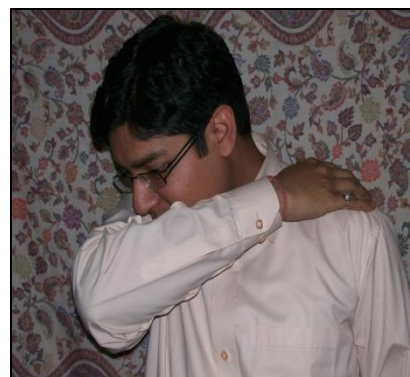
*If the diagnosis of any form of TB is confirmed, the client should be immediately referred back to the Nodal ART Centre for further evaluation with CD4 count and assessment for treatment failure.*



### **Treatment**

TB is completely treatable. Directly Observed Treatment Short Course (DOTS) regimens are available at the DOTS centre. The patient is referred to a DOTS centre for getting Anti-Tuberculosis treatment (ATT). The same regimens are used for the treatment of pulmonary and extra pulmonary TB. Around 6 to 8 months of treatment appears to be sufficient for pulmonary and many types of extra-pulmonary disease. Therapy for 9 to 12 months may be needed for bone TB, joint TB and tubercular meningitis.

If LAC clients are diagnosed with any form of TB, they should be immediately referred back to the Nodal ART Centre for further evaluation with CD4 count and assessment for treatment failure. All HIV/TB patients should receive Co-trimoxazole prophylaxis treatment (CPT) irrespective of their CD4 count during the period of ATT.



### **Prevention**

As the LAC counsellor, you should advise PLHIVs and their caregivers about the following:

- Every PLHIV should seek early medical attention if there is cough of any duration
- PLHIVs and their family should cover their mouth with a handkerchief / tissue paper / or the hollow of the elbow when coughing.
- PLHIVs and their family should spit into a closed container containing disinfectant and not on the ground. The contents should be thrown into a fire or covered with mud.
- PLHIVs and their family should avoid being in an unventilated space with a person who has been coughing.
- PLHIVs with cough should be segregated in a separate waiting area and fast-tracked to the Medical Officer.
- All homes, health facilities, workplaces and other places where people meet should be ventilated – that is, there is a way in and out for fresh air.
- All close contacts of TB patients in the family should be evaluated for TB and children below 6 years should be considered for Isoniazid prophylaxis (INH) if active TB can be ruled out in them.
- In addition, newborn babies should be immunized with the BCG vaccine.

#### **Counselling Points for a PLHIV with TB**

- Tuberculosis is very common but completely curable.
- Precaution to prevent the spread is very simple - covering the mouth while coughing.
- Treatment requires taking all the medicines regularly and completely.
- There is no danger to household and family if medicines are taken properly and the course is completed.
- Eating well and regularly is as important as medicines.
- Medicines for tuberculosis need to be taken for a long time. It can take many months to cure TB completely. Nobody should ever stop taking their medicines, even if they feel better, unless instructed.
- Avoid strenuous work, worrying, smoking, aerosol sprays, and dusty places while under treatment.
- Visit the doctor if in case of red or yellow eyes, unusual itching, rash and yellow urine after initiating medicines. Red-coloured urine is expected because it may be caused by rifampicin.
- Hospital care may only be required for certain problems that need special treatment.

Co-trimoxazole prophylaxis (CPT) is a simple, well-tolerated and cost-effective intervention for People Living with HIV. It is a key element of pre-ART care. Co-trimoxazole is a fixed-dose combination of sulfamethoxazole and trimethoprim. It is a broad-spectrum antimicrobial agent. It is useful for preventing *Pneumocystis carinii* pneumonia (PCP) (now called *Pneumocystis jirovecii* pneumonia), isosporiasis and toxoplasmosis. In turn it helps in reducing morbidity and mortality among persons living with HIV, especially children. CPT is given to all PLHIVs with CD4 less than 250 and to all those in Stage 3 and 4 at baseline assessment. CPT is also given to all HIV-exposed babies from age 6 weeks till HIV infection is definitively ruled out at 18 months.

### **Oral-pharyngeal Candidiasis (Thrush)**

Oral candidiasis is a rare condition in a healthy person, but is frequently the first indication of immune impairment in a PLHIV. It is caused by a micro-organism that grows on the mucous membrane (soft inner skin like in the mouth, tongue and intestines). It usually causes small white or yellow patches on the mouth cavity and on the tongue which come off easily when rubbed or scraped with a brush or fingernail. These patches may extend to the throat and oesophagus and is then called oesophageal candidiasis.

A PLHIV with oral candidiasis usually complains of:

- Oral ulcers
- Burning pain in the ulcers
- Altered taste sensation

A PLHIV with oesophageal candidiasis presents with

- Difficulty in swallowing (dysphagia)
- Painful swallowing (odynophagia)
- Pain in the chest
- Feeling of obstruction in food-pipe
- Heartburn or acidity

As per the WHO clinical staging, a PLHIV who has been diagnosed with oral candidiasis and oesophageal candidiasis is classified as a patient in WHO stage III and stage IV respectively. In PLHIVs, oral candidiasis occurs regardless of the CD4 counts. Oesophageal candidiasis will develop

in 10 to 20% of AIDS patients with CD4 count less than 100 cells/mm<sup>3</sup> and is the most common cause of the inability or difficulty in swallowing among PLHIV.

### **Treatment**

Oral candidiasis can be easily treated by scrubbing the tongue and the gums *gently* with a soft toothbrush or cloth at least three or four times in a day and then rinsing the mouth with a mild salt solution, a dilute mouthwash or lemon water. The counsellor can advise the PLHIV with thrush to suck a lemon if it is not too painful, as this slows down the growth of the fungus. The client can also apply 1% Clotrimazole mouth paint or gentian violet solution three or four times a day. Gentian violet solution is prepared by dissolving 1 teaspoonful of gentian violet crystals in half a litre of clean water (The client may use a mineral water bottle to estimate quantity of water). Chewing garlic or eating yogurt can also give some relief.

If the problem does not respond to simple treatment (Home-based care and general medicines) or if there is difficulty in eating and swallowing, the client should be immediately referred to the doctor.

Fluconazole may be prescribed orally for 7 to 14 days to treat candidiasis. However, for reducing the difficulties associated with infection, the counsellor can advise the client to:

- Eat soft rather than hard or crunchy foods
- Eat bland not spicy foods
- Use a straw for liquids and soups.
- Take cold foods, drinks or ice, if available, as this may help numb the mouth and relieve discomfort.

### *Remember*

**The client with oesophageal candidiasis (major OI) must be referred to the Nodal ART centre for treatment. Only clients with oral candidiasis may be treated at the LAC level.**

### **Prevention**

PLHIVs can prevent the development of this infection by avoiding stress, inadequate rest, poor diet, use of antibiotics, poor oral hygiene, smoking, excessive alcohol and sugar consumption. The LAC counsellor should also teach the client about oral hygiene and proper nutrition. Oral hygiene means rinsing the mouth with warm salt water, sodium bicarbonate solution or an antiseptic mouthwash solution after eating. Proper nutrition is covered in another section. It includes eating protective foods rich in vitamins, especially fruits like oranges, lemons and tomatoes. For a very



sick or bedridden client, family members may be counselled to take special care of the mouth and throat.

### **Cryptosporidiosis with diarrhoea that lasts longer than one month**

Cryptosporidiosis is caused by a micro-organism which lives in the intestine of humans and animals. It usually infects the small intestine and causes severe watery diarrhoea and malabsorption. In an immunocompromised individual it may also infect the large intestine. PLHIVs with CD4 less than 100 cells/mm<sup>3</sup> are at great risk of developing this infection.

This micro-organism can survive outside the body in an inactive phase for long periods of time and is resistant to chlorine disinfection. It is highly infectious and is transmitted through water, food, animal-to-human contact, human-to-human contact like oro-anal sex (that is licking the anus) and faecal contamination of water supply. Young children with diarrhoea can also transmit the infection to adults.

The PLHIV with Cryptosporidiosis complains of:

- Watery diarrhoea that may be self-limiting or may last longer than one month if not diagnosed early and treated appropriately
- Abdominal pain
- Nausea
- Vomiting
- Weight loss
- Loss of appetite
- Dehydration

### **Treatment**

Medical treatment will only be started after a conclusive diagnosis. Before that the client should be taught to manage diarrhoea at home using three simple rules:

- To drink more liquids than usual
- Continue to eat
- Recognize and treat the effects of excessive loss of water from the body (dehydration)

Dehydration can be easily recognized through a dry tongue, thirsty feeling, increased irritability or restlessness and lethargy. The body may become so dry that the skin goes back slowly when pinched and urine output becomes scanty. The client should be taught to note these early signs of

dehydration. If these signs appear or if diarrhoea does not reduce, then he/she should immediately seek help from a doctor. The counsellor should also inform the client that he/she should never use self-medications to stop the diarrhoea as these medications can interact with the ART drugs and can produce bad effects on the body.

### **Prevention**

The most effective way of preventing cryptosporidial infection is to avoid contaminated drinking water. HIV-positive people should be encouraged to drink bottled or boiled water or to use Zeoline solution or to use filters on tap water that can filter out the organism. Fruits and vegetables should be peeled and washed thoroughly in boiled water. PLHIVs should also avoid the direct contact with faeces (dirty diapers, sex with direct oro-anal contact). Practicing safe sex can also reduce the risk of other infections.

### **Herpes Zoster**

This is a painful rash with blisters caused by a virus that can appear on the face, scalp, neck, chest, back, stomach or limbs. This infection develops only if the PLHIV has been previously infected with chicken pox. The virus remains in inactive form in the nerves of the body and when the body gets weak due to old age, HIV infection, or prolonged stress, the rashes appear.

It usually starts with a sharp, burning pain, tingling, numbness, itching or aching in or under the skin of one side of the body or the face along the distribution of a nerve supplying that part of the body. After some days, vesicles develop. These are grape-like clusters of small, clear, fluid-filled blisters on red skin.

The blisters often combine, resulting in a large eroded or broken area, and there may be an intense burning feeling in the affected area. Healing takes several weeks and leaves discoloured areas on the skin which can be painful for a long time.

### **Treatment**

Medical Treatment of herpes reduces healing time and pain, and delays or prevents additional outbreaks/episodes.

Treatment with oral Acyclovir for 7 days should be started as soon as possible by the Medical Officer (MO) of the LAC Centre.

Along with the medical treatment, the counsellor should teach the client the following measures to reduce suffering:

- Apply calamine lotion to intact blisters twice daily to relieve pain and itching
- Keep the area around the rash dry and clean and avoid rubbing from clothes, if possible.
- Wear clean, loose-fitting, cotton clothing.
- Bathe the sores with warm, salt water three or four times a day
- Apply gentian violet solution or antibiotic skin creams or ointments once a day to the broken blisters.

The counsellor should encourage the client to maintain his/her personal hygiene, keep short nails and avoid scratching over the affected area. The counsellor should also educate the client and family members to avoid direct contact with the blisters as they are highly infective.

## **Cryptococcal Meningitis**

Cryptococcal Meningitis is caused by an infective organism which reaches the brain via the blood and produces the following illness symptoms:

- Headache which gradually increases over time. This goes away, then comes back and become continuous.
- Stiff neck
- Double vision
- Fever
- Nausea/Vomitting
- Altered consciousness

If left untreated, it is slowly progressive and ultimately fatal. *Thus, if any client comes to you with the above signs and symptoms, immediately refer them to the General OPD. If the client has the confirmatory symptoms then the physician will refer the patient to the ART centre.* The counsellor should help the client to collect the necessary referral documents and should inform him/ her that if this infection is left untreated it can slowly progress and can ultimately result in death. Also inform the client that he/she has to continue with ART drugs as this is important to prevent the progression of the disease.



You should also support the family members in ensuring patient's safety measures as the client can have injuries during seizures or because of change in mental status. Explain to family members that the client's ability to take decisions and to react to situation is altered. So they need to support the client during the illness.

## Toxoplasmosis

Toxoplasmosis infection is usually acquired by contact with cats or birds (Ingestion of food/water contaminated by the faeces of infected cats), and eating undercooked meat, especially pork. It most commonly invades the brain and lymph nodes and remains inactive in the body till the CD4 count becomes less than 100. Once CD4 is less than 100, the inactive infection gets activated and produces the following symptoms:

- Fever and headache (severe and localized)
- Confusion
- Vomitting
- Seizures, altered mental status and paralysis and coma.

*As an LAC counsellor when you encounter a client complaining of these symptoms, you should refer them to the physician for treatment and from there to the Nodal ART centre. Help the client in collecting the referral documents and assure the client that with treatment they could improve.*



Support and educate family members on safety measures as the patient may experience loss of balance, change in mental status, and seizures. Tell them to put side-rails on the bed on which the client sleeps or an obstacle such as a heavy chair. There should always be a person accompanying the client. Inform the family members that during seizures they need not panic and instead should make sure that the tongue does not fall back and the client is able to take breath. The client can be advised to sit in a quiet and calm setting when experiencing severe headache.

During regular counselling sessions, you as the LAC counsellor may inform clients that prevention measures include the following:

- Proper washing of hands and kitchen surfaces after handling raw meat/handling pets/gardening, etc.
- Avoiding handling cat faeces or gardening without gloves.
- Eating only completely cooked meats

## Pneumonia

Pneumonias are common causes of HIV-related morbidity and can occur even if PLHIVs have relatively higher CD4 counts. The most common symptoms are cough, fever, shortness of breath, chest pain, increased production of sputum (mucus), and occasionally blood-streaked sputum. But

if the following occurs with cough, then the client should be advised to immediately seek help from the doctor

- Sudden high fever with chills
- Severe chest pain or discomfort
- The color of the sputum changes to grey, yellow or green
- The sputum has blood in it
- Severe difficulty in breathing

For children, these lung infections can be very serious. So family members should be alert and if a sudden, high fever with fast or difficult breathing develops, they should seek immediate medical help.

### **Treatment**

With prompt and accurate treatment these infections can be treated. But usually clients do not complete their full course of therapy as they feel good within 2 to 3 days of treatment. Thus, the counsellor should encourage the client to complete their full course of therapy which is essential to ensure complete control of the infection and to prevent the development of therapy-resistant infections.

The following advice to PLHIVs may help to decrease respiratory problems:

- Keeping active by walking about, turning in bed and sitting up - This encourages the lungs to drain. Someone in the home can also massage or gently pat on the back of the chest over the lungs to encourage drainage.
- Holding a pillow to the chest or pressing the painful area with the hand while coughing - This can make the cough less painful.
- Coughing and clearing the lungs at least four times a day - This is an important way to clean the lungs of the accumulated mucus and disease-causing micro-organisms.
- Drinking lot of water along with medicines - This will replace the fluid lost through the lungs by rapid breathing and will help to keep the mucus from becoming too dry and sticky.
- For loosening the mucus the client can also breathe hot water vapour (steam). This could be done several times in a day.
- Home remedies like adding half a teaspoon of turmeric (*haldi*) powder in two tablespoon of the ginger (*adarak*) juice with two tablespoon of honey and little lemon juice can also help in soothing the cough and breathing.

- It is important to cover the mouth with a hand or cloth during coughing, since many germs can pass to other people through air. The home or room where you stay most of the time should be cross-ventilated (a way for fresh air to come in and another for it to pass out).

HIV-positive people who smoke, use crack cocaine, or inject drugs for recreational purpose, or consume alcohol, are at more risk of developing pneumonia. So, as the LAC counsellor, you should encourage clients to avoid these habits.

## **Pneumocystis Carinii Pneumonia**

Pneumocystis Carinii Pneumonia is a life-threatening respiratory disease which occurs in advanced HIV disease generally with a CD4 is less than 200 cells/mm<sup>3</sup>. The symptoms presented by the affected PLHIV differentiate it from other pneumonias. The condition, if not diagnosed appropriately, is dangerous and progresses slowly over the course of a few weeks. The onset is gradual, with **dry cough, progressive shortness of breath (difficulty in breathing which is not in proportion to the cough)** with or without fever (usually of low grade). The client may also report fatigue (tiredness) and night sweats before respiratory symptoms. If the patient is not taking co-trimoxazole prophylaxis regularly, the probability that the illness is PCP is very high.

*The infection can lead to death if early treatment is not given. Thus, if a client comes to you with a complaint of fever with progressive difficulty in breathing and dry cough, it is important not to assume this is a casual case of common cold. Refer the client to the medical officer. After proper diagnosis the client may be referred to the Nodal ART centre for the appropriate management of the infection.* Educate the client to cover his/her mouth while coughing and to maintain proper ventilation of the room. Inform the client that adequate nutrition, fluids and rest will help the client in the early recovery from the infection.



## **Role of the Counsellor in relation to OIs**

The counsellor plays a very important role as a member of the LAC team for prevention and early management of OIs and improved outcomes of the patients. Counselling sessions with adequate emphasis on prevention and early detection of OIs can reduce the illnesses as well as premature deaths among the PLHIVs.

The role of the LAC counsellor in monitoring and management of the symptoms of OIs are:

- Providing an environment conducive to exploration of feelings and emotions.
- Giving information on HIV/AIDS and OIs
- Giving information on the importance, prevention and early recognition of OIs
- Helping the client to seek medical help at the general OPD for the new or unusual symptoms suggestive of OIs
- Giving information on available treatment and home remedies for symptoms associated with OIs.
- Linking the client back to the Nodal ART centre if required
- Ensuring drug adherence and counselling the patient on safe sex, condom usage, proper nutrition and positive living.
- Explaining and emphasizing appropriate behaviours and habits to contain infections
- Discussing the impact of stress on the immune system and positive ways of coping.

Thus, the counsellor has to counsel the clients in the management of opportunistic infections with emphasis on drug adherence and compliance, nutrition, general hygiene, stress management, early recognition and treatment of infections. This will help in the achievement of two main medical functions of the Link ART Centre, i.e. monitoring the patients on ART in terms of OIs, side-effects and adherence and referring them back to the ART centre with regard to symptoms suggestive of OI or side-effect of drug.

Now we will discuss these roles of the counsellors in detail:

- Role of LAC counsellor in prevention of OIs.
- Role of LAC counsellor in management of OIs.

### **Role of the counsellor in OI prevention**

It is clear from the previous sections that most OIs are preventable and treatable. However, prevention is better than the cure. So, health services at the LAC should focus on avoiding and preventing the development of these infections in PLHIVs. As the counsellor you can play a lead role in this. During the monthly visits of the client to the centre, educate clients about various ways to prevent getting infected by germs.

The key preventive messages include that

- The client can live a healthy and longer life with HIV by eating a balanced diet, doing exercises moderately, getting enough sleep and avoiding both smoking and alcohol.

- Further he/ she must adhere to ART therapy, i.e. take the drugs in the prescribed dose, on time and regularly which will preserve the immune system and will allow for its recovery.

The other key injunction is to avoid any contact with infective organisms that cause OIs. This can be done by:

- Maintaining hygiene through
  - Daily baths to keep the body clean
  - Wearing shoes to avoid small injuries which may result in infections
  - Brushing the teeth after eating
  - Washing hands with soap after going to the toilet
  - Using and drinking clean water
  - Drawing water from recommended sources
  - Using boiled water or filtered water or adding Zeoline to drinking water
  - Storing water in a clean container
  - Observing cleanliness when preparing and serving food
  - Washing hands with soap and clean water before preparing food
  - Washing fruits and vegetables before cooking or eating
  - Using a clean table or chopping board to prepare the food
  - Serving food and water in clean and well-dried utensils
  - Ensuring that meat is well-cooked, i.e. until it is no longer pink in the centre.
  - Washing eating utensils and drying them in the sun.
  - Covering food or putting it in a cupboard away from flies.
  - Avoiding direct contact with pets and animals
  - Keeping animals and pets outdoors.
  - Asking someone else, if possible, to clean up after animals especially cats, kittens, chickens and other birds.
  - Always washing hands after handling pets and other animals.
  - Avoiding contact with young animals, especially those with diarrhoea
- Protecting self from HIV re-infection
  - If you have unprotected sex, you can be re-infected with a different strain of HIV.
  - ART does not protect against HIV re-infection.
  - If you get re-infected again with a different strain of HIV, your immune system gets weaker.



- Unprotected sex might result in contracting new sexually transmitted infections.
  - Protect yourself and your partner – always use a condom.
- Using prophylactic treatment when needed to prevent OIs. Tell the client that even if you are infected with some OIs, you can take medications that will prevent the development of active disease. This is called prophylaxis. This prophylactic treatment (Co-trimoxazole) is very effective against a variety of infective agents and is easily available at the LAC centre. This simple intervention if done on time can save your life and can delay disease progression.
- Inform the client that if he/she experiences any of these symptoms he/ she should immediately visit the doctor at the centre:
- Feeling dizzy
  - Pain when swallowing,
  - Trouble breathing
  - Frequent or very bad headaches
  - Problems in vision
  - Feeling more and more tired
  - Fever or feeling hot for more than a day
  - Sweat soaks the bed
  - Cough of any duration
  - Shaking and chills
  - Problems with balance, walking or speech
  - Losing weight for no reason
  - Watery diarrhoea for more than 4 times a day
  - Vomiting
  - Sore mouth or tongue
  - Stiff neck
  - Severe stomach or abdominal pain
  - Swelling, burning, itching, soreness, discharge or smell on or near the vagina.
  - Changes in menstrual cycle or menstrual flow.
  - Pain during sexual intercourse

He/she should not wait till he/she feels very sick to visit the doctor at the centre. Seeking early medical help for any new or unusual symptoms of the disease and complete treatment of OIs can reduce the complications and can also prevent the reoccurrence of the active disease.

Inform the client that at monthly visits to the LAC they will be screened by the medical officer at general OPD for the presence of any new or unusual symptoms related to the OIs. Also once in every six month they will be linked to the Nodal ART centre for a CD4 count as

well as for comprehensive clinical review. This will help in the early recognition and the treatment of the symptoms associated with OIs and identifying treatment failure.

- Another important responsibility of the counsellor is to assess for presence of TB and HIV among family members of the PLHIV (spouse, children).

## **Role of the counsellor in OI management**

Since Opportunistic Infections in persons with HIV infection are the main cause of illness and premature death, recognizing and managing them makes a marked difference to the PLHIV's health status. The counsellor can play an important role in early recognition and management of OIs. At every monthly visit of the client, the counsellor should discuss with the client if he/she has experienced any new or unusual symptoms. If so, the counsellor should refer the client to seek medical help at the General OPD where the doctor will screen the client for the presence of OI-related symptoms and will prescribe the necessary treatment. *Cough of any duration should be a trigger for the counsellor to refer the case to the Medical Officer to evaluate for TB.*



The following counselling activities have to be done when the client comes for follow-up visits and presents symptoms related to OIs.

- Discuss with the client the importance of early recognition and management of symptoms.
- Ask the client, if he/she has experienced any new or unusual symptom in the past one month period.
- Check for adherence to treatment or any side-effects of treatment.
- Help the client to check their weight and height and record the same on the LAC register sheet (column 3 & 4) and patient card. While doing so, observe the general health condition of the client, e.g. look for skin rashes, if any.
- Refer the client to the general OPD if the client has any symptom or complaints associated with OIs and explain to the client that ONLY a doctor can diagnose these illnesses and conditions. None of these diseases or conditions can be diagnosed by symptoms alone. All of these must be diagnosed by laboratory tests.
- Note the diagnosis and treatment made by medical officer , if any (column 7 and 8) on the patient page in the LAC register.
- Help the client to follow the prescribed treatment. Reinforce the importance of taking regular and complete treatment.

- Discuss with the client the simple interventions that he/she can do for managing and preventing the symptoms at home.
- Provide emotional, social, and psychological support to patients and/or direct the patient to the concerned person or organization that can do so.
- Address the concerns and worries of caregivers. Help the couple/family understand the infected person's condition/status and the importance of their support in its management.
- Encourage the client to avoid stress and to exercise regularly.
- Reinforce the importance of positive living, prevention and usage of the condoms.
- Make sure that the client and the family members understand your suggestions and will be able to implement them.

*Remember*

**Clients with major OIs are referred to ART centre for diagnosis and further management. So the counsellor should tell the client that he will be referred to the ART centre where other necessary investigations and treatment will be provided.**

When the patient is referred to the ART Centre, the counsellor should check whether the client has the following documents for follow-up at Nodal ART Centre:

- Photocopy of his/her page in the LAC register.
- Green book of the patient.
- LAC to NAC referral back form

The counsellor also needs to inform the Medical officer if the patient does not return on the due date after being referred to ART centre for the management of OIs.

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**Questions to LAC counsellors:**

- ✓ Are you aware of any cost-effective methods of water purifying?
  - ✓ What are some of the measures that should be followed to prevent the development of the Opportunistic Infections among PLHIV?
  - ✓ The list of precautions looks very long. Do you know of some easy ways to communicate this to clients?
-

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# Adherence Counselling at the Link ART Centre

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At the end of this unit, participants will be able to

- Describe the role of counselling in supporting a PLHIV's adherence to ART
- Demonstrate ART adherence counselling with special focus on issues relevant to the Link ART Centre
- List methods to monitor and support a PLHIV's adherence through counselling

One of the principal activities in a Link ART Centre is the provision of ARV drugs. Not surprisingly, the focus of counselling is on monitoring whether clients are regular about their drug intake, problem-solving and supporting them through the process. This is the art of adherence counselling. This chapter will focus heavily on how to calculate adherence and how to assist a client in maintaining it.

# Understanding Adherence

## Adherence

Adherence is defined as the extent to which a person's behaviour, the taking of medication and the following of a healthy lifestyle including a healthy diet and other activities, corresponds with the agreed recommendations of the health care providers (World Health Organisation, 2003)

It simply means following the treatment plan as prescribed by the doctor. This includes taking the correct dosage, at the prescribed time, in the correct manner. Apart from medicines, it also requires timely follow-up at the health facility, following a proper diet, and maintaining a healthy lifestyle. In the previous chapter, we have already seen why it is critical to encourage a 100% adherence to ART.

### Consequences of poor adherence for a PLHIV:

- Incomplete viral suppression
- Continued destruction of the immune system
- Faster disease progression
- Emergence of resistant viral strains
- Limited future treatment options
- Higher financial burden

### Consequences of poor adherence for society:

- Increased presence of drug-resistant viruses in society and treatment failure
- Increased chance for individuals to get infected with drug-resistant virus

# Adherence Counselling for ART

For a client to become/remain adherent to treatment he/she must change personal behaviours which can negatively affect adherence and must follow the instructions given by the health-care providers. There are many factors which hinder a client's life-long adherence to the treatment. Hence, he/she requires life-long support to continue taking medicines, particularly in terms of review of adherence and help in identifying and addressing issues which hinder adherence. Counselling plays a very vital role in preparing the client for treatment and also in supporting adherence.

## Objectives of Adherence Counselling

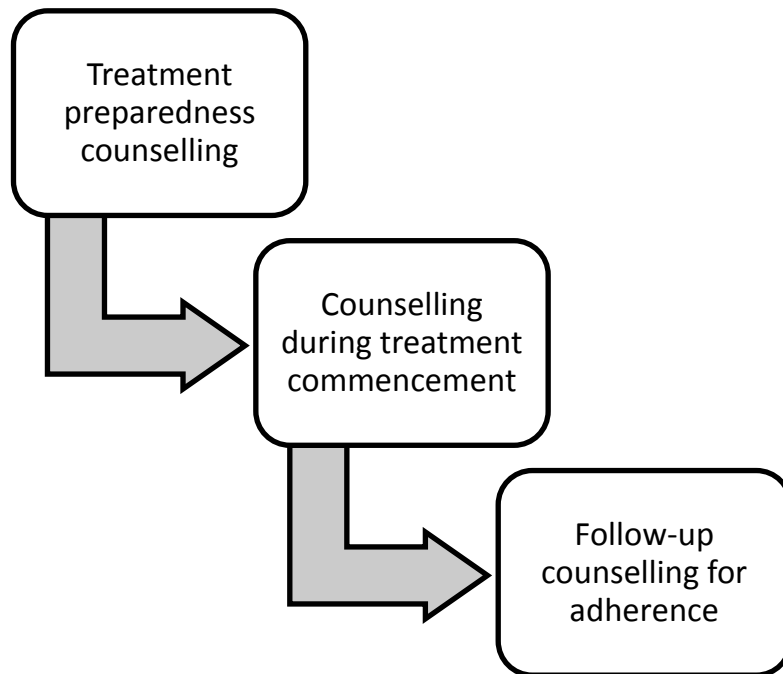
- Help the client develop an understanding of treatment and its challenges.
- Prepare the client to initiate treatment.
- Provide ongoing support to adhere to treatment over the long term.
- Help the client to develop good treatment-taking behaviour.

The counsellor helps the client to identify and adopt the most suitable way to ensure that he/she takes medicines. The focus must be on the client since, he/she is the person who knows best about his/her life situation and is best able to plan ways to integrate ART treatment in his/her life. This plan must suit the client's needs and resources; that is, it is a personalized strategy. The plan could include using mobile phone alarms, calendars, pill boxes, alarms, linking taking medicine with any other routine activity, using a treatment guardian who will directly monitor and support the client's pill-taking, etc.

## Adherence Counselling at Different Stages

The role of the counsellor could be described in three major stages.

- Treatment preparedness counselling
- Counselling during treatment commencement
- Follow-up counselling for adherence



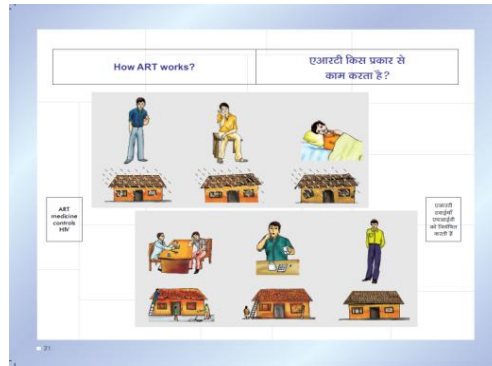
### **Treatment preparedness counselling**

At the preparation stage, the counsellor's focus is on client assessment and preparation for treatment. There is a process of gathering information regarding the client and an assessment of his/her ability to adhere to treatment. The counsellor also educates the client about treatment and the importance of adherence. This also involves the development of an individualized treatment plan for the client. Counselling at the preparation stage includes the following

- Establishing a strong rapport between client and ART team.
- Assessment of health, psycho-social status and economic conditions
- Pre-treatment education and adherence counselling
- Identifying possible barriers to adherence and plans to address them
- Assessment of the client's readiness to start and remain committed to treatment
- Development of an individual treatment plan

This may require more than one counselling session. The counsellor makes use of different tools like the Adherence Flip chart and Treatment Education Leaflets. Some ART centres use different interactive strategies to educate clients like the Balloon game. At the LAC, you may not have to do this.





Adherence Counselling Flip Book

### Counselling during Treatment Commencement

Once the client has declared a willingness to start ART, the counsellor focuses on the following

- Explanation of treatment such as names of various medicines, dosing instructions, instructions on dietary requirements, storage of medicine, possible side-effects and how to manage them at home.
- Identification of practical difficulties like how to take medicine while going out for work or in the presence of others who do not know the client's HIV status and managing side-effects.
- Planning follow-up visits to the centre and sharing contact details of both provider and client.
- Sharing take-home materials such as NACO's Treatment Education Leaflets. The image of one card is placed below. More cards are presented in the Annexures.

It is common to have side effects. They usually go away in 2-3 weeks. If you have them, do the following:

If you have	Do the following
Nausea	Take the pill with food.
Diarrhoea	Keep drinking and eating.
Muscle pain, fatigue	These will go away.

If Nausea or diarrhoea persists or gets worse, report to the health worker **AT THE NEXT VISIT.**

**Seek care urgently if:**

- Severe abdominal pain.
- Yellow eyes along with high fever, headache, running nose and body ache.
- Skin rash, along with fever and ulcer in the mouth and lips.
- Extreme paleness of face, hands or eyes.
- Fatigue and shortness of breath.

**Note:** Remember to take your cotrimoxazole prophylaxis tablet every day, if the doctor prescribes it. Always use condom during sex. Do not stop any drugs by yourself.

Phone:  Call ART centre if you have any questions or problems. (9 AM-4 PM)

Phone:  After 4 PM, contact the Hospital Emergency number.

Phone:  Call the local positive network number for support.

**NACO**  
National AIDS Control Organisation  
Ministry of Health & Family Welfare  
Government of India, 9th Floor, Chandralok Building  
36, Janpath, New Delhi - 110001, India  
Tel: 011-23325243, 011-23731774, 011-23731778, Fax: 011-23731746  
E-Mail: info@nacoonline.org

**ADULT**

**TREATMENT EDUCATION INFORMATION**

**ZDV + 3TC + NVP**

**REGIMEN - I**

ZDV + 3TC + NVP			
Zidovudine (300mg)	Lamivudine (150mg)	Nevirapine (200mg)	
<b>Day 1-14</b>		<b>Day 15 onwards</b>	
<b>Morning</b>			
Zidovudine+ Lamivudine+ Nevirapine	1 tablet	Zidovudine+Lamivudine+ Nevirapine	1 tablet
<b>Evening</b>			
Zidovudine+ Lamivudine	1 tablet	Zidovudine+Lamivudine+ Nevirapine	1 tablet

**REMEMBER THAT**

- If you miss doses (even 2 doses in a month) **DRUG RESISTANCE** can develop. This is bad for you and your community. (These drugs will stop working.)
- No doses should be missed as it is very important to maintain blood levels so ART can work.
- If you forget a dose, do not take a double dose.
- If you stop you will become ill within months or year.
- Drugs **MUST NOT** be shared with family and friends.
- If you find it difficult taking your pills twice daily, **DISCUSS** with health workers. **ASK** for support from your Treatment supporter, family or friends.

**Remember: Adherence is under your control**

Note: The color, shape and size of ARV drugs may be different due to different supplier each year.

## Follow-up counselling for adherence

After the commencement phase, each client is provided with drugs for one month. They are provided with a follow-up appointment on the 28th day following their current date of visit. During each follow-up visit to the centre, the client is monitored for his/her adherence to treatment and is provided with on-going support for adherence.

## Adherence monitoring

Adherence monitoring is the process of gathering information on all aspects of treatment adherence, including treatment of OIs, routine prophylactic treatment or other medication such as Anti-Tuberculosis Treatment (ATT). Once the treatment has started, adherence is assessed using various techniques. Counselling is provided according to the client's adherence to ART and other needs like psycho-social support. Some of the techniques for adherence monitoring are explained below

### Adherence from Pill Counts

Adherence can be calculated using the formula

$$\% \text{ Adherence} = \frac{\text{Number of pills the client should have taken} - \text{Number of pills missed}}{\text{Number of pills the client should have taken}} \times 100$$

Adherence could be less than 100% when clients have taken fewer pills than required or more than 100% when they have taken extra pills by mistake. A sample calculation is provided below

---

#### *Sample case for adherence calculation*

Mr Tanuj was provided with a drug, to be taken twice a day for 30 days. He came back to treatment centre on the 27th day and 10 pills remained in the pill box.

$$\text{The number of pills given to Mr Tanuj} = 2 \times 30 = 60$$

$$\text{The number of pills he should have been taken} = 2 \times (30 - 3) = 54$$

$$\text{The number of pills Mr Tanuj has taken} = 60 - 10 = 50$$

$$\text{So number of pills missed} = \text{No. of pills he should have taken} - \text{No. of Pills taken} = 54 - 50 = 4$$

$$\text{Hence, \% adherence of Mr Tanuj} = \frac{54 - 4}{54} \times 100 = 92.5\%$$

## Adherence from Self-Report

Adherence over a period of recall, such as last 3 days, can be measured using a self-report from the client. Here the counsellor asks the client about missed doses: “How many pills did you miss yesterday, the day before that and the day before that (3 days ago).” Adherence is calculated from the number of missed pills for the period. We do not follow this method in the Indian AIDS Control Programme.

$$\% \text{ Adherence} = \frac{\text{Number of pills the client should have taken} - \text{Number of pills missed}}{\text{Number of pills the client should have taken}} \times 100$$

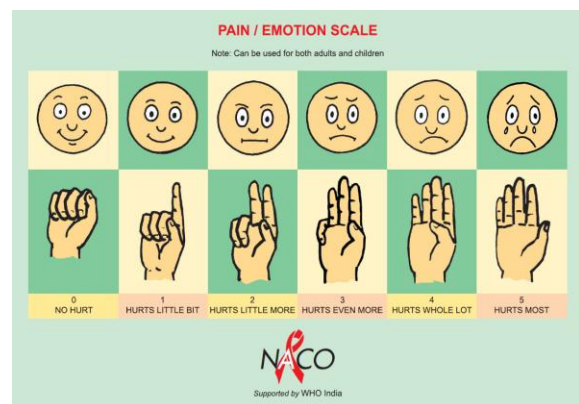
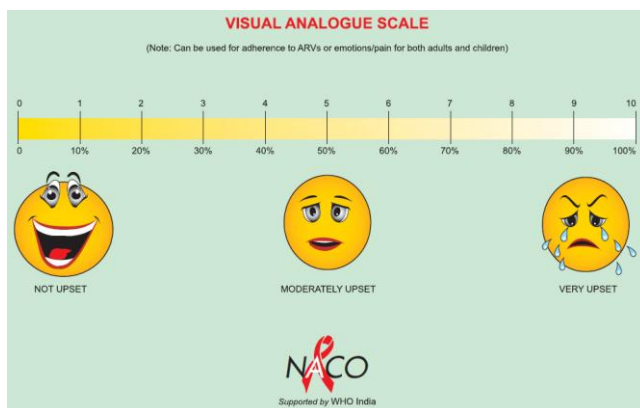
Number of pills the client should have taken

Example				
Number of tablets	Yesterday (missed pills)	Day before Yesterday (missed pills)	The day before that (3 days back) (missed pills)	% adherence
One tablet taken twice daily	0	1	1	$\frac{6-2}{6} \times 100$

(Refer to HIV Counselling Training Modules for VCT, PPTCT and ART Counsellors, NACO 2006)

## Adherence calculation using Visual Analogue Scale

Adherence to treatment can also be assessed using the Visual Analogue Scale (VAS). The VAS was originally used as a tool to help clients in quantifying their pain and emotional disturbances. In ART, the VAS can be used to elicit information regarding their perception on how much they adhere to treatment. It can be used effectively with clients who are illiterate.



Here the counsellor asks the client to think back over the past four days and identify the times when he or she either missed a dose or took it at the wrong time. Then the counsellor shows the client a copy of Visual Analogue Scale. Counsellor then explains by placing his/her finger appropriately, i.e., if the client had taken all medicine doses he/she can point to 10. If the client missed all the doses, he or she would point to 0. The client is asked to point out his/her level of adherence. If the client marks the scale at 4, then the percentage adherence would be 40 percent.

LAC counsellors may obtain the Visual Analogue Scale through the Care and Support Division of the SACS or through the Regional Co-ordinators.

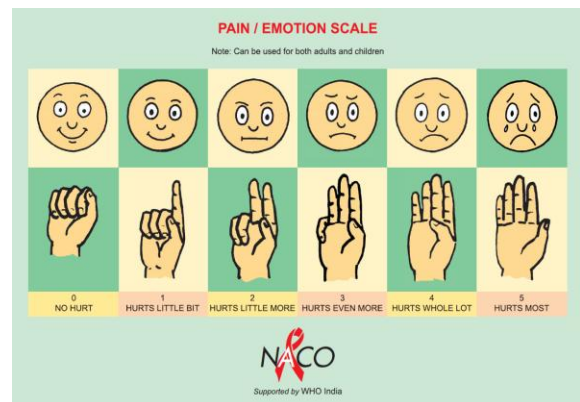
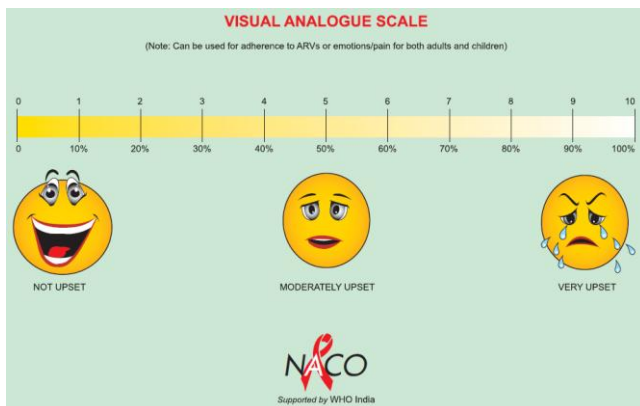
### Adherence calculation using a Look-up Chart

The Counselling Personnel of the National AIDS Control Organisation (NACO) have also pioneered a simple look-up chart to calculate the exact adherence percentage using the number of pills brought back in the bottle and knowing the date of the client’s visit. This was created to reduce calculation error.

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### Questions to LAC counsellors:

- ✓ Can you explain some of the advantages of the different methods used for monitoring adherence described above?
- 





## Disputing Statements Worksheet

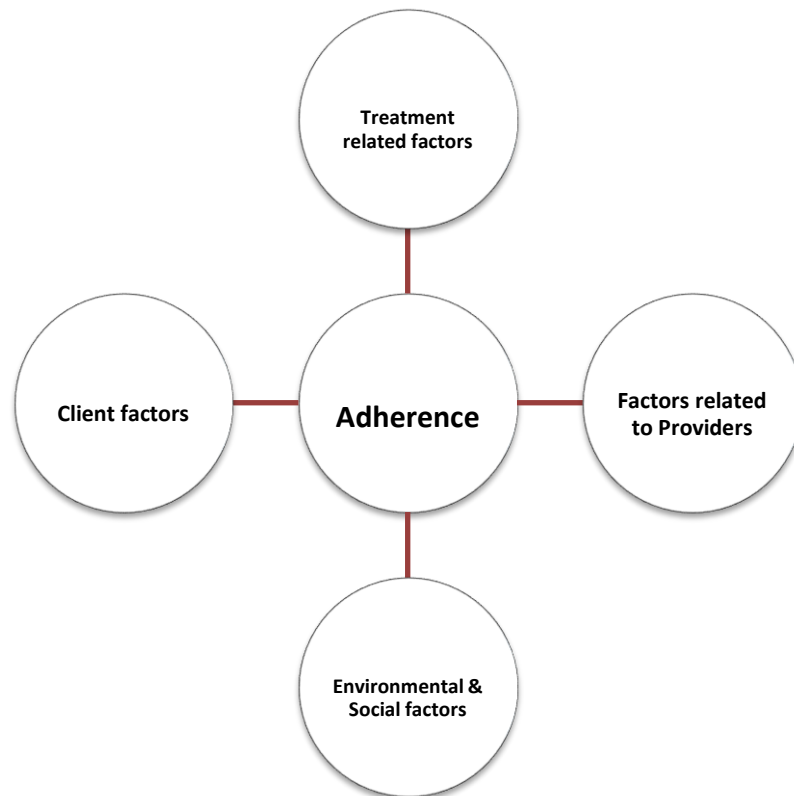
**Instructions: Read the client's statement and fill the corresponding counselling line.**

Sl. No	Client's Barrier Statement	Counselling Line
1	<i>"I don't think I can take the medicine for my life time"</i>	
2	<i>"I don't want to come to the Link ART centre. Staff behave rudely"</i>	
3	<i>"I don't think ART can help me"</i>	
4	<i>"I don't know how to take the medicines"</i>	
5	<i>"I can't come every month to this centre. I want to go to work"</i>	
6	<i>"Doctor had told me to take medicine after food only. So when I can't have food, I skip the medicine too"</i>	
7	<i>"The old counsellor never told me to come directly and bring the pill bottles. That is why I sent my wife to collect the medicine"</i>	

## Ongoing Support

Different barriers may challenge the client. The counsellor helps the client to identify and discuss such issues so that feasible solutions can be sought and implemented. Counselling also requires supporting the client in order to keep them confident about following life-long treatment. This includes the following

- Checking for any difficulty in taking medicines and helping the client to manage the same
- Checking for side-effects, and giving proper directions.
- Reinforcing the importance of adherence and clarifying any doubts.
- Reviewing and helping to develop support systems
- Reviewing the effects of ART on health status and personal life



# Challenges and Constraints to Adherence

As mentioned before, there are many challenges and constraints which a client may face during his/her life-time against treatment. These can be generally identified as related with treatment, providers, the client himself/ herself and their social situation.

## Treatment-Related Factors

- Side-effects of drugs
- Number of doses to be taken
- Duration of treatment
- Difficulties in taking the medicine - diseases like oral candidiasis (whitish patches inside the mouth), mouth sores, inability to take medicines, unconscious patient, etc.)
- Nature of the medication - some medications can interact with other medications (e.g., Rifampicin of TB treatment and Nevirapine of ART)
- Complexity of treatment if taking medicines for more than one illness (like TB) along with ART.

## Factors Related to the Attitudes and Behaviours of Providers

- Attitudes of the provider towards treatment and client
- Stigmatizing attitude and discriminating behaviours
- Lack of understanding of the client's personal and social circumstances
- Lack of knowledge and skills to provide good treatment
- Lack of skills to help clients assess their options to manage ART as successfully as possible
- Misconceptions such as becoming infected with HIV through contact with HIV-positive clients
- Higher number of patients and related service time with providers
- Incorrect assumptions about the client's level of understanding of the illness and the need for medicine
- Perceiving the client only as a passive recipient of instructions
- Gender biases

## **Client-Centred Factors**

- Inadequate understanding about the disease, treatment, adherence and side-effects
- Limited faith in the treatment
- Inadequate understanding of the prescribed instructions
- Forgetfulness or confusion
- Psychological issues - anger, depression, stress
- Lack of motivation
- Gender bias of the client vis-à-vis the service provider
- Fear of disclosure of HIV status/non-disclosure
- Reduction, disappearance or fluctuation of disease symptoms
- Physical disabilities limiting access
- Lack of family and social support
- Financial constraints/travel costs

## **Environmental and Social Factors**

- Social stigma and discrimination against People Living with HIV
- Lack of social support networks
- Lack of appropriate referral systems
- Lack of human resources
- Inadequate supply of drugs
- Poor monitoring and support
- Cultural beliefs and customs

Counselling alone does not provide solutions for all these barriers. However, counselling can help in identifying and addressing some among them and alleviating the impacts of others on the treatment taking behaviour of clients. Networking and linkages are important in this context.

## **Addressing Barriers to Adherence through Counselling**

Clients may miss medicines due to various reasons. Even when a client misses a minimal number of doses or is late in taking medicines a few times, the counsellor has to carefully assess their reasons for doing so. It requires conscious intervention from the counsellor. The client should be given a comfortable atmosphere where he/she feels able to openly share about missed doses and seek help from the counsellor for changing this pattern in future.



Even though an LAC client has shown good adherence for at least six months (at the ART Centre), there are still risks for him/her to lose the adherence as time passes. Hence the counsellor must routinely check for any kind of potential barriers for the client's adherence to medicine as well healthy life-style practices. Some examples are given below.

## **Types of Barriers**

### ***Health-related barriers***

- Ill-health may lead to
  - Decreased faith in treatment
  - Difficulty in taking medicine
  - Patient not collecting medicine from the centre due to hospitalization or ill-health
- Better health may lead to the irregularity in taking medicine, delaying medicines etc.

Counsellors can use questions like “How are you feeling now?”, “I understand that you are not feeling well for many days. Did you by any chance miss the ARV drugs?”, “Did you have difficulty in taking your medicines?” In both situations of ill-health and good health, the need to continue medicine must be emphasized. Counsellors can give examples of different individuals and how they have adhered to the treatment in such situations.

### ***Psychological barriers***

Counsellors should screen clients for symptoms of psychological and emotional disturbances which might make them forget to take medicines, get irritated with treatment or lose faith in others. Timely identification and referral to support is needed in such situations.

Counsellors can use observation skills and simple questioning for identifying psychological barriers. Some examples are given below

- Client becoming gloomy
- Client not willing to talk
- Sudden bursting out to the counsellor or other staff members
- Client not willing to sit.
- Client shares negative thoughts
- Client talking about death

Ask clients the following questions:

- *How are you feeling now?*

- *Are you getting enough sleep?*
- *How is your job /family?*
- *Are you worried about anything?*

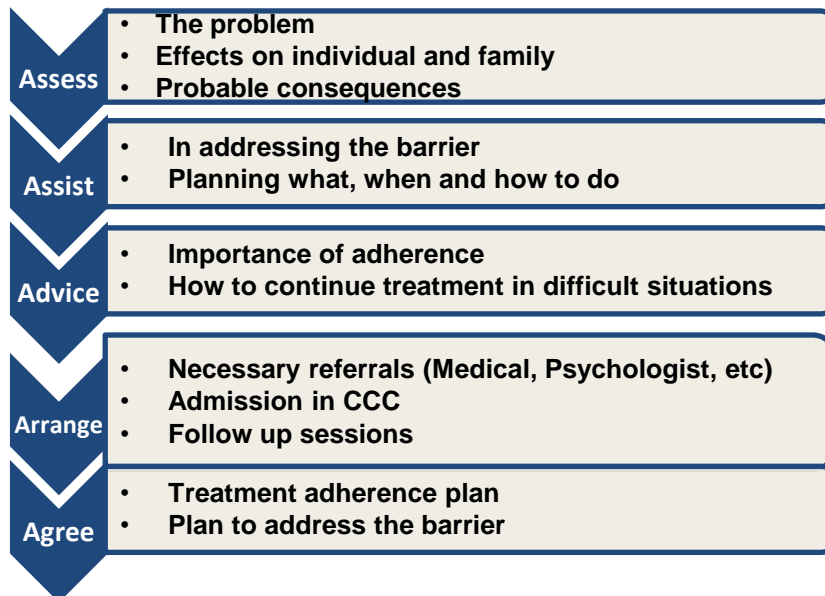
Ask caregivers the following questions:

- *Do you notice any change in the client's behaviour?*
- *How is the client's interaction with others in the family?*
- *How are his/her sleeping and food habits?*

### **Social barriers**

Social barriers may range from fear of being identified as an HIV-infected person in the community to discrimination and social rejection. Many clients face issues from their immediate environment including family. These can affect adherence to treatment. Such issues can be identified, if the counsellor has a good rapport with the client. He/she can encourage the client to share incidents which affected him/her during the last month. Some clues can be elicited with questions like

- *Did everything go well with you in the last month?*
- *Is there anything which you want to share with me?*
- *What have you been saying to your friends about coming here every month?*



*5 'A's in addressing social barriers*

Expressing support and understanding of the issues faced by the client can be the first thing the counsellor can do in such situations. The counsellor can help the client to analyze the situation and seek possible ways to address such issues. The 5 'A's principle can be utilized in such situations.

## **Adherence Fatigue**

Adherence fatigue is the state when the client gets bored with the routine of taking medicines, stops bothering about the disease and stops taking medicines subsequently. It is one factor which can lead to poor adherence and must be assessed during each follow-up visit.

### **Symptoms of adherence fatigue**

ART medical officers and counsellors report that the following symptoms are suggestive of adherence fatigue

- Client believes and tells others that he/she is no longer HIV positive
- Client says the following
  - “ Now I do not have any problem and I am cured”
  - “ I am fed-up with medicines”
  - “ I think I can stop medicine now, I don't think I have to take more”
  - “ I think I am not HIV-positive, I need to do the test once more”
  - “ I don't think there is any issue if I stop medicine for some time”
  - “ I forgot to take medicine”

Some clients develop side-effects in later stages (for example numbness of lower limbs start after 8 to 9 months on ART). This also may make them feel that ART does not benefit them and they may stop medicine.

### **How to address adherence fatigue?**

Counsellors have to keep in mind that adherence is a dynamic behaviour and it may change at any time. Proper counseling during each visit will prevent adherence fatigue to a great extent. If any client shows symptoms of adherence fatigue, the following can be tried:

- Reinforce the adherence messages
- Explain about the life cycle of HIV and how ART suppresses it (Please refer to the earlier chapter for details)
- Use case examples where poor adherence due to adherence fatigue has affected the clients badly and help them to analyze the situation

- Arrange experience-sharing among clients in a support group
- Use any interactive method, which teaches about importance of adherence (e.g., puppetry and story-telling)
- Seek the help of caregivers
- If needed, arrange for Directly Observed Treatment where the client takes medicine in front of a caregiver, for a short time

### *Balloon Game on the Importance of ART Adherence*

- Hold a balloon in the air and ask the client what it does.
- Check whether the client is able to tell that the balloon is free to move
- Put your hand on the balloon and ask the client what happened to it now.
- Relate the balloon to the HIV and your hand or object placed on the balloon to the ARV drug
- Now remove your hand and ask the client what happens to the balloon now
- Ask the client, what will happen to HIV, if ART is not present in the body.
- Discuss what will happen to him/her if HIV is continuously free to act in the



body.

- Discuss what the client has understood from the game

(The above pictures are from the ART centre at BMJ Medical College, Ahmadabad, Gujarat. The balloon shapes have space to keep ART drug containers on both sides. To stop the balloon's movement, one has to keep drug containers on both sides of the balloon)

# **Adherence counselling at the LAC**

Link ART Centres play a very important role in the client's adherence to treatment. They take care of a few big issues against adherence like the difficulties associated with monthly travel to a distant ART Centre and also the chances of losing personal attention and care at a crowded ART centre.

ART centres transfer only those clients to the LAC, who

- Are on treatment for more than 6 months
- Have a good record of adherence
- Do not have major OIs or side-effects
- Are willing to receive ART services at an LAC.

The counsellor at the LAC has to help these clients to continue their treatment successfully. He/she supplements the role played by the counsellor at the ART Centre in helping the client to adhere to ART through treatment education and support. The role of counselling at the Link ART centre is mainly related with adherence monitoring and follow-up. The specific functions to be undertaken by the LAC counsellor can be understood in the context of the client's visits to the Link ART Centre.

## **Adherence counselling during the Client's first visit to the LAC**

Counsellors have to keep in mind that clients reaching the LAC have already undergone a number of counselling sessions at the ART Centre including preparation, treatment commencement and adherence monitoring sessions. These experiences must have influenced their thoughts, attitudes and behaviours. Establishing a strong counselling relationship is vital to the counselling at the LAC also. Hence rapport building with client is among the first tasks at the Link ART Centre

### **Building rapport with the client**

Building rapport means developing a relationship of mutual understanding and agreement between the client and the service provider. The counsellor needs to consider the following while initiating a counselling relationship with the client at the LAC

- The client already had a set of counselling experiences before reaching the LAC - at the ICTC, ART and CCC respectively. He/she may have some expectations about counselling based on these prior experiences.

- What the client understands about HIV and treatment is crucial to adherence. Assessing this will help the counsellor in monitoring and supporting the client for adherence
- The client may feel that the ART centre was more comfortable than the LAC. At the ART centre the services are exclusively for PLHIV with trained staff members. At the LAC, the client is one of a group of people with other issues - for instance, pregnant women who have come for testing.
- He/she may have concerns about
  - The geographical proximity to his/her residence and the chances of his/her HIV status becoming known to their place
  - Quality/effectiveness of services at the LAC, especially because Link ART centres function at a small setting compared to the ART centre
  - Need to receive services from the General OPD at the hospital - especially seeing the doctor and collecting medicines, which has to be repeated every month.
  - Lack of confidence in the staff about shared confidentiality (that the HIV-positive status will be known to other staff members at the hospital, especially those who are not part of Link ART team)

To address these, the client's first visit to the LAC may focus on building a strong rapport and gaining the confidence of the client. The client's various concerns also may be identified and addressed properly and explicitly

### **Other Critical Procedures**

Besides building rapport, the counsellor must introduce a few key topics such as the nutrition plan. However, the advantage of on-going follow-up is that the counsellor can choose certain key issues to highlight in the first session, and defer other big items to subsequent sessions. However, one key procedure is the issuing of an LAC ID number.

A check-list for the initial visit of the client to the LAC is provided next.

<i>Rapport Building</i>	
✓ Introduce the whole LAC team to the client	<input type="checkbox"/>
✓ Explain the LAC procedures - consulting with MO, adherence monitoring, drug distribution and counselling	<input type="checkbox"/>
✓ Explain the differences between ART Centre and LAC <ul style="list-style-type: none"> <li>○ At the nodal ART centre, there is an MO dedicated to the ART Centre, while at the LAC a client has to consult the doctor within the General OPD.</li> <li>○ Medicine is distributed by the ART pharmacist in the ART Centre, while the general pharmacist or staff nurse dispenses medicine at the LAC</li> </ul>	<input type="checkbox"/>
✓ Gather information regarding the client - eg; family details, caregiver details, occupation, residence and health status (ask directly/check the green and white cards	<input type="checkbox"/>
✓ Extend support for the client and assure that his/her HIV status will be kept confidential in the LAC.	<input type="checkbox"/>
✓ Specifically ask for concerns regarding the LAC and address, if any	<input type="checkbox"/>
✓ Inform that he/she can consult the ART centre once in 6 months and in case of major health issues	<input type="checkbox"/>
<i>Adherence counselling</i>	
✓ Review the client's understanding regarding ART and adherence strategies used by the client	<input type="checkbox"/>
✓ Reinforce the need for continued adherence	<input type="checkbox"/>
✓ Ensure that he/she has drugs for one month	<input type="checkbox"/>
<i>Side-effects and OIs</i>	
✓ Check client's knowledge about side-effects and advise to return to LAC, if any occurs	<input type="checkbox"/>
✓ Check client's understanding about OIs and review the history of past OIs	<input type="checkbox"/>
<i>Complete the documentation procedures and provide the LAC ID-number. Provide the next follow-up date. Note this date in your follow-up diary</i>	<input type="checkbox"/>

## Adherence counselling during the Client's follow-up visits to the LAC

Similar to the follow-up counselling at the ART centre, the follow-up sessions at the Link ART Centre focus on adherence monitoring and supporting the client to adhere to treatment successfully. Other issues like STIs, need for Family Planning/MCH services, etc also must be addressed during these sessions. Positive prevention is another important aspect. A checklist for the follow-up session is given below

<i>Adherence</i>	
✓ Check whether the client has taken the morning tablet. Offer the tablet and water, if necessary and observe client consuming the medicine.	<input type="checkbox"/>
✓ Review the client's adherence to treatment <ul style="list-style-type: none"> <li>○ Number of doses missed since the last visit (Oral report)</li> <li>○ Check whether the client has taken the drugs at the right time</li> </ul>	<input type="checkbox"/>
✓ Count the pills remaining in the bottle and assess and categorize adherence accordingly (<80%, 80-95% and >95 %).	<input type="checkbox"/>
✓ Check the reasons for adherence levels below 95% <ul style="list-style-type: none"> <li>○ Assess client's current understanding about treatment and importance of adherence</li> <li>○ Check for signs of treatment fatigue</li> <li>○ Discuss any problems or issues the client in taking the medicine</li> </ul>	<input type="checkbox"/>
✓ Check the ART counselling diary and review any past issues pending	<input type="checkbox"/>
✓ Check whether the client has any plans for a change in his/her life in the coming month. Discuss how he/she will take medicine without interruption in the changed situation	<input type="checkbox"/>
✓ Reinforce the need of adherence	<input type="checkbox"/>
✓ Review the adherence strategy followed. If needed help the client to modify or change the same.	<input type="checkbox"/>



✓ Check the client's next month's supply of medicine	<input type="checkbox"/>
<i>Side-effects and OIs</i>	
✓ Check for signs and symptoms of OIs and drug side-effects. Encourage the client to report any symptoms to the doctor	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>○ If minor, refer to the trained doctor at the LAC</li> <li>○ If major, arrange for referral to nodal ART Centre</li> </ul>	
✓ Assess current understanding of the client regarding side-effects and OIs	<input type="checkbox"/>
✓ If the client has any symptoms of serious OIs or side-effects, arrange for referral to the Nodal ART Centre	<input type="checkbox"/>
<i>STIs</i>	
✓ Screen for STIs and refer for treatment, if necessary	<input type="checkbox"/>
✓ Reinforce the need of safe sex and address barriers, if any	<input type="checkbox"/>
<i>Nutrition and diet plan (Need not address on each visit)</i>	
✓ Assess the client's understanding about nutritional requirements, if not done before.	<input type="checkbox"/>
✓ Check the weight and compare it with the previous 3 months measurements. If any serious weight loss has happened, bring it to the notice of the doctor.	<input type="checkbox"/>
✓ Check for any conditions requiring additional nutritional intake (pregnancy, OIs, side-effects , etc).	<input type="checkbox"/>
✓ Check the quality and quantity of food and water intake.	<input type="checkbox"/>
✓ Discuss the diet plan, nutrition, exercise and suggest if any modification is required.	<input type="checkbox"/>
<i>Positive Prevention (Need not address on each visit)</i>	
✓ Assess the sexual practices of the client	<input type="checkbox"/>
✓ Discuss how the client can adopt safe sex practices in his/her life	<input type="checkbox"/>
✓ Address issues concerned with condom use and provide condoms	<input type="checkbox"/>
<i>Family Planning (Need not address on each visit)</i>	
✓ Discuss family planning methods adopted by the client	<input type="checkbox"/>

✓ If needed offer family planning counselling for partner	<input type="checkbox"/>
✓ Check with female client (who has a male partner) in reproductive age, whether she had any unprotected sexual intercourse in last few months	<input type="checkbox"/>
✓ Check with the female client whether she suspects pregnancy. If yes, provide her with counselling for preventing transmission to the child	<input type="checkbox"/>
<i>Positive living</i> (Need not address on each visit)	
✓ Encourage the client to share recent events in his/her life. Ask if these had any effect on adherence and positive living	<input type="checkbox"/>
✓ Discuss how treatment has affected other areas of his/her life	<input type="checkbox"/>
✓ Review social and familial support at regular intervals. Refer to the other agencies, if required	
✓ Check if the client that is taking any other medication. In such cases, reinforce the need to consult with the doctor.	<input type="checkbox"/>
✓ Reconfirm the appointment for the next month	<input type="checkbox"/>

## Visit prior to back referral to Nodal ART Centre

All clients transferred out to the LAC should be referred back to the nodal ART centre

- Once in every 6 months for repeat CD4 count and comprehensive clinical review
- Whenever,
  - any major OI is present
  - any major side-effect occurs
  - the client is pregnant

Counsellors need to focus on effective referral counselling during LAC visits prior to the client's visit to the Nodal ART centre. It will be a good practice to be in contact with the ART centre and get an appointment for visit to avoid communication gaps and communication issues during referral.

A checklist for the additional issues to be covered during such visits is provided below

<i>Additional issues for the counselling session prior to the client's six monthly visit to the Nodal ART centre</i>	
<ul style="list-style-type: none"> <li>✓ Remind the client about the visit to the nodal ART centre and its purpose: <ul style="list-style-type: none"> <li>○ CD4 testing</li> <li>○ review of client's health status by ART doctors</li> </ul> </li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Plan the date for the visit to the ART centre</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Ensure that you send all the required documents with the client to the ART centre <ul style="list-style-type: none"> <li>○ Photocopy of his/her page in the LAC register.</li> <li>○ Green book of the patient.</li> <li>○ LAC to NAC referral form</li> </ul> </li> </ul>	<input type="checkbox"/>
<i>Additional issues for linking in case of major OIs</i>	
<ul style="list-style-type: none"> <li>✓ Explain that a major OI needs more specialized treatment</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Try and get an appointment immediately. Call the ART counsellor, if possible.</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Ensure that you send all the required documents with the client to the ART Centre</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Check if the client has any transportation issues</li> </ul>	<input type="checkbox"/>

## **Counselling during special situations**

### **When client reports adherence is less than 80%**

When the adherence rate is less than 80% at any visit, irrespective of viral or clinical failure, the counsellor should

- Re-educate the client about the importance of adherence especially the long-term benefits.
- Evaluate if the required support structures are in place
- Review if all supporting strategies are followed.
- If needed, insist on participation in a support group (if such a group is available locally and you feel that it will help him/her)
- Check the family situation and help the client to find secondary support, if needed

## **When the client has missed a visit**

Usually clients are given tablets for 30 days and are given a follow-up date on the 28th day. A client is considered MISSED, when he/she does not come to collect the medicine on the scheduled day for the same. It is recommended that the counsellor maintain a note/document/list of the clients to come for follow-up visit on each day and mark whether they have turned up or not. This can be easily done if the counsellor maintains a diary/ calendar for follow-up dates and enters the patient's name next to the date of the next visit at the time of the current visit itself.

If anyone misses on their scheduled day, they may be contacted through phone or Out-reach workers or District Level Networks (DLN). This should have been covered when discussing shared confidentiality in the first session. When the client does visit the LAC, counselling should focus on helping the client to prevent further missed visits or becoming lost-to-follow-up. During counselling, the counsellor must

- Identify the reason/s for not turning up
- Analyze whether there is a chance for the same to happen again and how the client can handle the situation when repeated
- Re-emphasize the need for complete adherence, ie: the client should overcome all barriers and take medicine at the right time every day.
- Discuss ways for improving adherence. The aim will, therefore, be to prevent further missed doses and/or visits.

## **When the client is Lost-to-Follow-up (LFU)**

A client is considered Lost-to-Follow-Up when he/she does not come for follow-up visits to collect medicine continuously for three months. Counsellors should work with clients to prevent this happening through strong rapport, and through being familiar with key incidents in the client's life which pose challenges to adherence such as ill-health, shift in job and residence. Utilizing the services of outreach workers will be helpful to get in touch with the client. It is also important to focus on those who miss their visit, so that they do not end up becoming lost-to-follow-up.

Since clients who get transferred to LACs have a record of good adherence, it is unlikely that they will become LFU. However, if any client has been LFU, counsellors should undertake the following measures to trace them back to Link ART centre

- Contact the client through phone or directly
- Follow the client with the help of outreach workers in CCC or Drop-In-Centres

Once the client is back to the centre, the client should be counselled properly to

- Identify the reason for not coming to collect medicines
- Assess the client's situation and check for any complications due to missing of doses
- Check for practices like alternate treatment, treatment at private centres, etc.
- Re-emphasize the need for complete adherence, that is, the client should overcome all barriers and take medicine at the right time, every day.
- Review the client's treatment adherence strategy and the attitude towards the treatment
- Check if the client is not comfortable at the current facility and would like to be linked back to the nodal ART centre
- Also check if the client needs support for substance dependence, psychological morbidity like depression, psychiatric illness etc and arrange support if feasible.

Such clients who are re-found at the LAC after being LFU should be referred to the Nodal ART Centre for review and continued services.

- Inform the client that he/she needs to visit the Nodal ART Centre and consult the doctor there for ensuring the effectiveness of the treatment.
- Plan the client's visit to the ART Centre and get an appointment for the client at the ART Centre, at the earliest. If possible, directly talk with the counsellor at the ART centre.
- Ensure that the client has all the required documents with him/her for visiting the Nodal ART Centre. Mention that the client has been LFU at the LAC as the reason for referral. Put any other major observation in the space for remarks.
- If required, facilitate help from any family member/friend of the client, out- reach workers at CCC or DIC members for ensuring the visit by the client to the Nodal ART Centre.
- Ensure that the client reaches the Nodal ART Centre by contacting there. If not reached, follow- up the client through different means including DICs

### **When the client attempts to commit suicide**

People living with HIV are more likely to think about or attempt suicide when they feel hopeless. As the LAC counsellor, who regularly interacts with clients, you can monitor the clients for such thoughts related to suicide. When you notice that a client has suicidal thoughts or has already attempted to commit it, you need to be alert for two things to save his/her life

- Immediate measures to prevent suicide

- Long term measures to ensure his/her adherence to ART

### **Immediate measures**

- Assess the client's risk for suicide by asking the following questions
  - *"Do you wish to commit suicide/end your life?"*
  - *"Have you thought about the methods and tools for ending your life?"*
  - *"Do you have the tool/s for ending your life with you?"*



If the client answers "Yes" to any of the above questions, the client is at high risk of suicide. He/she should be referred to a psychiatrist or for a higher level counselling.

- The counsellor may also assess the reasons for the client to think about ending life.
  - *"I understand that you are going through a stressful time. May I know what makes you feel like this? Probably, I can help you."*

If the reason is related with disease and treatment, the client should be counseled on the benefits of ART. If required, doctor's help may be sought to address concerns of the client.

- The following may also be necessary
  - Counsel the caregiver or immediate family member of the client
  - Arrange to remove all the means of committing suicide from client's reach
  - Involve family members in the care of the client through home visits
  - Involve members from PLHIV networks in the care of the client, provided the client agrees/optes for it
  - Make sure that the client leaves with the next appointment date and some positive plan on his immediate future

### **Long term measures**

- Provide on-going support during follow-up sessions to
  - Restore hope in the client through helping him/her to resolve different issues faced by him/her
  - Encourage the client to share different issues with you and help to develop individual coping skills. Appreciate the client whenever, he/she makes a successful effort to cope with issues
  - Support the client's adherence to treatment through different strategies like a treatment guardian, participation in support groups, etc.

### *Treatment Guardian*

Some ART centres use Treatment Guardians to ensure that the client takes medicine at the right time, every day. This is a strategy which is more useful with clients who forget to take medicine like aged persons, clients with psychological disturbance, children and those who continuously fail to adhere to treatment, even with other adherence strategies.

Similar to the Directly Observed Treatment Strategy under RNTCP, an individual is identified to support and monitor the client in being regular in drug taking. The client can consume the medicines in front of the Treatment Guardian. Clients can choose a family member or a friend or a neighbour or a colleague as the treatment guardian. The Treatment guardian can also be a person who supervises and takes the responsibility of overseeing the treatment plan of the client even though he does not supervise medication every time. He/she should be available to the client, not far away from the client's place or residence or work, aware of the HIV status of the client and willing to support the client in taking medicines. The Treatment Guardian also requires education and counselling on treatment related matters and supporting client in adhering to it.

### **When the client takes an overdose or says more pills mean rapid recovery**

This may happen with clients who have not properly understood how ART drugs work in the body. Others may take overdoses when they feel sick. You can identify such practices when clients report earlier than their due date and/or bring back fewer pills than expected in the pill bottle. Some may report that they have taken both pills at a time. In such cases, you need to

- Check what the client understands about ART treatment and the cure of HIV.
- Re-educate the client about how ARV drugs work in the body to help the client to stay healthy.
- Emphasize that only the exact number of pills on a proper schedule will work to reduce HIV progression, and that they do not cure HIV.
- Discuss the dosing schedule of ART. The counsellor may refer to the change in CD4 count after starting treatment or missed doses or stopped medicine to help the client learn the importance of ARV drugs.
- Discuss the risks associated with overdoses, such as aggregated side-effects.

- If needed, plan strategies such as contacting the client on a weekly basis and ensuring that he/she takes medicine as prescribed

### **When the client moves to “*Bhuva / Sadhus*”**

Sometimes clients visit “*Bhuva / Sadhus*” for social/ personal reasons. The counsellor should not directly oppose the activity but should ensure that ART is not discontinued. The rapport established with the client and/or family member/friend will help the counsellor to know whether the client moves in such directions. In such situations,

- Encourage the client to share such interests during the counselling session
- Address the reasons for opting such practices
- Check whether the client has stopped/missed the ARV doses (the *Bhuva/Sadhu* may advise them to stop all such treatment, the client may stop taking medicine for some time or during *Pooja*, etc)
- Re-iterate the need for taking medicine as prescribed by the doctor.
- If required, counsel the care-giver also on ensuring the treatment without any disruption

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### **Questions to LAC counsellors:**

- ✓ What are the things you have to consider during the first counselling session for a client at the LAC?
  - ✓ Have you identified locally available resources in case you have to make a psychiatric referral?
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### **References:**

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# Adherence Counselling for Children at the LAC

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At the end of this unit, participants will be able to

- List the reasons why CLHIVs require counselling
- Identify children with developmental delays and take appropriate actions
- Demonstrate interactive strategies for working with children and describe appropriate uses for them.
- Discuss age-appropriate ways to handle disclosure of HIV status to children

## Introduction

As per the NACO sentinel surveillance estimates (2007), 3.5 % of persons infected with HIV are children. As counsellors, you may have to provide services to Children Living with HIV (CLHIV) in your ICTC or Link ART centre. You should recognize that HIV-infected children have the same needs as all children. They should be encouraged to lead a normal life as other children and should be helped to develop in a healthy environment. The National AIDS Control Programme has initiated different measures to provide quality care and support services to CLHIVs.

Paediatric HIV treatment is specialized ART treatment for children upto the age of 14 years. The treatment of paediatric HIV infection is more complicated than that of adults. There are many issues like physical, psychological and family issues. A clear understanding of these issues, combined with an idea of how to handle each of them will help you in supporting your child clients. Some issues and challenges are

- Children have an immature immune system compared to adults. Therefore, HIV does more harm to children, as it affects their immune system while it is maturing.
- Illness and treatment lead to physiological changes like changes in timing of sleep, food and toileting. When children do not eat properly, they lose weight and their growth gets affected.

- Children are dependent on adults and need a caregiver for treatment.
- Repeated morbidity within the family and hence changing of caregiver(s) affects children and their treatment.
- Children experience difficulty in communicating their feelings or thoughts with adults.
- Often parents/ caregivers are not aware about, or acknowledge, the child's feelings.

As a counsellor, you are in a position to support children and their caregiver/s to overcome these issues and undergo the treatment as prescribed. You can

- Help children to cope with their infection and look after their health properly.
- Counsel caregivers to support children in coping with infection and treatment requirements.
- Provide a comfortable and friendly environment at your centre so that both children and their caregivers feel comfortable and supported.

## **Counselling For Children - Some Basics**

### **Importance of Counselling for Children Living with HIV**

Counselling is an important support system for CLHIVs. Children Living with HIV face numerous traumatic events in their life, such as

- Chronic illness and pain
- Parental illness, death, loss of siblings, change in family structure or home environment
- Orphan status
- Stigmatization and social isolation
- Learning about HIV status and implications
- Often these events lead to psychological issues like depression, loneliness, anger, fear, mistrust and confusion.

HIV-positive children often live in difficult circumstances. They may

- Live with their parents, or
- Live with relatives or extended family because they have lost one or both parents (orphans), or
- Live in institutions (orphans or non-orphans), or

- Live on the streets with no caregiver, or
- Serve as caregivers to sick parents infected with HIV

The illness itself influences the child in many ways. They may face both physical issues and psychological ones:

- Physical Issues
  - Changes in sleeping, eating and toileting routines,
  - Weight loss, poor physical growth
- Psychological issues
  - Boredom and fussiness as they may be unable to play.
  - Lack of appetite leading to eating problems and change in eating habits
  - He or she may crave attention while sick
  - May think that nobody will punish him/her for misbehaviours while sick

Children have difficulties in accessing care, support and treatment services

- They may need someone to take them to the ART or Link ART centre
- They may not be able to communicate their issues to service providers

Like adults, children also need support to cope with, and overcome, such issues. They need emotional and social support to cope with their situations. For supporting children better in all these areas, counselling should focus on the child and his/her problems - it should be *child-centred*.

Child-centred counselling focuses on the child and his/her issues and concerns. It gives importance to his/her experiences and how he/she views and responds to the things in his/her life. The process should be oriented to build the child's capacity to understand his/her own situation and cope with it positively.

You have learned about many of these ideas in ICTC Refresher Training. So we will quickly revise them here. For more details, please refer to your handouts from ICTC Refresher Training. In case you have misplaced your copy, you may download the same from the NACO website.

## A counsellor working with children should know developmental milestones



### Developmental Milestones Worksheet

(The answers to this are in the ICTC Refresher Handouts)

Situation	Is this child facing a developmental delay?	When would a “normal child” complete this?
Ishani is 5 months old. When her grandmother holds her, her head falls to the side.		
Afsaana is 2 years old. He can walk without holding the wall.		
Dhanesh is 18 months old. He has just learned to sit up.		
Balbir Kaur was born 6 weeks ago. She delights her family with her new development – smiling.		
Bhavna is 3 months old. She has begun sliding around and will learn to turn over in a few days.		
Kamlesh is 6 months old. He is very pleased at his new trick – moving his rattle from one hand to the next.		

**Developmental milestones** are indicators of children’s health and response to treatment. They are a set of functional skills or age-specific tasks that most children can accomplish at a certain age. As a counsellor you have a role in monitoring the growth of the child. You can ask caregivers or directly assess the child for any signs of **developmental delay** (that is failure to reach the developmental milestone at the expected time). Such signs should be brought to the notice of the treating doctor. You may also need to address the concerns of the caregiver regarding the child’s delay in showing the expected motor skills or behaviours and direct them to required services such as special schools. CLHIVs may show delayed growth. Such signs of developmental delay should be brought to the notice of the treating doctor.



## Counselling for children matches their developmental milestones

You have seen this table before in ICTC Refresher Training

<i>Skills</i>	<i>3-6 years</i>	<i>6-9 years</i>	<i>9-12 years</i>
<i>Communication skills</i>	Begins to recognize written words and can read short sentences.	Understands and is able to follow sequential directions. Child starts reading.	Understands and is able to follow sequential directions. Reading and verbal communications are very well developed.
<i>Cognitive skills</i>	Understands concepts such as size, shape, direction and time. Enjoys rhyme and word play.	Peer recognition starts.	Peer recognition is important.
<i>Physical growth</i>	Enjoys doing most things independently.	Develops curiosity about genital organs and starts comparing them with other children.	Growth of armpit and pubic hair, breast development and menarche (beginning of menstruation) in girls



### Matching Counselling to Developmental Milestones Worksheet

On the next page you have an example given for ICTC clients and testing. This has been extracted from the ICTC Refresher Handouts. Now look at the table and think about how to use this information for LAC clients

Use the information in the table above to develop appropriate ways to counsel children

<i>Situation</i>	<i>3-6 years</i>	<i>6-9 years</i>	<i>9-12 years</i>
<i>ICTC Clients</i>	<p><b>Children in the age group of 3 to 6 years can follow directions.</b> You can take them around the ICTC and explain what happens there. You can create a small ritual for the actual testing process by asking them what a brave soldier would do – not mind a little pain which comes from being pricked. You can also use the child client’s ability to follow directions to encourage a little independence such as gathering the colouring materials and replacing them in the proper slot. Children like being treated as “grown-up” even if they are not.</p>	<p><b>Children in the age group of 6 to 9 years enjoy time spent with friends.</b> So you can ask them about their friends. This will help you to build the interest of the child in the counselling process as well as identify issues they face like difficulty with friends, avoidance from friends as a result of stigma, etc. A good counsellor will recall the names of the child’s friends because this is one way of entering their world. She/he will patiently listen to the stories of what “Adi said” and what “Kriti did.” This is important for child-centred counselling because it gives importance to those things which are important for the child.</p>	<p><b>Remember to ask adolescent clients about their physical milestones related to puberty.</b></p>
<i>LAC Clients</i>			

## Managing emotions of children

### Activity

- Read the table titled “Helping Children to Manage their Emotions” in the ICTC Refresher Handouts.
- Read the situations.
- Identify the emotion and prepare a role-play on how to help the client manage it. The trainer will tell you which type of interactive communication strategy you should use.
- Answer the questions at the end.
- You will have a lot of time to prepare and practise.

Bipin is feeling very low. He is 13 years old. He has been taking ART since the age of 3. He is fed up of having to take medicines all the time. His mother reports that he has become very irritable and snaps out over small things. He has stopped going to play with his friends. Whereas before he was able to complete his homework, he is now not able to do so.

Sharda is 8 years old. She lost her mother recently to HIV-related illness. Her grandfather who is her caregiver brings her to the LAC because he is upset over her temper tantrums.

Shiny is 11 years old. Her parents passed away some time back to HIV illness. She lives with her aunt. Her aunt brings her to the LAC and reports that she has not been eating well recently. She is very restless and has been pulled up in school. She has also become more “clingy”. When the counsellor asks Shiny’s aunt reports that she is also recently begun sleeping badly.

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### Questions to LAC counsellors:

- ✓ Do you know how to explain developmental delay in a “normal” child?
  - ✓ Do you know how to explain developmental delay in an HIV-infected child?
  - ✓ Do you know what to say to an anxious child client?
  - ✓ What is the first response to a child client who displays anger?
-

# Strategies for Communicating with Children

Please read your ICTC Refresher Handouts for Drawing, Story-Telling and Puppetry.

## When to find time for these activities at an LAC

As an LAC counsellor, you may wonder where to find time for these activities. Afternoons with a lighter load may be an appropriate time. You may also ask the caregiver to come later in the morning so that child clients do not get bored with waiting in OPD. Alternatively, you can set them a task to do, seat them in a quiet spot in your centre, meet other patients and then speak to the child about the task after half an hour.

## Personal Qualities for Counselling Children

As you are dealing with sensitive and critical issues of children and their families, you should demonstrate certain qualities to win their trust and confidence.

### Maintain confidentiality.

- ✓ Respect the client's confidentiality at all times.
- ✓ Store records in a confidential manner.
- ✓ Share personal information relating to the case only with concerned individuals when appropriate.
- ✓ Assure the child and caregiver at the beginning of the counselling process that confidentiality will be maintained. This will comfort them and help them to share their concerns.
- ✓ Some information may have to be shared with other members of the team, when it is beneficial for the child's treatment (shared confidentiality). Inform the child and caregiver about information that will be shared, and when and why it will be shared.
- ✓ Confidentiality also extends to small personal secrets shared by child clients. The only exceptions to this rule are when the child reveals sexual or physical abuse.

### Understand emotional needs and provide support.

- ✓ Provide a safe environment for the child to express emotions.
- ✓ Involve the person who matters most to the child in the counselling process.
- ✓ Explore any underlying fears or feelings that may cause denial, anger, guilt and shock.
- ✓ Acknowledge the child's fears and explain that these fears are normal for any child.



- ✓ Encourage the participation of multiple caregivers in treatment, so that the child feels thoroughly supported.
- ✓ In situations where the child and caregiver are distressed by conflicting values/ opinions/ attitudes, assist in resolving the conflict. You may have to play the role of an advocate for the child within your health institution.

### **Be empathetic and non-judgmental**

The personal beliefs of the counsellor should not influence the counselling session. While this is a general job description of counsellors, for children, it is more important to demonstrate an attitude of openness and acceptance, if you want to develop a good relationship with them.

### **Making the Centre Child-Friendly**

The atmosphere at the Link ART Centre is crucial for cementing the trust between the treatment team and the child. It is important to make your centre child-friendly. While a separate room for counselling of children is ideal, this is not always possible in a crowded hospital. Alternatively, you could plan a child-friendly corner with:

- ✓ A small blackboard at the child's level
- ✓ Drawing paper and other art material
- ✓ Inexpensive games and toys for children
- ✓ Notice-board with paintings by children such as calendars with complete adherence marked by children, or pictures drawn by them. (Here, remember to use a first-name only to protect their identity.)
- ✓ Story books
- ✓ Some festival decorations
- ✓ Coloured pictures from magazines/newspapers of popular sports persons or animals

You can mobilize these resources from

- ✓ Children in school
- ✓ Toy shops
- ✓ Publishers/distributors of children's magazines
- ✓ Service organizations/clubs like Rotary Club and Lion's Club
- ✓ Local philanthropists
- ✓ Nongovernmental organizations (NGOs)
- ✓ Government offices, suppliers of these goods, etc

# Adherence Counselling for Children

Adherence counselling for CLHIV focuses on helping the child to take the medicines as prescribed by the doctor and also to follow the related instructions. Since children depend on their caregiver, counselling involves caregivers also. The objectives of adherence counselling for children are

- Educate the children and caregiver about treatment
- Prepare the child and caregiver for treatment and life-long adherence
- Monitor the adherence and support to maintain it.
- Identify different barriers to treatment and helping to overcome them

Adherence counselling is an ongoing process from preparedness to follow-up, and should be provided both to the child and the caregiver. The information provided to the child should be based on the age of the child, level of understanding and on whether HIV status has been disclosed to the child or not.

## Stages of Adherence Counselling

Stages of ART Adherence counselling for children are similar to that of adults. They are

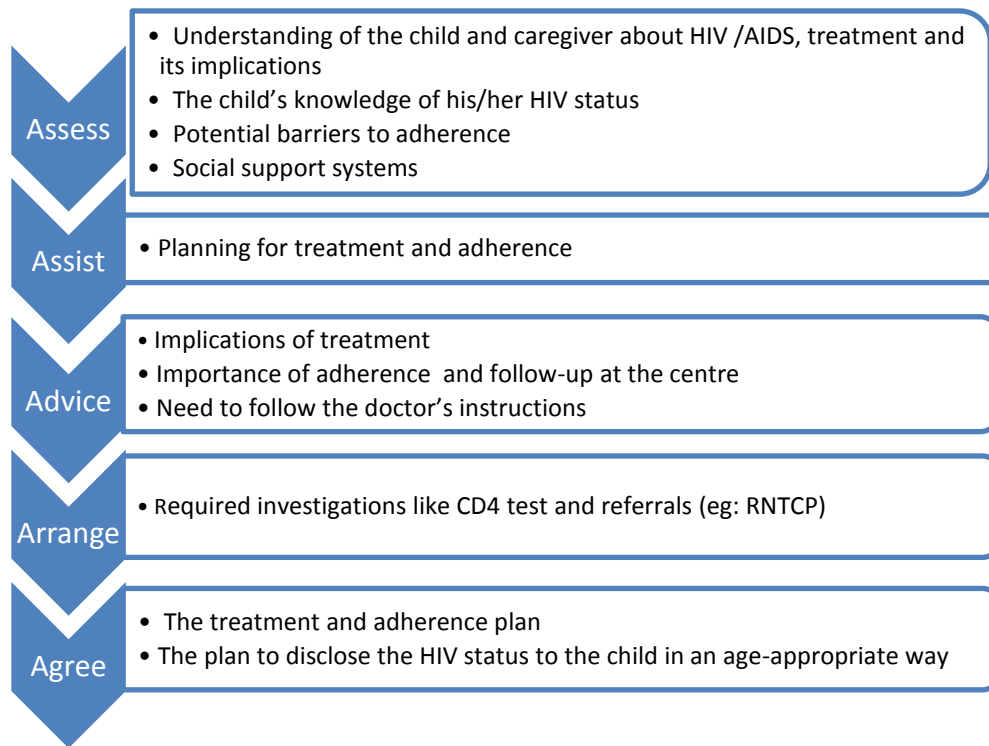
- Treatment-preparedness counselling
- Counselling during treatment commencement
- Follow-up counselling for adherence

As per the current protocols, ART registration, initiation and follow-up for at least 6 months is done at the ART centre. As a counsellor at the Link ART Centre, your main role is to provide follow-up adherence counselling and support. However, understanding of the complete process of adherence counselling will help you in framing the follow-up counselling sessions. Counsellors at LAC Plus may also be involved in treatment-preparedness as they do the work-up for pre-ART care. Adherence counselling at different stages is briefly reviewed below in the context of the needs of CLHIV.

## Treatment-Preparedness Counselling

Preparedness counselling for paediatric ART includes educating and preparing the child and caregiver for lifelong therapy. The '5 A's strategy is useful in preparing the child for treatment.

### 5 As of Treatment-Preparedness



### Preparing Children and their Caregivers for Treatment

Identify <b>WHO</b> will administer the medicines	Mother/ father/ grandmother/ other family member/volunteer
Explain <b>WHAT</b> medicines will be given	Familiarize the caregiver and child with the medicines. Describe or show them a picture or an actual sample
Specify <b>WHEN</b> the medicines should be given/taken	Establish specific times and routines with the child depending on the age of the child and responsibilities of the caregiver. Link it with the child’s current routine
Provide details on <b>HOW</b> the medicines will be given/taken	Details of administration: one or two tablets, measuring spoons, cutting and crushing tablets, with or without food, taking pills together/taking them after gaps or in a sequence, before or after meals.

### *How to Explain Giving Medicines to Children*

If the child is prescribed syrups

- Refer to the doctor's prescription on dosage
- Explain the dose and how to measure it. Ask the caregiver to
- shake the bottle before measuring
- wash the spoon before use
- measure the dose without touching the syrup
- give the spoon and watch the child take it (depending on child's age)
- give the child water after taking the medicines
- return the medicine and clean spoon to the appropriate storage area

If the child is prescribed dispersible tablets

- Refer to the doctor's prescription on dosage (e.g. ½ tablet in the morning, 1 tablet at night, etc.)
- Ask the caregiver to
- wash the dish/pot before use
- remove the tablet from its foil pack/bottle
- break as per the mark on the table, if half a tablet is prescribed
- retain the unused half carefully in the same manufacturer's foil or bottle
- use clean boiled water to dissolve the tablet
- give the medicine and watch the child consume it
- give additional water if the child requires it
- return the medicine to the appropriate storage area

### **Counselling during Treatment Commencement**

Once treatment is initiated, the counsellor ensures that the caregiver and child have correctly understood the daily dosages prescribed by the medical officer. The NACO Paediatric Treatment Desk Reference is used by the medical officer to identify the medicines and dosages appropriate for the child.

The counselling session on initiating treatment focuses on the following

- ✓ Reviewing information on treatment. The information provided to the child should be based on the age of the child, level of understanding and on whether HIV status has been disclosed to the child or not.
- ✓ Reviewing adherence: Different strategies are used based on the age and level of understanding of the child
- ✓ Identifying potential barriers.
- ✓ Developing strategies to strengthen adherence such as treatment calendars and alarms.
- ✓ Addressing any other support need of the child: This can include nutrition requirements, educational assistance, legal support and protection from exploitation.

### **Follow-up counselling for adherence**

Adherence is a dynamic behaviour. Hence follow-up counselling sessions play a very important role in helping the child to maintain adherence to treatment. This is very much a part of the LAC's activities. During these sessions, the counsellor should

- ✓ Monitor adherence
- ✓ Review the implementation of adherence strategies
- ✓ Identify potential barriers to adherence and develop/modify strategies to address them
- ✓ Reinforce earlier messages given to the child and caregivers
- ✓ Assess issues related to growth and development of the child
- ✓ Assess and address emotional and social concerns of the child and caregiver

### **Monitoring children's adherence to treatment**

A variety of strategies are available for monitoring adherence. A single strategy will not be applicable to all children. Also, as children grow, methods need to be changed. Older children can monitor themselves with support from the caregiver. In case of younger children, the caregiver has to take an active role in monitoring adherence. During every visit to the centre, the treatment team should monitor adherence.

The following methods are useful at the centres

#### **Pill counts**

This is the most reliable method. (Details are given in the chapter on Adherence Counselling at the Link ART centre).

## Report by the child/caregiver

The counsellor can ask the child (or caregiver), “How many doses did you (the child) miss” rather than “Did you (the child) miss doses?” Counsellors need to encourage honest self-reports from the child/caregiver. Children need positive messages (e.g. “If you take the pills regularly, you could be healthier.”) instead of negative messages (“You need not come here if you do not take the pills regularly.”).

## Refill boxes

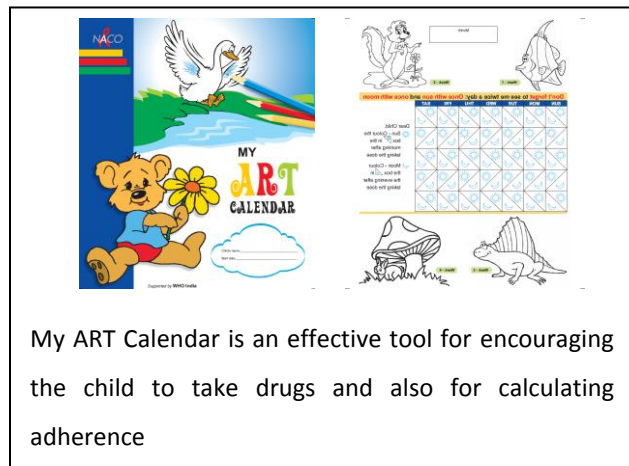
Here counsellor asks the child and caregiver to bring back the bottles with unconsumed tablets when they follow up. The remaining unconsumed tablets are counted for assessing adherence.

## Checking pill charts /calendars/diaries

Paediatric calendars are made available for children on ART through the Care, Support and Treatment Divisions at the SACS. You can ask the child to colour cells on each respective day after taking the pill. When the child visits the centre next time, the counsellor calculates the missed pills counting cells not painted in the calendar. It will provide an opportunity to motivate the child to colour all cells next time by taking all the pills given.

## Drawing

Here pictures of children are used to help child clients say whether they took all their medicines. The counsellor shows the pictures of someone who didn't take the medicine at all and is lying down as too sick, someone who took half of the pills and is sitting on the bed, someone who missed few pills and is standing with the help of somebody, someone who missed no pills at all and is playing.



My ART Calendar is an effective tool for encouraging the child to take drugs and also for calculating adherence

Then the counsellor asks the child, whom in the picture he/she resembles most. The same can be used with puppets also.

## Story telling

The child is asked to narrate his/her last month as a story and the counsellor probes gently for the habit of taking pills. The counsellor can check for particular situations like when the child was sick, when the caregiver was sick or busy, when he/she had exams, when they went out, etc.

## **Role-Play**

Here the child could be given an opportunity to act as the caregiver and counsellor acts as the child. The child is asked to imitate the caregiver. Care is taken to make the child comfortable. If needed, the counsellor can ask the caregiver to sit outside.

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### **Questions to LAC counsellors:**

- ✓ Which of the interactive strategies would you personally find easiest to implement?
- 

## **Factors Affecting Adherence**

### **Child-related factors affecting adherence**

- Children are dependent on adults
- Younger children are influenced by taste, smell and colour of medicine
- Older children may experiment with treatment: *“What will happen if I do not take the medicine for a week?”*
- Emotional factors such as mood swings, death of a parent or caregiver may influence adherence
- Children may use medicines to manipulate adults (The child may demand a favour for consuming medicines)
- Other infections and accompanying medications may reduce adherence.

### **Caregiver-related factors that can influence adherence**

- Knowledge and understanding of HIV/AIDS and treatment
- Misconceptions regarding treatment
- Caregiver’s health beliefs
- Caregiver’s daily routine
- Caregiver’s attitude towards adherence
- Relationship/closeness between the child and caregiver

## **How to address these factors**

Counsellors have to regularly check for different factors which act as potential barriers to the child's adherence to treatment. Asking reasons for missing pills is one way of checking barriers. But this alone will not suffice. During every visit, the counsellor has to

- ✓ Assess the current understanding of the child and caregiver about the infection he/she has and the treatment. Children do learn things about themselves in ways that their caregivers do not plan or anticipate. HIV status is one such thing that children may discover or realize and feel unable to discuss with caregivers.
- ✓ Assess what they feel about taking medicine routinely. (*"How do you feel about taking medicine?"*, *"Last month you told me that you don't want them, what you think now?"*)
- ✓ Ask them about their relationship with the caregiver and how the caregiver supports child in taking medicine.
- ✓ Assess the caregiver's attitude to the child's treatment. (*"What do you think about the treatment going on?"*)
- ✓ Both child and caregiver should be counselled to address any barriers to adherence.

Here it should be noted that asking the same questions in the same manner at each visit will be perceived as boring and repetitive. The child client may even get an impression that you as the counsellor are not really listening to them. So you need to try out different approaches at different visits.

## **Adherence fatigue**

Adherence fatigue is the state when the child, or caregiver, or both, get bored with the routine of taking/giving medicines and stop taking medicines. Counsellors should assess the child and caregiver in each visit for symptoms of adherence fatigue, irrespective of the level of adherence. Simple questions such as, *"Have you been able to take your medicine daily?"*, and *"Have you experienced any problems in taking your medicines?"* can be used.

Adherence fatigue may set in at any time during the course of treatment. The counsellor should not assume that a patient who is "once adherent, is always adherent". This is something about which an LAC counsellor may become complacent. Even though a child has been linked out from the Nodal ART Centre because they have demonstrated high levels of adherence for at least six months, it is important to check this at each visit. It is common when a child clinically improves that either the child or caregiver may feel that medicine is not needed any more. In case of changes such as



death of loved ones, the child and/or caregiver may lose their faith in treatment. This is also possible when the child or any other family member who is on ART falls sick often. Sometimes change in daily routine such as moving from a class routine which begins at 1 p.m. (in a shift system) to a class routine which begins at 7.15 a.m. may alter the child's adherence pattern. Counsellors should constantly watch for adherence fatigue and should reinforce the need to adhere through their counselling.

### **Warning signs of adherence fatigue in the child and/or caregiver**

- ✓ There is a marked change in the child's confidence level and attitude to treatment.
- ✓ The child expresses "feeling bad" for being the one who has to take pills within his/her peer group.
- ✓ There are observed symptoms of psychological distress such as depression, anxiety or fear.
- ✓ The child experiences repeated or severe side-effects of medication (nausea, vomiting, diarrhoea, skin infection).
- ✓ The caregiver expresses feelings of tiredness in administering/supervising medication.

### **Managing adherence fatigue**

If any of these signs are identified, the LAC counsellor should check the child's or caregiver's current understanding about adherence, examine how and why the situation has changed and provide adherence messages in the light of the changed family situation.

- ✓ If the child is not confident to take medicine, counsellor may help the child to identify his own abilities and boost his confidence. For example, *"Look, how well you completed the course for last month. You can continue the medicine like that in future also."*
- ✓ If the child is hesitant to take medicine, methods like the balloon game or stories can be used to make the child understand the importance of taking medicine. (Refer to previous chapter on Adherence Counselling at LAC for details)
- ✓ If the child is feeling bad about taking medicine, the counsellor may explain the consequences of not taking medicine, namely that he/ she may not be able to go to school or play with others. The caregiver can be asked to arrange the timing for medicine such that the child does not have to consume the medicines at school.
- ✓ If psychological or physical issues are present, the counsellor should refer the child to the ART centre or to appropriate professionals. However the child should be told about taking medicine regularly.

- ✓ If the caregiver expresses tiredness, the counsellor should listen to their problems and try to identify a solution for the same. For example, if giving medicine to the child affects their work timings, ask them to arrange for another caregiver.

## **Disclosure of HIV Status to Children**

This material is covered in your ICTC Refresher Handouts. Please read it carefully. Your trainer will inform you when there is a quiz on this topic.

### **Understanding Disclosure**

**Why should the HIV status be disclosed?**

**Barriers to disclosure of the HIV status to children**

**Advantages of disclosing the HIV status to the child**

**When should the HIV status be disclosed?**

**Age-specific advice on disclosure**

**How much information should be disclosed?**

**How should the HIV status be disclosed?**

**Suggestions for encouraging caregivers to disclose the HIV status to the child**

**Who else should know the child's status?**

## Common expressions among children following disclosure

You should be prepared to handle the responses of the child to the news of HIV status. The common expressions among children and how to counsel in such situations are given below.

<i>Common expressions among children</i>	<i>Possible explanation for the expression</i>	<i>Counselling content and skills</i>
<p>The child's perception and understanding of the causes of the disease. E.g. Verbal expressions such as</p> <ul style="list-style-type: none"> <li>✓ <i>"I am a bad boy and so I am suffering."</i></li> <li>✓ <i>"My friends are fine, why do I remain sick?"</i></li> </ul>	<ul style="list-style-type: none"> <li>✓ What is told to the child about his/her infection</li> <li>✓ The child's level of understanding</li> <li>✓ Family structure, functioning and communication within the family</li> </ul>	<ul style="list-style-type: none"> <li>✓ Provide the child with basics of HIV/AIDS</li> <li>✓ Ask the child: <i>"What makes you feel you are a bad boy?"</i></li> <li>✓ <i>"You seem very upset as you often fall sick."</i></li> <li>✓ Provide the child with information on OIs and side-effects of ART.</li> <li>✓ Counsel the caregiver on home management.</li> </ul>
<p>Guilt and distress associated with the disease</p> <p>Feeling agitated or angry</p> <p>Showing behavioural, cognitive and social difficulties. E.g. bedwetting, constant crying, etc.</p> <p>Verbal expressions such as <i>"I have made my family unhappy."</i></p>	<ul style="list-style-type: none"> <li>✓ A child may blame himself/herself, i.e., feel guilty.</li> <li>✓ Negative emotions expressed by the caregiver may be seen as a source of guilt for the child</li> </ul>	<ul style="list-style-type: none"> <li>✓ Encourage the caregiver to motivate the child and provide positive reinforcement for good actions.</li> <li>✓ Ask the child: <i>"What makes you unhappy?"</i></li> </ul>
<p>The child's perception of health affects self-esteem, confidence or self-image. E.g. Refuses</p>	<ul style="list-style-type: none"> <li>✓ The onset of OIs</li> <li>✓ The association of the child with his sick or deceased caregivers</li> </ul>	<ul style="list-style-type: none"> <li>✓ Provide the child with information on OIs and side-effects of ART.</li> <li>✓ Encourage the child to</li> </ul>

<p>to go out and play with other children</p>	<p>✓The difference between the child and healthy children, which often make them feel inferior</p>	<p>participate in CLHA groups.</p> <p>✓Develop the social skills of the child.</p> <p>✓Guide the child to participate in a role-play where the counsellor can take on the role of the child and the child of others in his/her environment.</p>
<p>Anticipated grief and anxiety E.g. Feeling a loss of security, fear of changes in family or caregiver structure, crying without reason, searching for people and ensuring they always remain around, etc.</p> <p><i>"I will also die soon."</i></p>	<p>✓The perception of death evolves with age. The fear of his/her own death and that of the caregivers haunts the child. This fear can be agonizing at times, particularly in cases where children have already lost one parent.</p>	<p>✓Encourage the child to express rather than suppress feelings.</p> <p>✓Assist the child in strengthening support systems and developing new friendships/relationships</p> <p>✓Ask the child: <i>"You seem worried about your physical well-being."</i></p>
<p>Inability or unwillingness to cope and adhere to treatment</p> <p>E.g. repeatedly reports that he has not taken his medicines: <i>"I forgot to take my medicines."</i></p>	<p>✓Coping with the disease and the additional burden of the treatment schedule</p> <p>✓Social, cultural, economic and personal beliefs of the caregiver and child regarding treatment</p>	<p>✓Involve the child and caregiver in CLHIV and peer group activities.</p> <p>✓Use interactive communication strategies to identify barriers to treatment and assist the child to overcome these barriers.</p> <p>✓Help the child identify and use reminder systems.</p> <p>✓<i>"Some children do forget to take their medication. Can you describe why this may happen?"</i></p>

# Role of Link ART Counsellor in Adherence Support

Your role as an LAC counsellor is mainly related with adherence monitoring and support. This can be seen as an extension of the counselling support provided by the ART counsellor. However there are some basic things you should consider.

- ✓ The Link ART centre is a new place for the child and caregiver. You have a very important role in making them feel comfortable in your setting.
- ✓ The caregiver may be concerned about the quality of services, medicines and treatment of the child when he/she becomes sick.
- ✓ As the LAC is a smaller facility, closer to the home of the CLHIV, the family may be worried about the child's HIV status being "outed", that is "becoming public".
- ✓ Child may not be willing to communicate with a new provider. Give the child time to be comfortable with you. Do not force the child to communicate with you. Some children may take more than one session to be comfortable.
- ✓ Since the child was on treatment for at least 6 months at the ART Centre, you should know the details of the same and how the child and caregiver experienced treatment. This will help you to provide them counselling effectively.
- ✓ Establishing a strong rapport with the child is the key to counselling.

## Initial Visit to the Link ART centre

Many of the concerns mentioned in the previous section will surface in the first visit of the client to your LAC. You can use the following checklist to cover the main points

<i>Building rapport with child and caregiver</i>	
✓ Warmly greet the child and caregiver	<input type="checkbox"/>
✓ Ask the caregiver to introduce the child ( <i>"May I know whom you have brought with you?"</i> )	<input type="checkbox"/>
✓ Ask the child's name and other personal details in a warm way ( <i>"May I know your</i>	<input type="checkbox"/>

<i>name?”, “It is a nice name”, “Who all are there in .....’s home?”)</i>	
✓ Children may like physical closeness. If the child is comfortable, gently touch the child on shoulder or head	<input type="checkbox"/>
✓ Tell the child that you would like to talk to the caregiver for some time.	<input type="checkbox"/>
✓ Engage the child with some activity and talk to the caregiver	<input type="checkbox"/>
✓ Obtain the details of the caregiver	<input type="checkbox"/>
✓ Elicit details about the child’s family and the HIV status.	<input type="checkbox"/>
<i>Address different concerns regarding shift in centre</i>	
✓ Ask the child about the experience with the ART Centre. Explain that this is also a similar centre and he/she can be comfortable here	<input type="checkbox"/>
✓ Inform the caregiver that the services and medicines are the same and all personnel in the centre are trained. Also inform them that the child can return to ART centre, if any illness or side-effect develops	<input type="checkbox"/>
✓ Assure the caregiver about confidentiality. Also inform about the shared confidentiality and who on the LAC team will be informed about the child’s HIV status for treatment purposes	<input type="checkbox"/>
<i>Assess the child’s and caregiver’s understanding about the treatment</i>	
✓ Collect the details of current treatment (You can use the White Card and also ask the caregiver) <ul style="list-style-type: none"> <li>○ Drugs and dosages</li> <li>○ Method of administration</li> </ul>	<input type="checkbox"/>
✓ Assess what the child knows and feels about treatment (“What do you understand about going to the clinic/taking medicine?”, “How do you feel about coming here?”)	<input type="checkbox"/>
✓ Assess what the child feels about being sick often (“What do you understand about falling sick often?”, “How did you feel when you fell sick last time?”)	<input type="checkbox"/>
✓ Assess what the child understands about others in family falling sick (“How are others at home doing?”, “What do you know about their sickness?”)	<input type="checkbox"/>

<p>✓ Assess what the caregiver knows about the treatment (<i>“May I know what you understand about the treatment we are giving to the child”, “Can you tell me how you are supporting the child in taking medicine?”</i>)</p>	<input type="checkbox"/>
<p>✓ Identify the caregiver’s concerns regarding treatment. (<i>“What do you think about the treatment? Is the child able to take medicine as prescribed? Is there anything which you fear that will be a problem in taking medicine?”</i>)</p>	<input type="checkbox"/>
<p><i>Reinforce the importance of adherence</i></p>	<input type="checkbox"/>
<p><i>Identify any potential barrier to adherence and plan strategies to address them</i></p> <ul style="list-style-type: none"> <li>✓ Ill-health of the child, caregiver or anyone in the family</li> <li>✓ Changes in family situation, social situation, etc.</li> <li>✓ Concerns regarding confidentiality</li> </ul>	<input type="checkbox"/>
<p><i>Complete the documentation procedures and provide the child with the LAC ID-number. Provide the next follow-up date. Note this date in your follow-up diary</i></p>	<input type="checkbox"/>

### Monthly Follow- Up Visits

During monthly follow-up visits the LAC counsellor has to focus on adherence monitoring and support; and emotional support for the children and their caregivers. Assess the changes in the family situation, if any and the developmental delay in the child during the visit. All these need to be framed in such a way to suit the child’s age and comprehension level.

<p><i>Greet the child and caregiver</i></p>	<input type="checkbox"/>
<p><i>Assess the child’s adherence for the last month using one or more of the following methods</i></p> <ul style="list-style-type: none"> <li>○ Pill count</li> <li>○ Treatment calendar/diary</li> <li>○ Report by child</li> <li>○ Report by caregiver</li> </ul>	<input type="checkbox"/>
<p><i>Record last month’s adherence on the White Card</i></p>	<input type="checkbox"/>
<p><i>Assess the reason for poor adherence or missing doses from child using the interactive strategies</i></p>	<input type="checkbox"/>

<i>described</i>	
<i>Assess/verify the reason for the child's poor adherence or missing doses with the caregiver</i>	<input type="checkbox"/>
<i>Discuss with the child and /or caregiver how to resolve the reason for missing doses</i>	<input type="checkbox"/>
<i>Assess other potential barriers to adherence and address them</i>	<input type="checkbox"/>
✓ Child's current understanding about his/her health status, treatment, etc.	
✓ Caregiver's current understanding about importance of adherence and his/her attitude towards treatment.	
✓ Health status of the child (measure weight, check for health issues, etc.)	
✓ Family situation of the child and relationships (Parent's/sibling's caregiver's ill-health or death, any disruption in the family, poverty, etc.)	
✓ Social situation of the child (School, neighborhood, experience of stigma, etc.)	
✓ Symptoms of adherence fatigue	
✓ Any other factors	<input type="checkbox"/>
<i>Reinforce the importance of adherence</i>	<input type="checkbox"/>
<i>Review the adherence strategies in place and modify, if needed</i>	<input type="checkbox"/>
<i>Review with the caregiver, the need for informing the child about his/her HIV status and process the same accordingly</i>	<input type="checkbox"/>
<i>Check for any developmental delay: you can observe the child or ask the caregiver for details. Inform the doctor in case of any delay noticed</i>	<input type="checkbox"/>
<i>Discuss the diet plan, nutrition, etc.</i>	<input type="checkbox"/>
<i>Review the support systems in place for the child and family</i>	<input type="checkbox"/>
<i>Check for any other concerns of the child and/or caregiver and address them properly</i>	<input type="checkbox"/>
<i>Complete the documentation and provide the next follow-up date. Note this date in your follow-up diary</i>	<input type="checkbox"/>



## Special Issues of Caregivers

- ✓ If the caregiver himself/herself is on ART, his/her own adherence to treatment may influence the adherence of the child. You have to focus on this separately in counselling.
- ✓ The caregiver's awareness of potential risks to the child due to no or low adherence is crucial in supporting the child's adherence. Educate and remind them from time to time.
- ✓ Address any anxiety that 'the medicine harms the child.'
- ✓ The caregiver's cognitive capacity and literacy level to understand the nature of treatment and importance of adherence is important. You may need to employ a variety of methods like the use of pill charts, demonstration, and pictures to supplement counselling.
- ✓ The caregivers' health status, ability to cope with the infection of the child and personal illness should also be assessed from time to time.
- ✓ They also need emotional and social support, guidance on disclosure and support to the sick child. Link them with potential service providers if required.
- ✓ Help them to report discriminatory experiences with relevant authorities working to fight against stigma.

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### Questions to LAC counsellors:

- ✓ Which method of adherence monitoring would you find easiest to implement?
  - ✓ What are some problems in the methods of adherence monitoring?
- 

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# Nutrition Counselling

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At the end of this unit, participants will be able to

- Identify appropriate nutrition actions to promote effective treatment; ensure adherence to drug regimens; manage side-effects of ART drugs; and minimize negative effects of interaction of ARV drugs with food
- Provide comprehensive Nutritional Counselling to LAC clients with HIV-related symptoms and ART side-effects

Infection with HIV reduces the body's natural capacity to defend itself against infections leading to AIDS. The amount of time it takes for a person to advance from HIV infection to AIDS depends on the person's general health and nutritional status. A person who is well-nourished is stronger and better able to fight infections. This is true for all people but is especially important for PLHIVs who are more susceptible to recurring infections. PLHIVs are also at a higher risk of malnutrition as HIV increases nutritional needs even during early stages of HIV infection, when no symptoms are apparent. The demand increases significantly during the course of HIV infection.

**Good nutrition cannot cure AIDS or prevent HIV infection. However, PLHIVs who are well-nourished are stronger and better able to fight infections.** Good nutrition will also complement and ensure effective ARV treatment. Thus, it can help people live longer, be more comfortable and lead lives that are more productive.

Nutritional care and support, includes counselling, education and information-sharing. It is a fundamental part of a comprehensive package of care and support for every PLHIV. LAC counsellors should make sure that nutritional care and support is started at the early stages of the infection in order to prevent weight loss and malnutrition.

# Understanding Nutrition

Read the section on Counselling on Dietary Intake in the ICTC Refresher Handouts

## Understanding the Relationship between HIV and Nutrition

The relationship between nutrition and HIV is a vicious cycle. HIV compromises nutritional status, and poor nutrition further weakens the immune system, increasing susceptibility to opportunistic infections (OIs).

### How Nutrition affects HIV

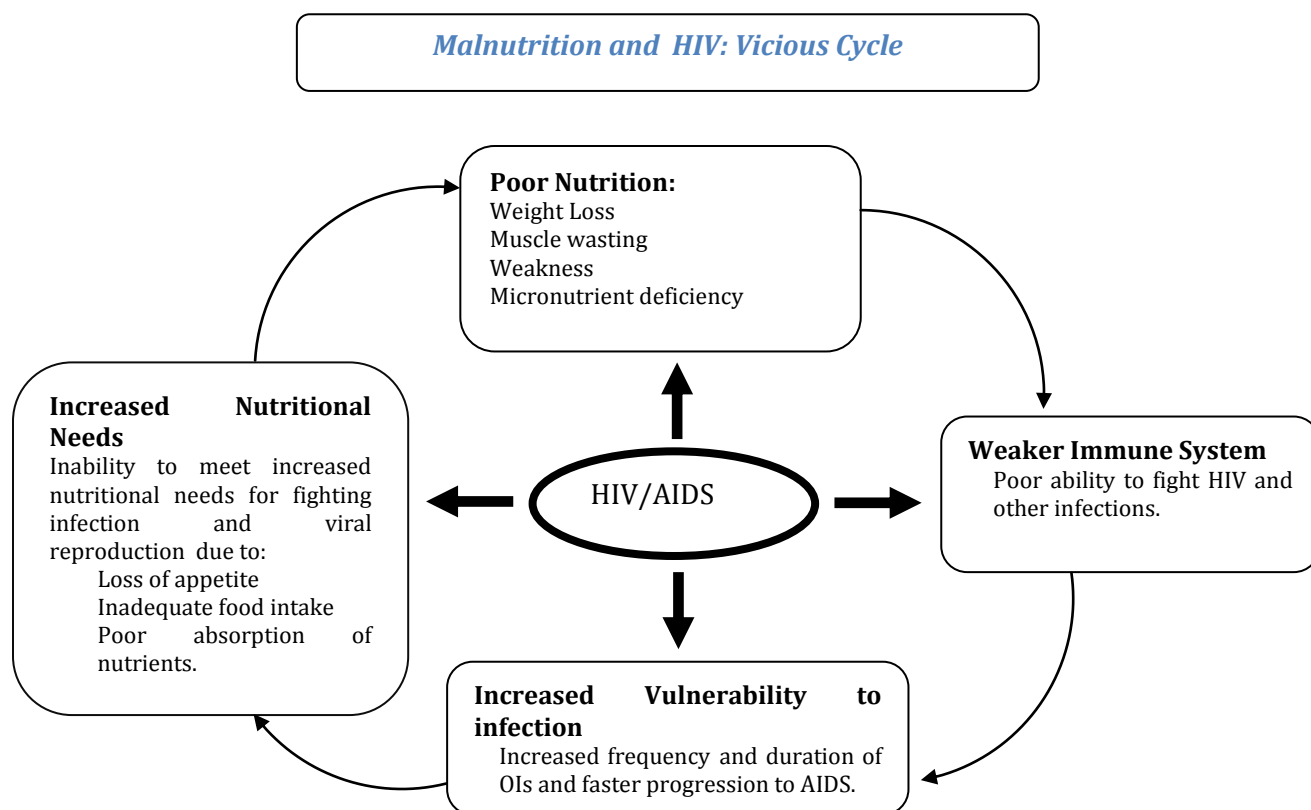
#### Poor nutrition and HIV: A vicious cycle

HIV weakens the body's natural defence system against disease and infection. As a result, the body's ability to fight infection is greatly reduced and the body becomes more vulnerable to infections.

HIV and frequent infections increase the nutrition needs of PLHIVs. However, they may not be able to take enough food to meet these needs. This is usually due to loss of appetite, poor absorption and changes in the way food is utilized by the body resulting from HIV and frequent infections.

The poor intake of food leads to loss of weight, body weakness, and malnutrition, which further weakens the body's natural defence mechanism, thus aggravating this cycle.

In the early stages of infection a person shows no visible signs of illness. But later many signs of AIDS become apparent, including weight loss, fever, diarrhoea and other opportunistic infections such as, oral candidiasis or thrush and tuberculosis (TB). Poor nutrition may accelerate the onset of these infections.

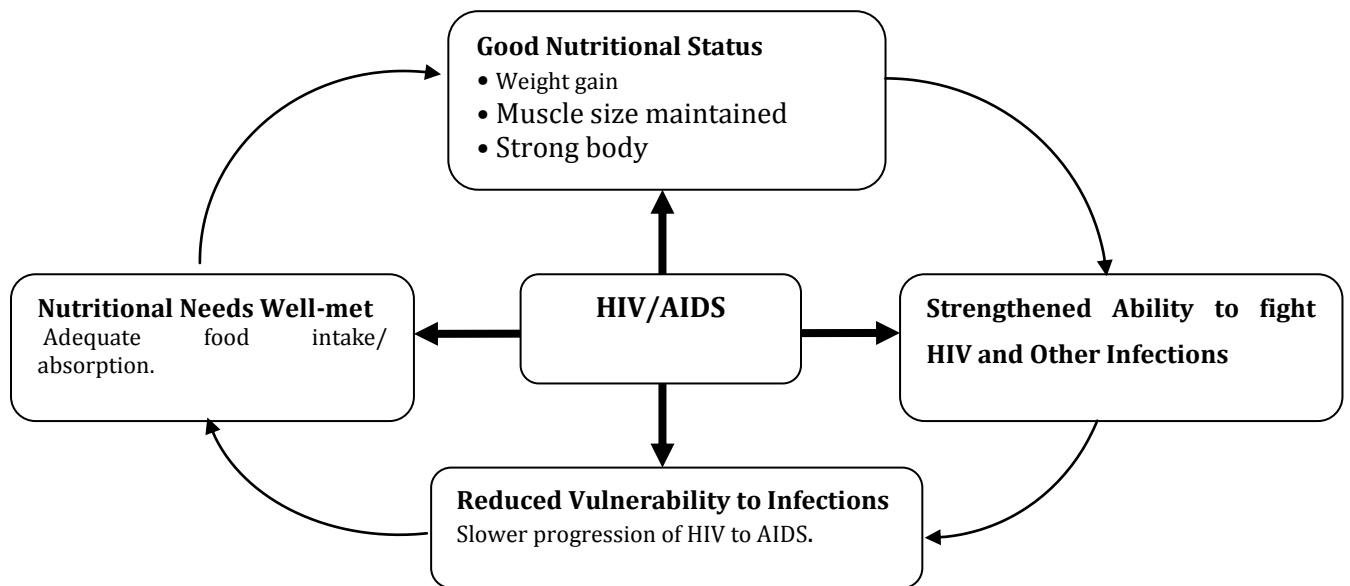


### Breaking the vicious cycle

An adequate nutrient-dense diet, proper hygiene, food safety, and nutrition management of symptoms can help in breaking this cycle of infection and poor nutrition. The figure below illustrates how these interventions can help transform the vicious cycle of HIV and undernutrition into a positive relationship.

With enough stores of nutrients, the body's defence system is strengthened against disease and infection. When a PLHIV is able to meet the food needs of his/her body, he/she will not lose weight but will stay strong and well-nourished. The well-nourished body is able to build strength to fight HIV and other infections. The immune system is strengthened even further and the cycle continues.

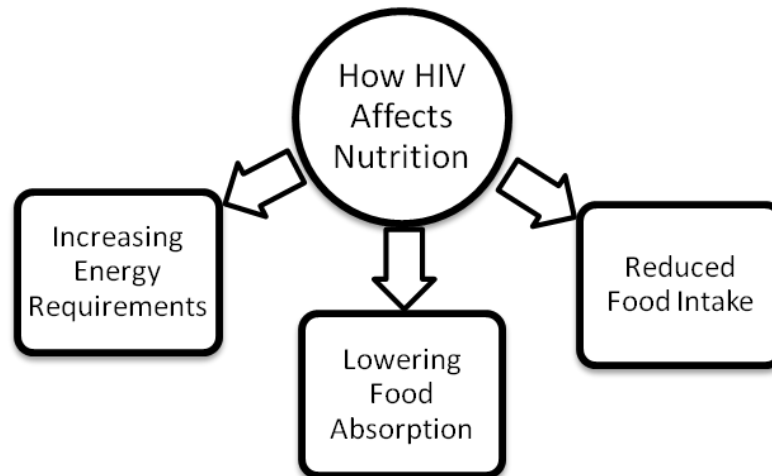
## *Nutrition and HIV: Benefits from Nutrition Interventions*



### **How HIV affects Nutrition**

HIV interferes with the ability to access, handle, prepare, eat and utilize food, thus increasing the nutritional needs of PLHIVs. If these needs are not met then this may result in malnutrition.

The three ways in which HIV can affect the nutritional status of a person:



### **Reduced food intake**

Reduced food intake in a PLHIV can result from one or more of the following reasons:

- Difficulties with eating or swallowing because of painful sores in the mouth and/or throat.
- Altered taste of food, nausea and vomiting.
- Poor appetite as a result of tiredness, depression and other psychological factors.
- Reduced quantity and quality of food in the household because the main earner is unable to work or has a reduced income because of HIV-related illness.
- Difficulties in shopping and preparing food.
- Lack of awareness of how important nutrition is – especially when recovering from illness.
- Side-effects of medications, including nausea, vomiting, metallic taste in the mouth, diarrhoea and abdominal cramps.

### **Lower food absorption**

During digestion, the food we eat is broken down into nutrients. These nutrients are absorbed through the intestine into the bloodstream for use by the body. Reduced absorption of nutrients can result from one or more of the following reasons:

- Damage of the intestine due to infection and/or the breakdown of its cells can result in lower food absorption.
- Infections such as diarrhoea make the food pass too quickly through the gut, reducing the time for digestion and absorption.

- Poor absorption can cause difficulty in controlling blood sugar levels, which may lead to diabetes.
- Poor absorption of fat also reduces the absorption and use of fat-soluble vitamins such as Vitamins A and E. This can further compromise nutrition and immune status.

### **Increased energy requirements**

If food intake and absorption are not sufficient for a PLHIV to meet to his/her increased energy needs, then his/her muscle breakdown takes place ('muscle wasting'). Excessive muscle breakdown, in turn, leads to:

- Weight loss
- Swelling of the feet and/or other parts of the body
- Reduced production of saliva and other digestive fluids needed to break down foods into nutrients, which further reduces the absorption of food.

Since the effects of HIV start in the early stages of HIV infection, nutrition becomes an important aspect of care for PLHIVs as soon as they learn about their status. It is thus important for the LAC counsellor to help the client find appropriate ways of healthy eating as early as possible so that the PLHIV stays healthy. Ideally, the counsellor should start nutritional counselling from the first visit of the client to the LAC centre by exploring their nutritional practices.

## **Nutrition Management of HIV-related Symptoms**

Being infected with HIV can make it hard for PLHIVs to eat. This is very common. They may be unable to digest certain foods that they used to eat previously. They may have infections in their mouth which make the mouth hurt while swallowing. They may just feel too tired to eat. All these symptoms may affect their food intake.

Proper nutrition management of the HIV-related symptoms can help reduce the severity of symptoms, increase functioning and quality of life, and improve the ability to eat, thereby improving and maintaining their nutritional status.



## Objectives of Nutrition Management of HIV-related Symptoms

- Reduce severity of symptoms.
- Improve functioning and quality of life.
- Enable adequate food intake and absorption during symptomatic periods.
- Prevent malnutrition and wasting.
- Complement and strengthen medical treatment.
- Minimize discomfort and pain while eating.

The LAC counsellor should help the PLHIV to select those foods and nutrition practices which will help in managing the effects of HIV-related symptoms and maintaining food intake and nutrient absorption. During the session, the counsellor can share the general recommendations for managing and taking care of symptoms with the clients. She/he should:

- Explain the nutrition implications of HIV-related symptoms.
- Describe the dietary management of HIV-related symptoms.
- Explain the advantages of proper nutrition for PLHIVs.

## General Recommendations for Managing HIV-related Symptoms.

<i>Symptoms</i>	<i>Management</i>
<i>Loss of Appetite</i>	<ul style="list-style-type: none"> <li>✓ Eat small, frequent meals (5-6 meals/day)</li> <li>✓ Eat nutritious snacks</li> <li>✓ Drink plenty of liquids</li> <li>✓ Take walks before meals - the fresh air helps to stimulate appetite</li> <li>✓ Have family or friends assist with food preparation.</li> <li>✓ Take light exercise and do light activity</li> <li>✓ Add flavour to food and drink.</li> </ul>
<i>Mouth Ulcer</i>	<ul style="list-style-type: none"> <li>✓ Avoid citrus fruits, acidic and spicy foods</li> <li>✓ Eat food at room temperature</li> <li>✓ Eat soft and moist food</li> <li>✓ Avoid caffeine and alcohol.</li> <li>✓ Mouth hygiene can help them feel better.</li> </ul>
<i>Candidiasis</i>	<ul style="list-style-type: none"> <li>✓ Eat soft, cool and bland foods (like rice porridge, oatmeal, mashed vegetables, apple juice, milk).</li> </ul>

	<ul style="list-style-type: none"> <li>✓ Add garlic (optional)</li> <li>✓ Avoid sugar (glucose, cane sugar), yeast, caffeine, spicy food, carbonated drinks and alcohol</li> </ul>
<i>Nausea and Vomitting</i>	<ul style="list-style-type: none"> <li>✓ Eat small, frequent meals (5-6 meals/day)</li> <li>✓ Avoid an empty stomach as this makes nausea worse.</li> <li>✓ Eat bland food</li> <li>✓ Avoid food with strong or unpleasant odours</li> <li>✓ Drink plenty of liquids</li> <li>✓ Rest and relax after meals</li> <li>✓ Avoid lying down immediately after eating</li> <li>✓ Avoid coffee and alcohol</li> </ul>
<i>Constipation</i>	<ul style="list-style-type: none"> <li>✓ Eat fibre-rich food and sprouted food</li> <li>✓ Do light exercises</li> <li>✓ Drink plenty of water</li> <li>✓ Take warm drinks</li> </ul>
<i>Anaemia</i>	<ul style="list-style-type: none"> <li>✓ Eat organ meat, fish and eggs.</li> <li>✓ Eat cereals like <i>ragi</i> and <i>bajra</i></li> <li>✓ Eat variety of green leafy vegetables (raddish greens, mint, <i>chaulai</i>, cauliflower leaves and <i>sundaikai</i>). The best way for the body to utilize iron from plant sources is to combine food rich in Vitamin C, like <i>amla</i>, guava, oranges, lemons.</li> <li>✓ Take jaggery and dates between meals.</li> </ul>

## Managing Drugs Interactions with Food and ART Side-effects

ART medications do help the client to delay the progress of HIV but they can also interact with certain foods or other drugs. They also produce side-effects. Failure to manage the interactions between various foods and ARV drugs (and their side-effects) may result in reduced food intake. The patient may also interrupt or stop taking the medication which can result in

- Poor health, frequent infections and faster progression of the disease
- Drug-resistant HIV leading to failure of treatment.

Thus, to ensure successful ART, the LAC counsellor should help clients understand the food and nutrition implications of the drugs they are taking as well as help them to avoid any negative interactions between medicines and food.

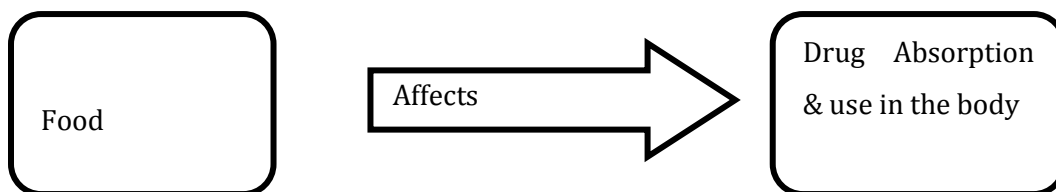
*How to Explain the Importance of Nutrition for PLHIVs on ART*

- Explain to the client that ART works better in people who have good nutritional practices. Good nutrition will strengthen the body's ability to absorb medication and reduce side-effects. It will improve the effect of ART and will help the body in repairing the defence shield – that is, to use the analogy from the earlier chapter, fighting back with HIV arrows. However, PLHIVs need to plan their diet and follow certain instructions related to the drugs they are taking because some drugs can interact with food and produce bad effects. Also, some drugs only work properly when taken at a specific time in relation to a meal.
- Ensure that the client avoids certain food items and takes food at the proper time. This will help him/her in managing drug interactions with food as well as drug side-effects.

**Interactions between Drugs, Food and Nutrition**

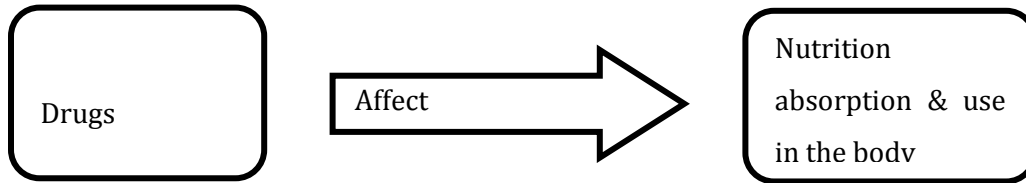
Food can affect the absorption, metabolism, distribution and excretion of medication. Medications too can affect the metabolism of food. Let us see how ART and food interact with each other.

**Certain foods may increase or reduce use of ARV drugs by the body.**



Example: Fatty foods and fatty meals may reduce absorption of ARV drugs such as Efavirenz and Indinavir.

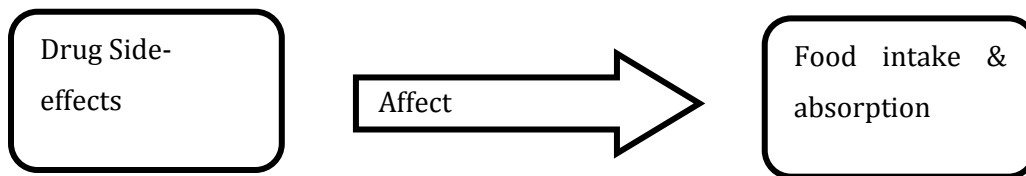
**Certain ARV drugs affect the way nutrients are used by the body.**



Example: ARV drugs such as d4T may change the way the body uses fat and carbohydrates. Ritonavir causes changes in fat metabolism.

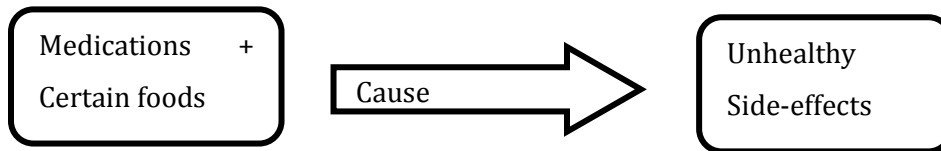
**Side-effects adversely affect the consumption and absorption of food.**

These may include changes in taste, headache, fever, diarrhoea and vomiting.



Example: Some medications, like 3TC and d4T may lead to change in taste, AZT may also cause nausea and vomiting, resulting in reduced food intake and weight loss.

**Interaction of certain ARV drugs with certain foods may create unhealthy side-effects.**



Intake of alcohol together with ARV drugs may cause problems of the liver and pancreas. Example: Taking Zidovudine together with alcohol may result in pancreatitis. Alcohol is also often the cause of poor adherence to treatment and may reduce the appetite of the PLHIV.

LAC counsellors need to educate their clients about the interactions of such foods with the drugs they are taking so that these foods can be avoided or reduced.

**Foods to be avoided or taken in small quantities when taking ARVs**

**Alcohol**

Reduces effectiveness of drugs and can cause dangerous side-effects.

**Too much coffee/tea**

Increases fluid loss and interferes with the absorption of some nutrients.

### Undercooked meats and raw eggs

Can cause food-borne illnesses.

### Expired tinned products, stale food

Can cause food-borne illnesses.

## Nutrition Practices for Managing the Side-effects of ARV Drugs

ART centres transfer only those clients to the LAC Centre who are on treatment for more than 6 months. Usually by this time the major side-effects are resolved. However, the long-term usage of the drugs by the client may result in side-effects that can affect the ability to eat food. The frequency and severity of these side-effects varies for different ARV drugs and different individuals. LAC counsellors should help the client in identifying appropriate dietary changes which can manage and reduce the impact of these side-effects on nutrition. The suggestions for nutrition practices should be based on a clear understanding of the specific requirements of the drugs that a PLHIV is taking.

<i>Medication</i>	<i>Potential Side-effects</i>	<i>Recommended Nutrition Practices</i>
<i>Zidovudine</i>	Fatigue, anaemia, gastrointestinal intolerance (nausea, vomiting, diarrhoea, constipation), taste disturbance, headache, fever	<ul style="list-style-type: none"><li>✓ Take with food to reduce side-effects.</li><li>✓ Do not take with a high-fat meal.</li><li>✓ For weakness and anaemia take iron-rich food (beans, eggs, dry fruits, dates, jaggery, organ meat) and food rich in folic acid and vitamin B12 (fortified cereals, fish, dairy products, tofu)</li></ul>
<i>Lamivudine (3TC)</i>	Nausea, vomiting, diarrhoea, abdominal pain, headache, fatigue, insomnia, malaise, fever, rash	<ul style="list-style-type: none"><li>✓ Take without regard to meal</li></ul>
<i>Stavudine (d4T)</i>	Nausea, vomiting, diarrhoea, constipation, anorexia, abdominal disturbance, lipodystrophy, neuropathy	<ul style="list-style-type: none"><li>✓ Take without regard to meal</li><li>✓ Avoid alcohol</li><li>✓ To prevent redistribution of fat:<ul style="list-style-type: none"><li>○ Reduce intake of fat</li><li>○ Eat more fibre-rich food (whole</li></ul></li></ul>

		<p>cereals and millets).</p> <ul style="list-style-type: none"> <li>○ Limited intake of refined sugars like sweets</li> </ul> <ul style="list-style-type: none"> <li>✓ Exercise regularly.</li> <li>✓ For tingling numbness take more Vitamin B12 (fish, liver, poultry products).</li> </ul>
<b><i>Nevirapine (NVP)</i></b>	Rash, nausea, headache, hepatitis	<ul style="list-style-type: none"> <li>✓ Take without regard to meal</li> </ul>
<b><i>Efavirenz (EFV)</i></b>	Rash, abdominal pain, diarrhoea, nausea, vomiting, anxiety, depression, dizziness, headache, insomnia, abnormal dreams	<ul style="list-style-type: none"> <li>✓ Take on an empty stomach.</li> <li>✓ Do not take with high-fat meal.</li> <li>✓ Should be taken only at bedtime.</li> </ul>
<b><i>Ritonavir (RTV)</i></b>	Taste changes, gastrointestinal intolerance (nausea, diarrhoea, abdominal pain, vomiting), throat irritation, headache, drowsiness, dizziness, sleep disturbances, fatigue, rash, dry mouth.	<ul style="list-style-type: none"> <li>✓ Take with food to decrease side-effects.</li> </ul>
<b><i>Tenofovir</i></b>	Headache, diarrhoea, nausea, vomiting, abdominal pain, anorexia, dizziness, headache, sweating, depression, rash.	<ul style="list-style-type: none"> <li>✓ Take without regard to meals.</li> <li>✓ Tablets can be dissolved in at least 100 ml water, orange juice or grape juice for patients who experience difficulty swallowing.</li> </ul>

\* This list includes only those drugs currently provided under the NACP.

\* Discuss only those symptoms the client is experiencing.

\* Encourage the client to discuss and use home remedies, which have helped him deal with the side-effects. Use the table for managing common side-effects (in chapter 2 Basics of ART).

***Remember:***

In addition to the above suggestions the counsellor should also explain to the client that not all symptoms experienced are due to ART or other drugs.

- Presence of some symptoms may be due to HIV infection or opportunistic infections. For example, diarrhoea may be caused by a bacterial infection. In this case nutritional management is the same, but medical care should be sought for the underlying infection immediately.
- Refer the client to General OPD to seek medical help for the persistent symptoms. This will help in identification of other infections that may be contributing to the persistence of symptoms.
- Dietary management of these symptoms is not meant to cure them; it only helps to reduce negative effects on nutritional status.

ART can improve the health of PLHIVs but it can also create additional food and nutritional needs. As an LAC Counsellor you should always follow up with clients to assess any such difficulties and provide support in making necessary adjustments.

## **Nutrition Counselling for PLHIVs on ART**

PLHIVs may seek the counsellor's guidance when they develop illness symptoms and side-effects because of life-long ART and opportunistic infections. These symptoms and side-effects increase their nutritional needs, but PLHIVs are usually not aware of these increased needs and seek help from the counsellors only for resolving their symptoms and side-effects. The LAC counsellor can utilize this opportunity for explaining the importance of nutrition in managing the symptoms and side-effects, thus delaying the progression of disease and improving their quality of life.

However, as the effect of HIV on nutrition begins early in the course of the disease, the counsellor should ensure that nutritional counselling and education is provided to the client as early as possible and at every visit of the client to the LAC.

### *2 ways to get maximum nutrients out of your food*

When you cook foods (vegetables or meats) the best way to retain nutrients is to cook in a water-based sauce and consume it as a stew. Soup is a very good nutrient source as a lot of the nutrients that are depleted from the food during cooking, remain in the sauce of the soup.

#### **1. Cook your meats in a water-based sauce**

This is the healthiest way to cook your meats. Harmful substances such as free radicals are formed during frying. What you need to do is put your meats in a frying pan in a water-based sauce and then cook with the lid on. This is called steam frying.

#### **2. Cook your fruit and vegetables as part of a soup**

You should use green, leafy vegetables as these have the highest nutrient density and are quite difficult to eat raw. Ensure that these make up the larger portion of your diet for good health. Putting them in a soup is a very good idea.

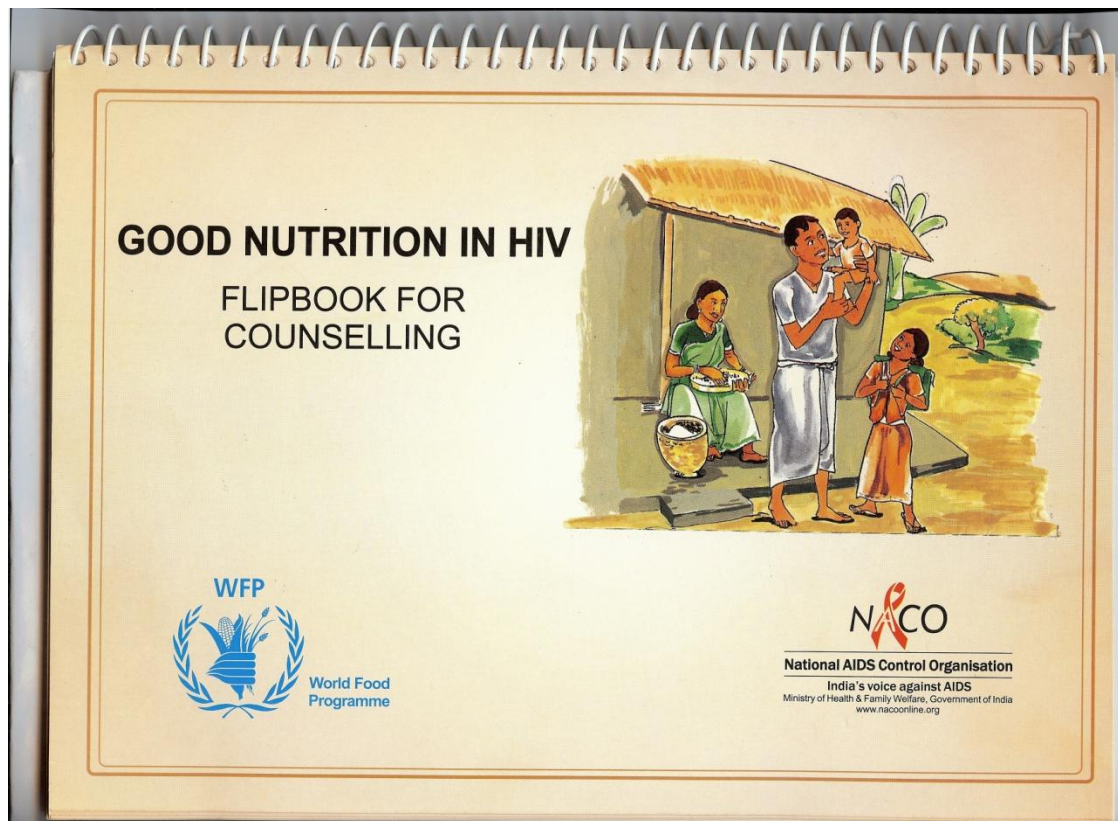
## **Goals of Nutrition Counselling for PLHIVs**

Effective nutrition counselling sessions at the LAC should aim at the following:

- Improving nutritional status of PLHIVs by maintaining weight and preventing loss of weight and muscle mass.
- Ensuring adequate nutrient-intake by clients by improving their eating habits and building stores of essential nutrients that are necessary for the functioning of the immune system.
- Reducing side-effects that can result in reduced food intake.
- Preventing food-borne illnesses by promoting good hygiene and food safety.
- Improving the general well-being of PLHIVs by managing symptoms that affect food intake.
- Extending the period from infection to the development of AIDS disease.
- Keeping clients active and productive, allowing them to take care of themselves, their family and children.



Good nutrition counselling is simple and practical. The patient's socio-economic status, religious and cultural beliefs and other barriers are considered during counselling.



### **Key Points in Nutrition Counselling:**

- The importance of nutrition for PLHIVs.
- Nutritional care of PLHIVs: Monitoring weight, preventing weight-loss and regular exercise.
- Advantages of locally available food items and their nutritious content.
- Foods that should be avoided.
- Safe cooking/storage practices in order to avoid infections.
- Interactions between food and ARV drugs.
- Recommendations specific to symptoms and side-effects faced by the client.

LAC counsellors should first collect the basic information about the client's nutritional status and his/her practices and needs related to nutrition. Based on this initial assessment they should fine-tune counselling and determine other interventions that are needed.

## **Nutrition Counselling during the first visit to the LAC**

During the first visit of the client to the LAC the counsellor should keep in mind that the client has already undergone a number of sessions at the ART Centre. So while developing a relationship of mutual understanding and agreement with the client the LAC counsellor should assess what the client understands about nutrition and HIV. After this initial assessment, the counsellor should identify the client's concerns and should address them properly.

Some additional points to add to the check list for the initial visit of the client to the LAC

- Briefly review what the client's understands about HIV and nutrition
- Based on the assessment, explain to the client about the importance of nutrition for PLHIVs using the Nutrition flipbook
- Ask the client if he/she is experiencing unintended weight loss or is not able to recover lost weight
- Help the client to check his/her weight and height and document the same in the LAC register sheet (column-3 & 4)
- Ask the client to recall the 24-hour menu that he/she is following
- Ask about any nutrition-related concerns

## **Nutrition counselling during follow-up visits at the LAC**

During follow-up sessions at the LAC, the counsellor should focus on monitoring and maintaining the body weight and healthy eating practices by the client. He/she should gather the information about the client's nutrition practices that will help in decisions on their nutritional care and support as well as referrals to other services to improve their well-being. A check list for the follow-up session is given below.

- Ask the client to recall the 24-hour menu that he/she is following and assess whether the diet is diverse enough to provide the necessary nutrients
- Help the client to check their weight and height and record the same on the LAC register sheet (column-3 & 4) and Patient Green Card. Tell them it is important to avoid any unplanned weight loss.
- Compare the current weight with the weight on the previous visit. Refer the client to see the MO in General OPD if any significant unexplained weight loss has occurred. (For an average adult, serious weight loss is indicated by a 10% loss of body weight or 6-7 kg in one month.)

- Discuss with the client about the importance of maintaining a BMI between 18.5-25 Kg/m<sup>2</sup>. For explaining the BMI, use the BMI chart in the Nutrition Flip Book.
- Reinforce the need for increasing food intake and eating a variety of foods.
- Ask the client if they have any symptoms or side-effects. Ask them to seek medical help as these may be a sign of an OI.
- Discuss simple dietary actions that can be taken to alleviate some common symptoms and side-effects. Reinforce the message that the dietary management of symptoms can only reduce negative effects, not cure the condition.
- Help the client to prepare a suitable dietary plan
- Discuss with the client ways to meet their daily requirements by making meals 'nutrient dense' for example, adding milk powder to *Kheer*, adding honey/jaggery to drinks or food, adding vegetables to *roti*, rice, pulse preparations, adding *dal* to soups and *rasams*
- Encourage the client to exercise regularly and avoid alcohol and smoking as they may interact with the drugs
- Check for any food-safety issues affecting the client and suggest ways of ensuring proper food hygiene.
- Check that any suggestions you give suit their preferences, culture, habits and beliefs
- Address the concerns and worries of family caregiver. Reassure them that HIV does not spread by eating together. Involve them in planning meals for the client
- Make sure that the client and the family members understand your suggestions and will be able to follow the plan

#### *Ways to make meal "Nutrient dense"*

A meal/ snack can be made more nutrient-dense by adding locally available ingredients such as *besan*, skim milk powder etc. These can be incorporated in the following way:

- *Besan* in *parantha/ chapati* to make it a *paushtik roti*.
- One handful of peanuts in 1 serving of *poha, upma* or *pulao*.
- 2 tsp. of skim milk powder in regular 1 glass of milk (250 ml).
- Around 2 tsp. of nutrela in *aloo tikki*. Even peanut powder can be added to it.

## **Counselling for Unexplained weight loss**

For an average adult, serious weight loss is indicated by a 10% loss of body weight or 6-7 kg in one month. This type of weight loss may indicate underlying illness or treatment-failure. The counsellor must:

- Refer the client to seek immediate medical help to the General OPD.
- Help the client to follow the instructions given by the MO for early treatment of the underlying infection.
- Suggest simple dietary measures to manage the symptoms so that the effect of the illness symptoms on the nutritional status of the client is reduced.
- Tell the client to continue to eat during periods of illness and infection. Eat snacks such as *paneer*, roasted *chana*, fruits and *nimbu pani* (sweet or salty), coconut water and *jaljeera*.
- Elicit and respond to feedback about the feasibility of chosen options, how to improve them and any challenges faced.
- Assess adherence to drugs, reasons for non-adherence and the drug-food timetable.
- Help the client make adjustments as needed.
- Educate the client that once the infection is over and the person is feeling better, he or she should start eating normally again. It is important to regain the weight lost as soon as possible and to restore the body's nutritional reserves.

## **Barriers to good nutrition**

Many people may not do what you suggest. So, counsellors should identify barriers affecting the client's decisions and should help them to plan meals which fulfill their nutritional needs. Some common barriers are:

- Barriers related to information: provider barriers, client barriers, system barriers
- Barriers related to food choice: economic, geographical, physical, time constraints
- Barriers related to cooking and supplying: who will cook/supply
- Cultural, social and religious barriers (e.g. vegetarians)
- Personal barriers: depression, loss of appetite, concurrent substance abuse, alcohol use.

Thus, when suggesting food to a person, consider their preferences, culture, habits and beliefs. Foods may be chosen or avoided because of religious beliefs, family tradition, local customs or

personal preference. As a counsellor you could include in your counselling tool box a set of relevant and low-cost recipes.

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**Questions to LAC counsellors:**

- ✓ What type of meal pattern should be followed particularly at the time of acute illness?
  - ✓ What are some of the traditional methods of making food nutrient-dense in your state or district?
  - ✓ Are you aware of any cost-effective protein supplements available in the market?
- 

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# Pre-ART Care

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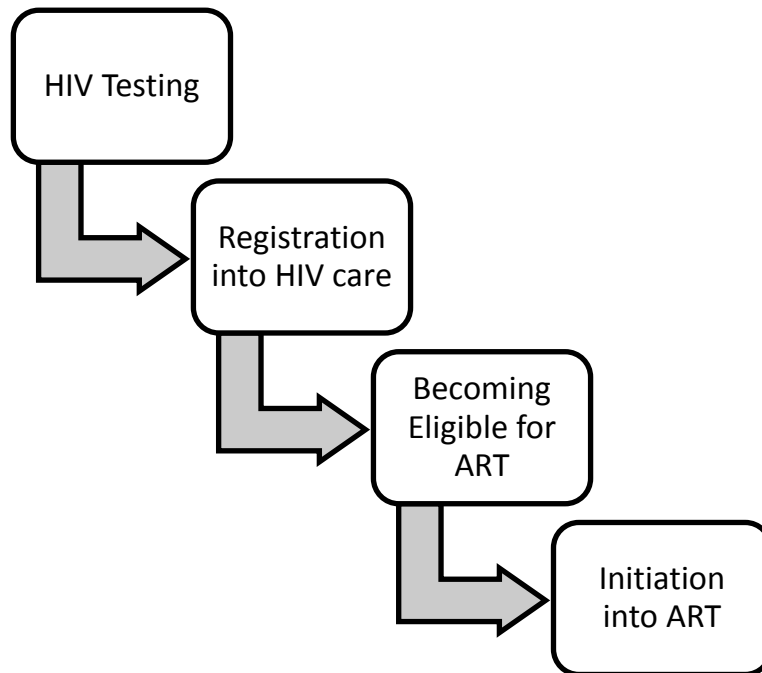
At the end of this unit, participants will be able to

- Define Pre-ART Care and Retention
- List the issues that are critical to Pre-ART Care
- Describe counselling strategies to enhance retention during the pre-ART phase

Pre-ART Care is not a new idea for LAC counsellors. If you have ever built rapport with clients who test positive at your ICTC and engage with them successfully beyond your post-test counselling, then you are already practicing some of the ingredients of Pre-ART Care. Here you will discuss issues related to keeping them healthy and building their immunity. But there are also other issues.

Pre-ART Care is, in short, a package of services for clients who are infected with HIV but whose physical condition is not yet so bad that they require to be immediately initiated into ART. This chapter will examine closely how to deal with such individuals.

# Stages in the HIV Continuum of Care



ICTC Counsellors are already familiar with the first stage in the HIV Continuum of Care:

- HIV Testing,
- Registration into HIV care,
- Becoming eligible for ART and
- Initiation into ART.

## HIV testing

Every person who enters the continuum of care services undergoes a test to determine if they are infected with HIV. As the ICTC counsellor you will interact with them.

## Registration into HIV Care

Once the individual's status is known, he/ she has to visit an ART Centre or an LAC Plus service. Here they will undergo the procedures for enrollment into the services of the ART Programme. If your centre serves as an LAC Plus, then you will interact with the client at this stage. Otherwise, these tasks are undertaken at the ART Centre.

## **Becoming eligible for ART**

A person becomes eligible for ART if their CD 4 count is low enough (at present 350) to require ART. Alternatively, this is determined by WHO Clinical Staging. Again, if you are an LAC Plus counsellor, then you will interact with the client at this stage as they undertake the CD4 test. Otherwise, these tasks are undertaken at the ART Centre.

## **Initiation into ART**

Once a PLHIV is determined to require antiretroviral treatment, the service should start them on ART as soon as they are ready. Under current programme guidelines, this step is undertaken at the ART centre.

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**The period of pre-ART care is the period from HIV testing to becoming eligible for ART.** For people whose immunity is already very low, this period is a short one. For people whose health and immunity is still strong, this period may stretch over months, even years.

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# **Retention**

At each stage in the continuum PLHIVs are lost. This means that they may drop out of the HIV services or they may die. Retention in HIV care is a challenge at every step of the way. WHO (2012) defines it as “continuous engagement from diagnosis in a package of prevention, treatment, support and care services (p. i).” There are challenges in retaining PLHIVs at every stage.

## **Challenges to Retention from HIV testing to Registration**

From HIV testing to registration, people might drop out because of the distance to the ART centre. LAC Plus centres try to reduce this problem because they may be geographically closer to the person’s house. People might fail to show at the LAC Plus centre or at the ART centre because of concerns over stigma and discrimination. They may not believe the test result, or the post-test counselling may not have been effective enough in convincing them to make a visit to the ART centre. Sometimes people are in denial. They may feel they are healthy and do not require treatment. Sometimes they are not aware of the range of services that registration will make available, especially that it is free.



## Challenges to Retention from Registration to Becoming Eligible for ART

The time between registration and a person becoming eligible for ART could be a long one because the PLHIV's immune system is not yet compromised (weak). This is seen through a high CD4 count. Drop-out or being lost-to-follow-up is very high at this stage.

The reasons could be the person feels healthy and does not see the need for treatment. Also, the gap between routine 6-monthly CD4 testing may be too long for people to remember. Their recall of the messages they heard in counselling and the initial medical check-up may fade. Some people may move away and not know how to access the HIV services in their new place of residence.

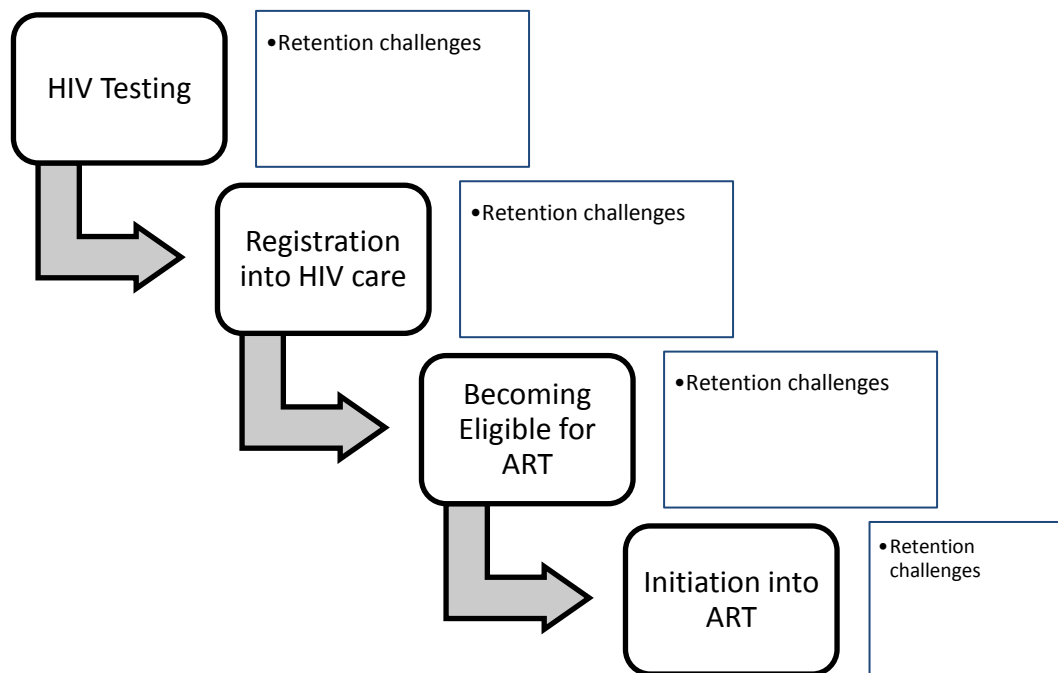
Thus the challenges to retention are very great here.

## Challenges to Retention from Becoming Eligible for ART to Initiation into ART

The challenges at this stage have already been discussed in previous chapters.



### Exercise



## **Retention and Pre-ART Care**

Research shows that the highest drop-out or Loss-to-Follow-up occurs in the Pre-ART Care. Counsellors who deal with PLHIVs whose immune system is not yet compromised (weak) face a particularly big challenge. Clients may misunderstand a good CD4 count to indicate not needing further treatment. He or she may feel healthy and not understand why they need to keep coming back to the centre. As the client does not visit too frequently, it is likely that the client will forget the next appointment to visit the centre for a CD 4 six-monthly check. Also, it is human even for the counsellor to forget unless they have a written system of tracking the person down. Further, the limited number of interactions may mean that rapport is poorly established.

But it is critical to retain clients in treatment because timely treatment of Opportunistic Infections and timely initiation of ART will prolong their lives and give them an improved quality of health. Counsellors play a key role here.

## **Pre ART Care**

Pre ART Care includes

- basic health investigations (such as screening for TB, haemoglobin count),
- management of health related issues (such as minor OIs),
- regular CD4 testing at the time of registration into pre-ART care and then every six months subsequently,
- referral to required services: these could be medical, psychological or social

Pre-ART Care requires a team approach:

- The medical officer clinically monitors the Pre-ART client.
- The nurse completes the registration formalities.
- The laboratory technician collects the sample for the CD4 testing
- The counsellor provides pre-ART counselling.

# **Counselling in Pre-ART care**

As a counsellor at an LAC Plus Centre, you are responsible for counselling clients who are not yet eligible for ART. These can be clients referred from the ICTCs (your ICTC and the peripheral ICTCs) and pre-ART clients linked out to your LAC from the nodal ART Centre. While those referred by ICTCs may have undergone only pre and post-test counselling sessions at the ICTC, the latter might have attended some pre-ART counselling sessions at the ART centre.

## **Pre-ART counselling: An opportunity for supporting positive living**

Clients in Pre-ART care may have received some basic information about HIV/AIDS and may have started coping with the infection. Pre-ART counselling is an opportunity for them to build hope in their lives and learn how to improve their coping with the fact of living with an infection which cannot be cured. This is an opportunity for counselling on nutrition, exercises, family planning. You should also motivate the client for positive prevention.

## **Disclosure counselling**

Some research shows that clients who have not yet shared their HIV status with loved ones are at greater risk of dropping out of treatment. During Pre-ART Care, the counsellor can help the client to prepare to disclose their status to persons who matter to them. The counsellor can either support the client in disclosure or may facilitate the disclosure in the presence of the client. While the person is not yet on treatment, the presence of supportive people in her/ his life may help to keep them hopeful as well as eager to get suitable treatment.

## **Treatment Preparedness counselling**

Anti-Retroviral Treatment is an important factor which helps PLHIVs to stay healthily. Drug adherence is the key to treatment success. Pre-ART counselling sessions can lay a strong foundation for strong adherence by educating the client and preparing him/her for its initiation. Treatment Preparedness Counselling can and should start much before the person is eligible for treatment.

Check what information the client may have received about ART prior to the pre-ART counselling session. You need to provide basic information on treatment in simple and understandable way to the client. The idea is to help her/ him understand about the treatment, how it helps her/ him, and when she/ he should start treatment. The client should know the importance

of adherence and also the limitations of treatment (that it does not cure HIV, should be taken life-long and there may be side effects for a short time)

While educating clients about ART,

- It is better to check what they know and build on it.
- The ART flipbook will be useful to explain how the drugs work and importance of adherence
- Checking in between whether the client understands the information given will help you to repeat or simplify the information for the client
- Distributing leaflets on ART will help literate clients to internalize the information given
- You may need to check the client's knowledge level and revisit the same information in the follow-up visits also.

### **Counselling about routine medical procedures**

CD4 Testing is a key aspect of monitoring the person's condition. You should motivate the client for regular check-ups and CD4 tests. A high CD4 count should be understood as a good sign – namely the person's immune system is still responding well. But the counsellor should also be prepared to dampen any complacency or belief on the part of the client that they need not worry about their health.

### **Preventing MIS or LFU for CD4 testing**

The Pre-ART phase for some clients may extend for years. Regular CD4 testing is important for them. However, as time pass by, there may become lax about visiting the LAC for CD4 testing. This is likely when they do not have any health complications. Here, you need to prevent such tendencies at the initial visits. Prepare them for this by explaining that it is common for people to become less worried as time passes but that it is necessary to follow up despite feeling it is not necessary.

### **Some strategies for preventing MIS/LFU for CD4 testing**

- Reinforce the need of regular health check-up and CD4 tests
- Remind that when not on ART, HIV infection progresses and CD4 count declines
- During counselling sessions, discuss issues other than ART and CD4 testing also. This will make the client feel that the visits are helpful to him/her. One example is the impact of HIV on various aspects of client's life.

- Offer follow-up counselling sessions and remind the clients that they can come to your centre for help. This is the skill of leaving the door open.
- While discussing client's life with HIV, praise for the positive steps taken by him/her.
- Give a feeling that he/she is important and involved rather than a feeling that he/she is inferior and incapable
- Continuously convey warmth and supportive attitude.

Some people may not return for regular CD4 tests. Here you may use other mechanisms such as contacting by phone, tracking through Out Reach Workers/District Level Network Members.

### **Preparing a client for the first CD4 test**

Clients taking a CD4 test for the first time have a right to know about the details of the test and how the results affect him/her. Explain the procedures at LAC with regard to blood drawing (amount, procedure), the procedures at the ART centre (that it is sent to the ART centre) and indicate the time required to get the result.

### **Conveying the CD4 test result**

While you share the result of the test, you should explain to the client its implications: A positive test result means that their immune system is weak and they need to begin ART at once. The person may again experience a break-down because the hope of receiving a "good" CD4 count may have kept them hopeful. The counsellor should help them cope.

A negative result while satisfactory should not be seen as a reason to relax and become complacent or lazy about one's health. Positive prevention here would emphasize measures to keep the immune system strong. If the client is not required to start ART immediately, you should start laying the foundation for regular visits to your centre in case they feel ill, and routine 6-monthly visits for CD4 testing. You can offer follow-up counselling sessions to the client to discuss his/her needs and issues. In counselling knowledge this is known **leaving the door open**.

### **Why clients need to undergo repeat CD4 test at every 6<sup>th</sup> month?**

- The CD4 count of a PLHIV changes from day to day
- If a PLHIV is not on ART, the HIV infection progresses to kill more and more CD4 cells. Thus the CD4 count will decrease
- The pattern of CD4 count will show the effect of HIV on the PLHIV's immune system
- With regular CD testing, the doctors can
  - Monitor effect of HIV on the person

- Diagnose whether he/she has reached AIDS stage
- Decide when to start ART
- Evaluate the person's risk for contracting OIs
- Deciding when to start CPT

### **Referral to ART centre**

Referral skills are very important for an LAC counsellor. Referral means sending the patient to another facility for a required service. Clients may experience fatigue at having to move from one facility to another. A complete referral process explains the reason/ need for the visit/ transfer, the services that would benefit the client, how to access these services and any other relevant issue. LAC Plus counsellors may have to refer clients who become eligible for ART to the nodal ART centre where treatment will be initiated.

A successful referral requires you to

- Explain the need of referral and where you are referring
- Provide details of the centre/facility to where you refer, if possible in writing
- Explain the services and procedures available at the ART centre
- Plan the date of visit to the ART centre
- Inform what are the documents they need to carry to the ART centre
- Discuss concerns related with visiting the ART centre
- Follow-up with the client and ART centre to ensure that the client reached there

One technique in referral counselling is Anticipatory Guidance. Here you prepare the client about what to expect when he/she visits the ART centre (the services, who will be there, the procedures, the wait time, etc.). This will help the client to better adjust with situations such as long waiting time and sessions with different staff (care coordinator, counsellor, nurse, MO).

### **How to ensure a successful referral to ART centre**

NACO has recommended the following mechanisms to track a referral

- Linelisting of the referred clients
- Confirming the client's visit by phone call to the ART centre/client
- Checking with ART centre during monthly coordination meetings
- Verifying the referral forms returned by the nodal ART centre

## Checklists for Pre-ART counselling at LAC

### First Visit

<p>Assess <span style="float: right;"><input type="checkbox"/></span></p> <p><i>Impact of HIV on clients life and psychological status</i></p> <p><i>Disclosure status</i></p> <p><i>Any other key factor</i></p>
<p><i>Inform CD4 test result and its implications</i> <span style="float: right;"><input type="checkbox"/></span></p>
<p><b><i>Eligible for ART initiation</i></b></p>
<p>Assess <span style="float: right;"><input type="checkbox"/></span></p> <ul style="list-style-type: none"> <li>○ <i>Understanding about treatment</i></li> <li>○ <i>Readiness to start ART</i></li> <li>○ <i>Family support</i></li> </ul>
<p><i>Reinforce key messages on ART- life-long nature, adherence</i> <span style="float: right;"><input type="checkbox"/></span></p>
<p><i>Refer to the ART Centre</i> <span style="float: right;"><input type="checkbox"/></span></p> <ul style="list-style-type: none"> <li>○ <i>Plan the date of visit</i></li> <li>○ <i>Discuss concerns related with starting ART</i></li> <li>○ <i>Discuss any concerns related with visiting ART centre</i></li> <li>○ <i>Provide written details of the centre</i></li> <li>○ <i>Ensure that all required documents are available with the client</i></li> </ul>
<p><i>Assure continued support from your side</i> <span style="float: right;"><input type="checkbox"/></span></p>
<p><b><i>Not eligible for ART initiation</i></b></p>
<p>Assess <span style="float: right;"><input type="checkbox"/></span></p> <ul style="list-style-type: none"> <li>○ <i>Understanding about HIV/AIDS</i></li> <li>○ <i>Prior use of ART (perhaps from the private sector)</i></li> <li>○ <i>Coping with HIV diagnosis</i></li> <li>○ <i>Family and social support</i></li> <li>○ <i>Use of alcohol and drugs</i></li> <li>○ <i>Living conditions (housing, employment, income)</i></li> </ul>

<ul style="list-style-type: none"> <li>○ <i>Understanding about treatment</i></li> </ul>	
<i>Assure continued support from your side</i>	<input type="checkbox"/>
<i>Refer for CD4 testing</i> <ul style="list-style-type: none"> <li>○ <i>What is CD4 test</i></li> <li>○ <i>Need of CD4 test</i></li> <li>○ <i>Implications of result</i></li> <li>○ <i>Process and time taken</i></li> </ul>	<input type="checkbox"/>
<i>Discuss</i> <ul style="list-style-type: none"> <li>○ <i>OIs</i></li> <li>○ <i>Nutrition</i></li> <li>○ <i>Disclosure</i></li> <li>○ <i>Positive prevention</i></li> </ul>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<i>Provide</i> <ul style="list-style-type: none"> <li>○ <i>Condoms</i></li> <li>○ <i>Reading materials on ART, nutrition, etc</i></li> </ul>	<input type="checkbox"/>
<i>Refer to the Medical Officer</i>	<input type="checkbox"/>

**Second visit (When CD4 test result is discussed)**

<i>Assess</i> <ul style="list-style-type: none"> <li><i>Impact of HIV on clients life and psychological status</i></li> <li><i>Disclosure status</i></li> <li><i>Any other key factor</i></li> </ul>	<input type="checkbox"/>
<i>Inform CD4 test result and its implications</i>	<input type="checkbox"/>
<b><i>Eligible for ART initiation</i></b>	
<i>Assess</i> <ul style="list-style-type: none"> <li>○ <i>Understanding about treatment</i></li> </ul>	<input type="checkbox"/>



<ul style="list-style-type: none"> <li>○ <i>Readiness to start ART</i></li> <li>○ <i>Family support</i></li> </ul>	
<i>Reinforce key messages on ART- life-long nature, adherence</i>	<input type="checkbox"/>
<i>Refer to the ART Centre</i> <ul style="list-style-type: none"> <li>○ <i>Plan the date of visit</i></li> <li>○ <i>Discuss concerns related with starting ART</i></li> <li>○ <i>Discuss any concerns related with visiting ART centre</i></li> <li>○ <i>Provide written details of the centre</i></li> <li>○ <i>Ensure that all required documents are available with the client</i></li> </ul>	<input type="checkbox"/>
<i>Assure continued support from your side</i>	<input type="checkbox"/>
<b><i>Not eligible for ART initiation</i></b>	
<i>Assess</i> <ul style="list-style-type: none"> <li>○ <i>Understanding about treatment</i></li> <li>○ <i>Implications of CD4 test results</i></li> <li>○ <i>Need for regular check-up</i></li> <li>○ <i>Healthy life-style practices</i></li> <li>○ <i>Prevention of OIs</i></li> <li>○ <i>Future plans of the client</i></li> </ul>	<input type="checkbox"/>
<i>Inform/Discuss follow-up dates</i>	<input type="checkbox"/>
<i>Assure continued support from your side</i>	<input type="checkbox"/>
<i>Collect consent for contacting over phone/visit by ORW</i>	<input type="checkbox"/>
<i>Discuss</i> <ul style="list-style-type: none"> <li>○ <i>OIs</i></li> <li>○ <i>Nutrition</i></li> <li>○ <i>Disclosure</i></li> <li>○ <i>Positive prevention</i></li> </ul>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<i>Provide</i>	<input type="checkbox"/>

- *Condoms*
- *Reading materials on ART, nutrition, etc*

### **Follow-up visits**

#### *Assess & Discuss*

- *Impact of HIV on different aspects of client's life* 
  - *Health*
  - *Psycho-social well-being*
- *Disclosure*
- *Positive prevention*
- *Understanding about ART*
- *Diet & Nutrition*
- *STIs*
- *OIs, specifically TB*
- *Regular visit to the centre*
- *Next follow-up date*

### **References:**

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# Annexures

## Annexure 1: LAC Counselling Checklists for Adult Clients

### Initial visit to the LAC

<i>Rapport Building</i>	
✓ Introduce the whole LAC team to the client	<input type="checkbox"/>
✓ Explain LAC procedures - consulting with MO, adherence monitoring, drug distribution and counselling	<input type="checkbox"/>
✓ Explain the differences between ART Centre and LAC <ul style="list-style-type: none"> <li>○ At the nodal ART centre, there is an MO dedicated to the ART Centre, while at the LAC a client has to consult the doctor within the General OPD.</li> <li>○ Medicine is distributed by the ART pharmacist in the ART Centre, while the general pharmacist or staff nurse dispenses medicine at the LAC</li> </ul>	<input type="checkbox"/>
✓ Gather information regarding the client - eg; family details, caregiver details, occupation, residence and health status (ask directly/check the green and white cards	<input type="checkbox"/>
✓ Extend support for the client and assure that his/her HIV status will be kept confidential in the LAC.	<input type="checkbox"/>
✓ Specifically ask for concerns regarding the LAC and address, if any	<input type="checkbox"/>
✓ Inform that he/she can consult the ART centre once in 6 months and in case of major health issues	<input type="checkbox"/>
<i>Adherence counselling</i>	
✓ Review client's understanding about ART and adherence strategies used by him/her	<input type="checkbox"/>
✓ Reinforce the need for continued adherence	<input type="checkbox"/>

✓ Ensure that he/she has drugs for one month	<input type="checkbox"/>
<i>Side-effects and OIs</i>	
✓ Check client's knowledge about side-effects and advise to return to LAC, if any occurs	<input type="checkbox"/>
✓ Check client's understanding about OIs and review the history of past OIs	<input type="checkbox"/>
<i>Complete the documentation procedures and provide the LAC ID-number. Provide the next follow-up date. Note this date in your follow-up diary</i>	
	<input type="checkbox"/>

## Subsequent or Follow-up visits to the LAC

<i>Adherence</i>	
✓ Check whether the client has taken the morning tablet. Offer the tablet and water, if necessary and observe client consuming the medicine.	<input type="checkbox"/>
✓ Review the client's adherence to treatment <ul style="list-style-type: none"> <li>○ Number of doses missed since the last visit (Oral report)</li> <li>○ Check whether the client has taken the drugs at the right time</li> </ul>	<input type="checkbox"/>
✓ Count the pills remaining in the bottle and assess and categorize adherence accordingly (<80%, 80-95% and >95 %).	<input type="checkbox"/>
✓ Check the reasons for adherence levels below 95% <ul style="list-style-type: none"> <li>○ Assess client's current understanding about treatment and importance of adherence</li> <li>○ Check for signs of treatment fatigue</li> <li>○ Discuss any problems or issues the client in taking the medicine</li> </ul>	<input type="checkbox"/>
✓ Check the ART counselling diary and review any past issues pending	<input type="checkbox"/>
✓ Check whether the client has any plans for a change in his/her life in the coming month. Discuss how he/she will take medicine without interruption in the changed situation	<input type="checkbox"/>
✓ Reinforce the need of adherence	<input type="checkbox"/>
✓ Review the adherence strategy followed. If needed help the client to modify or change the same.	<input type="checkbox"/>
✓ Check the client's next month's supply of medicine	<input type="checkbox"/>
<i>Side-effects and OIs</i>	
✓ Check for signs and symptoms of OIs and drug side-effects. Encourage the client to report any symptoms to the doctor <ul style="list-style-type: none"> <li>○ If minor, refer to the trained doctor at the LAC</li> <li>○ If major, arrange for referral to nodal ART Centre</li> </ul>	<input type="checkbox"/>

✓ Assess current understanding of the client regarding side-effects and OIs	<input type="checkbox"/>
✓ If the client has any symptoms of serious OIs or side-effects, arrange for referral to the Nodal ART Centre	<input type="checkbox"/>
<i>STIs</i>	
✓ Screen for STIs and refer for treatment, if necessary	<input type="checkbox"/>
✓ Reinforce the need of safe sex and address barriers, if any	<input type="checkbox"/>
<i>Nutrition and diet plan (Need not address on each visit)</i>	
✓ Assess the client's understanding about nutritional requirements, if not done before.	<input type="checkbox"/>
✓ Help the client to check their weight and height and record the same on the LAC register sheet (column 3 & 4) and Patient Green Card. Compare it with the previous 3 months measurements. If any serious weight loss has happened, bring it to the notice of the doctor.	<input type="checkbox"/>
✓ Check for any conditions requiring additional nutritional intake (pregnancy, OIs, side-effects, etc).	<input type="checkbox"/>
✓ Check the quality and quantity of food and water intake.	<input type="checkbox"/>
✓ Discuss the diet plan, nutrition, exercise and suggest if any modification is required.	<input type="checkbox"/>
<i>Positive Prevention (Need not address on each visit)</i>	
✓ Assess the sexual practices of the client	<input type="checkbox"/>
✓ Discuss how the client can adopt safe sex practices in his/her life	<input type="checkbox"/>
✓ Address issues concerned with condom use and provide condoms	<input type="checkbox"/>
<i>Family Planning (Need not address on each visit)</i>	
✓ Discuss family planning methods adopted by the client	<input type="checkbox"/>
✓ If needed offer family planning counselling for partner	<input type="checkbox"/>
✓ Check with female client (who has a male partner) in reproductive age, whether she had any unprotected sexual intercourse in last few months	<input type="checkbox"/>
✓ Check with the female client whether she suspects pregnancy. If yes, provide her with	<input type="checkbox"/>

counselling for preventing transmission to the child	
<i>Positive living</i> (Need not address on each visit)	
✓ Encourage the client to share recent events in his/her life. Ask if these had any effect on adherence and positive living	<input type="checkbox"/>
✓ Discuss how treatment has affected other areas of his/her life	<input type="checkbox"/>
✓ Review social and familial support at regular intervals. Refer to the other agencies, if required	
✓ Check if the client that is taking any other medication. In such cases, reinforce the need to consult with the doctor.	<input type="checkbox"/>
✓ Reconfirm the appointment for the next month	<input type="checkbox"/>

## Visit prior to back-referral to the Nodal ART Centre

<i>Additional issues for the counselling session prior to the client's six monthly visit to the Nodal ART centre</i>	
<ul style="list-style-type: none"> <li>✓ Remind the client about the visit to the nodal ART centre and its purpose:               <ul style="list-style-type: none"> <li>○ CD4 testing</li> <li>○ review of client's health status by ART doctors</li> </ul> </li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Plan the date for the visit to the ART centre</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Ensure that you send all the required documents with the client to the ART centre               <ul style="list-style-type: none"> <li>○ Photocopy of his/her page in the LAC register.</li> <li>○ Green book of the patient.</li> <li>○ LAC to NAC referral form</li> </ul> </li> </ul>	<input type="checkbox"/>
<i>Additional issues for linking in case of major OIs</i>	
<ul style="list-style-type: none"> <li>✓ Explain that a major OI needs more specialized treatment</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Try and get an appointment immediately. Call the ART counsellor, if possible.</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Ensure that you send all the required documents with the client to the ART Centre</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Check if the client has any transportation issues</li> </ul>	<input type="checkbox"/>



# Annexure 2: LAC Counselling Checklists for Child Clients

## Child's Initial visit to the LAC

<i>Building rapport with child and caregiver</i>	
✓ Warmly greet the child and caregiver	<input type="checkbox"/>
✓ Ask the caregiver to introduce the child (“May I know whom you have brought with you?”)	<input type="checkbox"/>
✓ Ask the child’s name and other personal details in a warm way (“May I know your name?”, “It is a nice name”, “Who all are there in .....’s home?”)	<input type="checkbox"/>
✓ Children may like physical closeness. If the child is comfortable, gently touch the child on shoulder or head	<input type="checkbox"/>
✓ Tell the child that you would like to talk to the caregiver for some time.	<input type="checkbox"/>
✓ Engage the child with some activity and talk to the caregiver	<input type="checkbox"/>
✓ Obtain the details of the caregiver	<input type="checkbox"/>
✓ Elicit details about the child’s family and the HIV status.	<input type="checkbox"/>
<i>Address different concerns regarding shift in centre</i>	
✓ Ask the child about the experience with the ART Centre. Explain that this is also a similar centre and he/she can be comfortable here	<input type="checkbox"/>
✓ Inform the caregiver that the services and medicines are the same and all personnel in the centre are trained. Also inform them that the child can return to ART centre, if any illness or side-effect develops	<input type="checkbox"/>
✓ Assure the caregiver about confidentiality. Also inform about the shared confidentiality and who on the LAC team will be informed about the child’s HIV status for treatment purposes	<input type="checkbox"/>
<i>Assess the child’s and caregiver’s understanding about the treatment</i>	

<ul style="list-style-type: none"> <li>✓ Collect the details of current treatment (You can use the White Card and also ask the caregiver) <ul style="list-style-type: none"> <li>○ Drugs and dosages</li> <li>○ Method of administration</li> </ul> </li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Assess what the child knows and feels about treatment (<i>“What do you understand about going to the clinic/taking medicine?”</i>, <i>“How do you feel about coming here?”</i>)</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Assess what the child feels about being sick often (<i>“What do you understand about falling sick often?”</i>, <i>“How did you feel when you fell sick last time?”</i>)</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Assess what the child understands about others in family falling sick (<i>“How are others at home doing?”</i>, <i>“What do you know about their sickness?”</i>)</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Assess what the caregiver knows about the treatment (<i>“May I know what you understand about the treatment we are giving to the child”</i>, <i>“Can you tell me how you are supporting the child in taking medicine?”</i>)</li> </ul>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>✓ Identify the caregiver’s concerns regarding treatment. (<i>“What do you think about the treatment? Is the child able to take medicine as prescribed? Is there anything which you fear that will be a problem in taking medicine?”</i>)</li> </ul>	<input type="checkbox"/>
<p><i>Reinforce the importance of adherence</i></p>	<input type="checkbox"/>
<p><i>Identify any potential barrier to adherence and plan strategies to address them</i></p> <ul style="list-style-type: none"> <li>✓ Ill-health of the child, caregiver or anyone in the family</li> <li>✓ Changes in family situation, social situation, etc.</li> <li>✓ Concerns regarding confidentiality</li> </ul>	<input type="checkbox"/>
<p><i>Complete the documentation procedures and provide the child with the LAC ID-number. Provide the next follow-up date. Note this date in your follow-up diary</i></p>	<input type="checkbox"/>

## Child's Subsequent or Follow-up visits to the LAC

<i>Greet the child and caregiver</i>	<input type="checkbox"/>
<i>Assess the child's adherence for the last month using one or more of the following methods</i>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>○ Pill count</li> <li>○ Treatment calendar/diary</li> <li>○ Report by child</li> <li>○ Report by caregiver</li> </ul>	
<i>Record last month's adherence on the White Card</i>	<input type="checkbox"/>
<i>Assess the reason for poor adherence or missing doses from child using the interactive strategies described</i>	<input type="checkbox"/>
<i>Assess/verify the reason for the child's poor adherence or missing doses with the caregiver</i>	<input type="checkbox"/>
<i>Discuss with the child and /or caregiver how to resolve the reason for missing doses</i>	<input type="checkbox"/>
<i>Assess other potential barriers to adherence and address them</i>	<input type="checkbox"/>
✓ Child's current understanding about his/her health status, treatment, etc.	
✓ Caregiver's current understanding about importance of adherence and his/her attitude towards treatment.	
✓ Health status of the child (measure weight, check for health issues, etc.)	
✓ Family situation of the child and relationships (Parent's/sibling's caregiver's ill-health or death, any disruption in the family, poverty, etc.)	
✓ Social situation of the child (School, neighborhood, experience of stigma, etc.)	
✓ Symptoms of adherence fatigue	
✓ Any other factors	<input type="checkbox"/>
<i>Reinforce the importance of adherence</i>	<input type="checkbox"/>
<i>Review the adherence strategies in place and modify, if needed</i>	<input type="checkbox"/>
<i>Review with the caregiver, the need for informing the child about his/her HIV status and process the same accordingly</i>	<input type="checkbox"/>
<i>Check for any developmental delay: you can observe the child or ask the caregiver for details.</i>	<input type="checkbox"/>

<i>Inform the doctor in case of any delay noticed</i>	
<i>Discuss the diet plan, nutrition, etc.</i>	<input type="checkbox"/>
<i>Review the support systems in place for the child and family</i>	<input type="checkbox"/>
<i>Check for any other concerns of the child and/or caregiver and address them properly</i>	<input type="checkbox"/>
<i>Complete the documentation and provide the next follow-up date. Note this date in your follow-up diary</i>	<input type="checkbox"/>

# Annexure 3: Quick Reference Boxes

## *Quick Reference Box 1: Signs of treatment fatigue*

Client says the following

- “ I am no longer HIV positive.”
- “ Now I do not have any problem and I am cured.”
- “ I am fed-up with medicines.”
- “ I think I can stop medicine now, I don’t think I have to take more.”
- “ I think I am not HIV-positive, I need to do test once more.”
- “ I don’t think there is any issue if I stop medicine for some time.”
- “ I forgot to take medicine.”

## *Quick Reference Box 2: Possible Signs and Symptoms of OIs and ART Side-Effects*

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>✓ Feeling dizzy</li> <li>✓ Pain when swallowing,</li> <li>✓ Trouble in breathing</li> <li>✓ Frequent or very bad headaches</li> <li>✓ Problems in seeing</li> <li>✓ Feeling more and more tired</li> <li>✓ Fever or feeling hot for more than a day</li> <li>✓ Sweat soaks the bed</li> <li>✓ Cough lasting over 2 weeks</li> <li>✓ Shaking, chills</li> <li>✓ Problems with balance, walking or speech</li> <li>✓ Skin rashes</li> </ul> | <ul style="list-style-type: none"> <li>✓ Losing weight for no reason</li> <li>✓ Watery diarrhoea for more than 4 times a day Nausea, despite treatment</li> <li>✓ Vomiting</li> <li>✓ Dry mouth</li> <li>✓ Sore mouth or tongue</li> <li>✓ Stiff neck</li> <li>✓ Severe stomach or abdominal pain</li> <li>✓ Swelling, burning, itching, soreness, discharge or smell on or near the vagina.</li> <li>✓ Changes in menstrual cycle or menstrual flow</li> <li>✓ Pain during sexual intercourse</li> </ul> |
|--|---|

<i>Quick Reference Box 2: Signs and Symptoms of STIs</i>	
<i>Males</i>	<i>Females</i>
<ul style="list-style-type: none"> <li>✓ Sores, ulcers, blisters on genital area</li> <li>✓ Small hard lumps</li> <li>✓ Rashes around and in the sexual organs including mouth/anus</li> <li>✓ Burning sensation while passing urine</li> <li>✓ Frequent urination, and discharge from penis or anus</li> <li>✓ Infection or inflammation inside rectum/anus</li> <li>✓ Swelling of the scrotum/groin area</li> <li>✓ Sore throat</li> </ul>	<ul style="list-style-type: none"> <li>✓ Excessive/foul smelling vaginal discharge</li> <li>✓ Sticky greenish and yellowish vaginal discharge</li> <li>✓ Itching in genital area</li> <li>✓ Lower abdominal pain</li> <li>✓ Sores, ulcers, blisters</li> <li>✓ Small hard lumps</li> <li>✓ Rashes around and in the sexual organs</li> <li>✓ Painful itching</li> <li>✓ Burning while passing urine</li> <li>✓ Swelling in and around vaginal area</li> <li>✓ Inflammation of rectum</li> <li>✓ Pain when having sex</li> <li>✓ Frequent urination</li> <li>✓ Sore throat</li> </ul>

# **Annexure 4: Adherence Calculator**

**Instructions for calculators on the next page:**

**1) Count the number of pills remaining in the bottle.**

For example the client came with 8 pills

**2) Look down the first column of the chart for that number.**

Go to Pills Remaining = 8

**3) Move your finger in that row till you reach the column for the day of the client's visit.**

If the client attends on the 29th day after the last visit, adherence is 90% (Example based on 60-pill regimen)

# Adherence Calculator for SLN/ ZLN/ TDF-3TC-EFV



		Day of Visit for 60-Pills											Day of Visit for 120-Pills ( <b>TWO MONTHS</b> )														
		24	25	26	27	28	29	30	31	32	33	34	35	55	56	57	58	59	60	61	62	63	64	65			
<b>Pills Remaining</b>	0						100	97	94	91	88	86						100	98	97	95	94	92				
	1						98	95	92	89	87	84						99	98	96	94	93	92				
	2						100	97	94	91	88	85	83					100	98	97	95	94	92	91			
	3						98	95	92	89	86	84	81					99	98	96	94	93	91	90			
	4					100	97	93	90	88	85	82	80				100	98	97	95	94	92	91	89			
	5					98	95	92	89	86	83	81	79					99	97	96	94	93	91	90	88		
	6				100	96	93	90	87	84	82	79	77				100	98	97	95	93	92	90	89	88		
	7				98	95	91	88	85	83	80	78	76				99	97	96	94	93	91	90	88	87		
	8			100	96	93	90	87	84	81	79	76	74				100	98	97	95	93	92	90	89	88	86	
	9			98	94	91	88	85	82	80	77	75	73				99	97	96	94	93	91	90	88	87	85	
	10		100	96	93	89	86	83	81	78	76	74	71				100	98	96	95	93	92	90	89	87	86	85
	11		98	94	91	88	84	82	79	77	74	72	70				99	97	96	94	92	91	89	88	87	85	84
	12	100	96	92	89	86	83	80	77	75	73	71	69				98	96	95	93	92	90	89	87	86	84	83
	13	98	94	90	87	84	81	78	76	73	71	69	67				97	96	94	92	91	89	88	86	85	84	82
	14	96	92	88	85	82	79	77	74	72	70	68	66				96	95	93	91	90	88	87	85	84	83	82
	15	94	90	87	83	80	78	75	73	70	68	66	64				95	94	92	91	89	88	86	85	83	82	81
	16	92	88	85	81	79	76	73	71	69	67	65	63				95	93	91	90	88	87	85	84	83	81	80
	17	90	86	83	80	77	74	72	69	67	65	63	61				94	92	90	89	87	86	84	83	82	80	79
	18	88	84	81	78	75	72	70	68	66	64	62	60				93	91	89	88	86	85	84	82	81	80	78
	19	85	82	79	76	73	71	68	66	64	62	60	59				92	90	89	87	86	84	83	81	80	79	78

Developed by Melita Vaz (PO-Counselling), Kanagasabapathy (TO - Training), Sumitha Chalil (TO - Counselling) & Nisha Kadyan (TO - Nursing)



# Adherence Calculator for SL-Efv/ ZL-Efv/ TDF-3TC-ATV



## Day of Visit for 90-Pills

		24	25	26	27	28	29	30	31	32	33	34	35
<b>Pills Remaining</b>	0							100	97	94	91	88	86
	1							99	96	93	90	87	85
	2							98	95	92	89	86	84
	3						100	97	94	91	88	85	83
	4						99	96	92	90	87	84	82
	5						98	94	91	89	86	83	81
	6					100	97	93	90	88	85	82	80
	7					99	95	92	89	86	84	81	79
	8					98	94	91	88	85	83	80	78
	9				100	96	93	90	87	84	82	79	77
	10				99	95	92	89	86	83	81	78	76
	11				98	94	91	88	85	82	80	77	75
	12			100	96	93	90	87	84	81	79	76	74
	13			99	95	92	89	86	83	80	78	75	73
	14			97	94	90	87	84	82	79	77	75	72
	15		100	96	93	89	86	83	81	78	76	74	71
	16		99	95	91	88	85	82	80	77	75	73	70
	17		97	94	90	87	84	81	78	76	74	72	70
	18	100	96	92	89	86	83	80	77	75	73	71	69
	19	99	95	91	88	85	82	79	76	74	72	70	68
20	97	93	90	86	83	80	78	75	73	71	69	67	
Developed by Melita Vaz (PO-Counselling), Kanagasabapathy (TO - Training), Sumitha Chalil (TO - Counselling) & Nisha Kadyan (TO - Nursing)													

# Annexure 5: Steps in making Paper Bag Puppets

Step 1: Fold the paper bag. Once folded, you should be able to move folded bottom by putting your fingers inside.



the

Step 4: Cut out the face.



Step 2: Draw the outline of the face of the character you want to make on a separate cardboard or paper plate. The breadth of the picture should be more than the base of the paper bag.



Step 5: Paste the picture on the base of the paper bag.



Step 3: Paint the picture and wait until it is dry. Make sure that the eyes and mouth are clearly visible



Step 9: Beautify the puppet. This can be painting of the bag with appropriate colours, making the body of the character by painting the same and pasting it on the paper bag, etc.



# Annexure 6: Samples for Puppets









# **Annexure 7:**

## **A little interest goes a long way Case Study of the Link ART Plus Centre at Gondal, District Rajkot, Gujarat.**

Prepared by Melita Vaz PhD (NACO)

With inputs from Dr. Tarak Shah (CDC) & Dr. Govind Bansal (NTSU-NACO)

### **About the Gondal ICTC**

This write-up features the work of Ms Dipti Raval – an enterprising ICTC counsellor at Gondal sub-district CHC within Rajkot district of Gujarat. Last year, the Gondal ICTC handled 3254 clients for HIV testing as per NACO-CMIS. This includes 1084 pregnant women and works out to a minimum of 12 clients per day. It was designated as a Link ART Centre (LAC) in 2010. An LAC is an ICTC that – besides testing - also provides ART drug dispensing facilities to PLHIV clients who have been stable on ART for at least 6 months. This LAC has 53 patients as on January 27, 2012.

The centre is led by the Medical Officer-incharge, Dr. Kotadiya under the overall supervision of the Superintendent – Dr. B.M. Bagada. Day-to-day work is handled by Ms Dipti, a nurse, Ms Bharti Suthar, a pharmacist, Mr. Dinesh and an outreach worker. This centre first came to the notice of NACO during the DAPCU National Resource Team’s visit to Gujarat (July, 2011). This report is based on both the report of the DAPCU team’s visit as well as a telephone interview of Ms Dipti on 27<sup>th</sup> January 2012.

Ms Dipti has been the ICTC counsellor since 2006. Earlier she was a counsellor in another organisation. She also participates as a Peer Support Counsellor – a programme initiated by Gujarat SACS to develop a support structure for counsellors using the existing counsellors with more experience. When interviewed by telephone, she was serving as part of an evaluation team of Targetted Intervention projects in Bihar.

Even before the LAC was established at her ICTC, she established a monthly support group of PLHIVs which meets on the third Thursday of every month. This group includes PLHIVs who are on ART and those whose health is still strong enough to avoid initiating anti-retroviral treatment. This support group is also supported by the local network of Positive People.

### **Advent of the LAC**

As part of the establishment of the LAC, the Gondal counsellor spent two days in observation visits at the ART Centre. She was accompanied by nursing staff from her hospital as well as other counsellors and nurses from other ICTC-hosting institutions. During the two days, they shadowed the ART centre staff. This earned them familiarity with the personnel as well as the ART procedures such as maintaining the white cards, etc. When faced with problems initially, they felt comfortable placing calls to specific persons at the ART centre for clarification. The number of these calls has today reduced mostly to consultations over possible instances of Opportunistic Infections

in clients and calls about the stock position to the ART pharmacist. However, the availability of on-phone support reduced initial concerns of “how to manage.”

One of Dipti’s good practices was to share her learnings with other members of the LAC team at Gondal. Thus, even while away on an evaluation at Bihar, she remains confident that the nurse and the Outreach worker at her centre are capable of managing routine activities. Meanwhile she is remains available on phone for non-routine queries. As she expresses it, there are several occasions when a key member of a counselling centre may be away – say on leave – and the centre must continue to function as normal. In such situations, it is a good team that makes all the difference.

It is important to recognise the role of institutional support. Ms Dipti categorically acknowledges that the LAC is benefitted by the assistance of a full-time nursing staff. Even before NACO mandated a nurse position in light of the additional workload caused by linking out more ART patients, the Medical Officer InCharge assigned a full-time nurse to the LAC. However, Dipti’s nurturing of her team members is equally critical as she is clear that there can be little question of “your work” and “my work.” What motivates this team is the need to provide the best possible services.

#### **LAC innovations.**

Till this point, this case study would read like any other well-functioning LAC. What drew the attention of the DAPCU team was the ability of the LAC to track its patients in a timely manner. The efficacy of ART is limited to how regularly it is consumed. Any ART practitioner must worry about adherence at all times.

Ms Dipti Rawal uses the existing white board to track the due dates of the LAC clients by their LAC number. (Please see photograph). This enables the team to identify clients who miss their LAC appointment. The team follows up these individuals by telephone. Permission for such telephone calls is obtained during the LAC intake visit itself. On the same whiteboard, the team tracks by month, the date for the LAC client’s six-monthly CD4 test. A quick glance at the board during the counselling session is enough for Dipti to remind herself and the client that they should visit the ART centre prior to their next visit to the LAC for the monthly drug refill. The use of patient numbers maintains patient confidentiality. Clients who fail to complete their CD4 test are circled for follow-up and in-depth counselling. The board also displays the details of 2 PLHIV schemes (Rs. 500/month for nutritional support and Educational support for Children) with specific prerequisites for enrolment. In addition, this board carries the date and time of the monthly support group meeting.

It is this simple aide-memoire that assists Dipti’s team to keep track of their LAC clients. When asked how she manages, she explains that the LAC workload built up gradually. The initial clients linked out were few. This enabled her to find her feet. As the numbers grew, she developed more confidence (She has already been notified by the ART centre to expect a new client in February 2012). She explains that she is committed to ensuring that none of her clients drop out of treatment. The whole team takes it to heart when any client develops an OI.

The LAC team recognises that certain clients merit special attention. So even though the LAC has designated days for drug dispensing, she permits clients to come in on other days as well. The practicality of co-scheduling the



LAC visit day and the Support Group meeting on Thursdays should also be noted. With regard to special needs, she has 5 children who are on ART. Four of these are school-going. In order to avoid disruption of school schedules, child clients are allowed to visit on non-school days.



### Impact of the LAC and the innovations

Ms Dipti reports that prior to the establishment of the LAC, clients who had tested positive at her ICTC balked at having to go to another centre for further services. Possibly having experienced the initial shock of hearing their HIV diagnosis, they were not keen to relive the difficult moments by having to share this news with another set of strangers. Further, some did not want to travel the 40-km distance to the Rajkot ART centre. Having the LAC facility permits the counsellor to reassure clients that though they need to access further treatment at the Rajkot ART centre, they do have the option of being linked back to the Gondal hospital (provided they are stable on ART).

As a counsellor, she sometimes lost track of clients once they went to the ART centre, especially those who were put on ART. But this situation has altered since the establishment of the LAC. Many of her LAC clients were those who were tested at her own ICTC.

When asked if rapport-establishment is an issue with clients being moved from one facility to another, she replies that these are clients who are stable on ART. They know the importance of ART adherence and require only

gentle reminders from time to time. But one might also suspect that it is the open attitude of the team that makes clients more likely to “stick” to the centre.

Further, clients report that by attending the LAC, they avoid the hassle of travel to Rajkot. They no longer have to wait long hours to see the doctor and the counsellor. At Gondal, they are able to access care for routine visits in a speedy manner. Further, the LAC team is flexible enough to give them attention even on the non-LAC days (“Mangal” and “Guru”) in case they have a conflicting appointment on the day of their designated visit.

The simple yet innovative tracking procedures documented are not solely used for LAC clients. As per Ms Dipti’s report, the ICTC tracks, on a similar whiteboard, the Expected Date of Delivery of their positive pregnant women and the DBS testing schedule of Exposed Babies. This creates a simple tool for the Outreach Worker attached to the centre to ensure coverage to all positive pregnant women and Exposed Babies. This good practice in diligent tracking will take this team in this corner of Rajkot district a long way as the new efficacious regimens are rolled out.

**For more details, please contact Ms Dipti Rawal, 'Hari Park' Ashapura Society, Gondal, Dist. Rajkot. (Gujarat) 360 011, Contact No: 09428462075, 0282522345, diptidec@gmail.com**

# Annexure 8: LAC Formats

## LAC/ LAC Plus MONTHLY REPORTING FORMAT

1. General information about LAC/ LAC Plus						
1.1. Nodal ARTC Name		1.2 Nodal ART Centre CMIS Code:				
1.3. Name of Link ART Centre/ LAC Plus:						
1.4. Address:						
1.5 City:	Pin Code:		District:		State:	
1.6. Reporting Period:	Month		Year			
1.7 . Name of Link ART Center In-charge:						
1.8 Contact Details of Link ART Center incharge:		Phone		Email		
2. Enrolment in HIV Care- Pre ART Patients (ONLY FOR LAC Plus)						
Indicator	Adults			Children		Total
	Male	Female	TS/TG	Male <15 Years	Female <15 Years	
2.1 Number of PLHIV registered in HIV care at the beginning of this month (Same as 2.6 of previous month)						0
2.2 Number of new PLHIV registered in HIV care (Pre ART) during the month						0
2.3 Number of PLHIV in HIV care ( Pre ART) reported died during this month						0
2.4 Number of PLHIV in HIV care ( Pre ART) reported "lost to follow up" during this month						0
2.5 Number of PLHIV 'linked in' to NAC this month						0
<b>2.6 Number of PLHIV in HIV care at LAC Plus the end of this month (=2.1+2.2-(2.3+2.4+2.5))</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>

2.7 Total number of PLHIV ever undergone baseline CD4 count						0
2.8 Total number of PLHIV ever eligible for ART						0
2.9 Total number of PLHIV ever initiated on ART						0
2.10 Out of 2.6, the number of new Ante natal cases reported in HIV care this month						0
<b>3. Treatment Status of PLHIV on ART (For all LAC &amp; LAC Plus)</b>						
Indicator	Adults			Children		Total
	Male	Female	TS/TG	Male <15 Years	Female <15 Years	
3.1 Number of PLHIV on ART linked out to LAC by NAC (Number at the beginning of this month)						0
3.2 Number of PLHIV on ART "linked out" from Nodal center during this month						0
3.3 Cumulative number of PLHIV ever linked out on ART (Number at the end of this month) = 3.1+ 3.2	0	0	0	0	0	0
3.4 Number of PLHIV linked in (referred back) to nodal center this month for ART side effects/ major OI (ART will not be dispensed in this case to patient)						0
3.5 Cumulative number of PLHIV who were retained back at NAC						0
3.6 Cumulative Number of PLHIV who are lost to follow-up (LFU)						0
3.7 Cumulative number of PLHIV who died at LAC till the end of this month						0
3.8 Number of PLHIV who were supposed to collect drugs and did not collect drugs (MIS) in this month						0
3.9 Total number of PLHIV alive and on ART (OT) at the end of this month = 3.3 - (3.4+3.5+3.6+3.7)	0	0	0	0	0	0
3.10 Out of 3.9, Number of new ANC cases (pregnant women) on ART linked out to LAC from nodal ART centre this month						0

**Patient wise monthly information of ON ART Patients linked out to LAC/ LAC Plus**

Name of LAC Plus: \_\_\_\_\_

Date of operationalisation: \_\_\_\_\_

1	2	3	4	5	6	7	8			9	10	11	12	13					14			15	16	
S. No.	ART No.	Patient's name	Age	Sex	Date of Link out	Regimen	Drug Transfer			LAC No	Date of first vist to LAC	OI Code	CPT	Monthly visit					CD 4 Testing			If not being followed up at LAC , indicate reasons for same(MIS/LFU/ Death/Ret ained by nodal ART centre	If patient being referred to ART centre during this month , reason for referral*	
							Date of drug transfer	Due date for next drug transfer						Date of Visit	Adherence						Date of Last CD4 test			Due date
							Date of last drug transfer						Date of Visit	Adherence							Date of Last CD4 test	Due date		

\* 1. Routine assessment & CD4 testing at 6 month . 2. OI. 3. TB 4. Drug toxicity 5. Pregnancy (if required) 6.Any other reason ( Specify)

This format will originate at nodal ART centre . The nodal ART Centre shall send the updated format ( including information about already linked out patients as well as those linked out during the reporting period) to LAC at the end of every month. LAC/ LAC Plus will send back the same after filling up required sections by 25th of next month.

Section 1 to 8 will be filled by nodal ART centre.

Section 9 to 16 will be updated by LAC. Due date for CD4 count in LAC will be filled in red colour.

The print out of this format will be maintained by nodal ART centre in separate files ( one for each LAC) on monthly basis . Overall responsibility of mainataining this format at ART centre lies with Data Manager

Nodal ART Centre will also maintain the soft copy of the format sent to LAC every month

## Format for Patient wise monthly information of PRE ART Patients registered at LAC Plus

Name of LAC Plus: \_\_\_\_\_

Date of operationalisation: \_\_\_\_\_

1	2	3	4	5	6	7	8	9	10	11	12	13			14			15			16			
S. No.	Pre-ART No.	LAC No	Patient's name	Age	Sex	Date of Pre-ART registration at LAC Plus	Baseline CD 4 count	Clinical Stage	OI Code	CTX prophylaxis	Pregnancy	CD 4 Testing			If not in Pre-ART at LAC , indicate reasons for same(MIS/ LFU/ Death/Linked in to nodal ART Centre)			If patient being "linked in" to ART centre during this month , reason for referral*			Date of ART initiation if started on ART			
												CD count												
												Due date												
												CD count												
												Due date												

\* 1. ART initiation . 2. OI. 3. TB 4. Pregnancy (if required) 5. Any other reason ( Specify)

This format will originate at LAC Plus & will be sent to nodal ART centre by 25th of every month. ART centre will send back the same after filling up the relevant section by last day of that month.

Section 1 to 15 will be filled by LAC Plus. Due date for CD4 test will be written in red

Section 16 will be filled by nodal ART centre.

The print out of this format will be maintained by nodal ART centre in separate files ( one for each LAC) on monthly basis . Overall responsibility of maintaining this format at ART centre lies with Data Manager

Nodal ART Centre will also maintain the soft copy of the format received from LAC Plus every month

