

## Module 5

### Submodule 1: Antiretroviral therapy: Counselling and medical aspects

#### Session objectives

- To understand the process of viral replication and the action of ARVs
- To understand the various categories of ARVs, their effects and side-effects
- To explain the relationship between virological efficacy and adherence to potent combination antiretroviral regimens
- To identify factors that can affect adherence to antiretroviral regimens
- To describe the strategies and proactive measures that counsellors and other care providers can adopt to improve or facilitate antiretroviral adherence

#### INTRODUCTION

The development of antiretroviral therapy (ART) marks a turning point in the management of the HIV/AIDS epidemic. The use of these medications has dramatically reduced HIV-associated morbidity and mortality. Very high levels of adherence are a prerequisite for a successful immunological response. Low adherence increases the risk of treatment failure and disease progression. A more significant consideration is the fact that low adherence is likely to lead to further transmission of resistant viruses. This is a strong indicator of a highly negative impact on the cost-effectiveness of HIV management.

#### LIFE-CYCLE OF HIV AND ACTION POINTS FOR ANTIRETROVIRAL AGENTS

Understanding the life-cycle of HIV, as it infects the human system, helps in comprehending the action of ART on the body.

As the virus enters the bloodstream, the virus is attracted by the lymphocytes, which mature in the thymus and bear the CD4 molecule on their surface. The virus binds to the CD4 receptor via its outer glycoprotein Gp120 cover and enters the cellular cytoplasm, where it uncoats and sheds its envelope. Viral RNA and the unique enzyme **reverse transcriptase** become active and facilitate the conversion of viral RNA into DNA known as proviral DNA. The proviral DNA then replicates (creates a mirror image of itself) and, with the help of the enzyme **integrase**, integrates with the host genome and becomes a part of the host cell. Once the DNA enters the nucleus of the infected cell, it goes on multiplying and producing messenger RNA (mRNA)

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along with the multiplication of the nucleus of the host cell. This mRNA directs the machinery to produce new viral particles, which develop into new virions with the help of an enzyme called **protease**. These virions then bud off from the cell and affect other cells with CD4 receptors. Thus, one infected cell turns into a factory churning out billions copies of the human immunodeficiency virus (HIV).

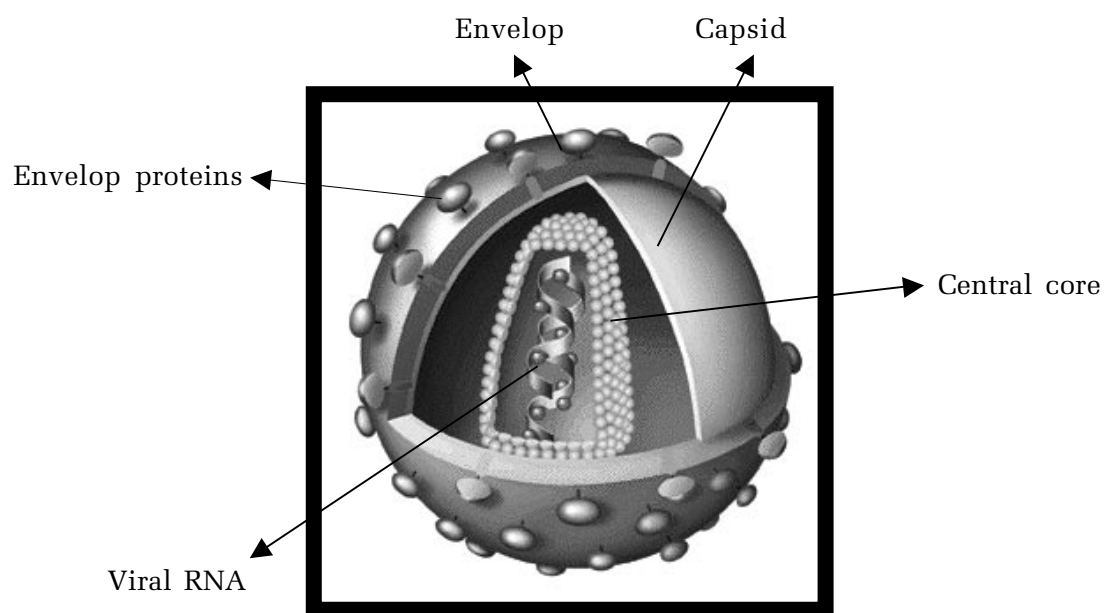
### STRUCTURE OF HIV

- Central core of viral RNA
- Surrounded by a viral capsid
- Envelop is the outermost membrane
- Envelop is studded with two envelop proteins (antigens) Gp41 and Gp120, which are important in pathogenicity.
- Core protein antigen is called p24, which is detectable early in the infection.

Based on the life-cycle, the possible targets for ART are:

- Blocks binding of HIV to the target cell
- Blocks the cleavage of viral RNA
- Inhibits the reverse transcriptase
- Blocks the enzyme integrase
- Prevents the production of viral protein
- Blocks the enzyme protease
- Inhibits viral budding

Antiretroviral drugs (ARVs) act on various stages of the life-cycle of HIV on the human body. These drugs act by interrupting the process of replication of the virus



and hence reduce the destruction of CD4 cells. These drugs are therefore instrumental in delaying disease progression. ARVs have improved and lengthened the lives of thousands of patients fighting the disease.

### Classification of antiretroviral drugs

All patients on ART may not experience lasting benefits. There are several reasons for treatment failure, including an individual characteristics such as gastrointestinal conditions that interfere with response to medications, dosing errors by physicians, existing resistance to a medication or inability to adhere to the treatment regimen.

**Table 5.1** Classification of antiretroviral drugs

Nucleoside reverse transcriptase inhibitors (NRTIs)	Non-nucleoside reverse transcriptase inhibitors (NNRTIs)	Protease inhibitors (PIs) 3000
Zidovudine 750	Nevirapine 800	Saquinavir
Lamivudine 550–600	Delavirdine	Ritonavir 3500
Stavudine 550–600	Efavirenz 2180	Indinavir
Didanosine 1200		Amprenavir
Zalcitabine (ddC)		Lopinavir
Abacavir 5000		Nelfinavir

### What is resistance?

HIV is 'resistant' to a drug if it keeps multiplying rapidly while the patient is on ART. Changes (mutations) in the virus cause resistance. HIV mutates almost every time a new copy is made. Not every mutation causes resistance. Antiviral drugs control most types of the virus. However, they will not control resistant virus. It can 'escape' from the drug. If the client keeps taking the drug, the resistant virus will multiply the fastest.

The best way to prevent resistance is to control HIV by taking strong antiviral medications. However, if the patient misses doses of medication, HIV will multiply more easily. More mutations will occur; some of them could cause resistance.

### Types of resistance

There are three types of resistance:

- Clinical resistance: HIV multiplies rapidly in the body even though the patient is taking antiviral drugs
- Phenotypic resistance: HIV multiplies in a test tube when antiviral drugs are added
- Genotypic resistance: The genetic code of HIV has mutations that are linked to drug resistance

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#### **Viral resistance**

When patients take their medications irregularly, or when providers prescribe inappropriate doses or combination of medication, the virus is exposed to inadequate (subinhibitory) concentrations of ARVs. This leads to ongoing viral replication and to the development of resistance to ARVs. Resistance to antiretroviral medication is a major cause of treatment failures.

The critical problem is the issue of '**cross-resistance**'. Once the virus becomes resistant to a particular antiretroviral medication, the virus may also exhibit resistance to other medications of the same class that have not yet been prescribed to that patient. This limits the choice of drugs available to replace the failing regimen. For example, resistance to nevirapine would mean that the patient cannot use other NNRTIs such as delavirdine (Rescriptor) or efavirenz (Sustiva).

The second issue with viral resistance is that **resistant strains of the virus can be transmitted**. It has been seen that some patients diagnosed for the first time with HIV, who have never taken ARVs, are already resistant to some antiretroviral medications. It is important for patients to take their medications regularly and correctly, to avoid the emergence of resistance.

#### **Disease stage**

A discussion of past history and severity of OIs in the patients will help to understand the importance of adherence to treatment. It should be emphasized that progress of the disease can be delayed with treatment if taken regularly and correctly.

The modified WHO staging for HIV infection and disease uses clinical and laboratory staging to determine disease stage. This staging has been used to predict the progress of the disease to stage IV. The predicted time for disease progression from stage III to IV is about 2 years and the estimated survival for patients in stage III and IV is 3.7 years and 1.7 years, respectively. Even among patients with the advanced disease, care must be taken not to discourage them with prediction of life expectancy.

When started on time, ART delays disease progression and death. When started very late in the disease process, medications may not be able to control disease progression.

#### **CD4 counts**

It is important to discuss the CD4 cell count with patients. The discussions should cover the following points:

- CD4 cell counts are a measure of the patient's immune status
- HIV attacks CD4 lymphocytes

**CD4+ T cell counts**

- CD4 cells are lymphocytes with CD4 receptors that play a critical role in the function of the immune system to fight off infections. They are also called T cells.
- The virus is particularly attracted to CD4 cells and destroys them, thus lowering the body's immunity against infections. Measuring the number of CD4 cells in the body is one method of determining how well the immune system is functioning. A person with a normally functioning immune system has between 600–1200 CD4 cells.
- When CD4 counts fall to below 200, patients who have HIV infection and are not on preventive medications may develop a host of opportunistic infection (OI), PCP–AIDS (related pneumonia, recurrent herpes zoster, fungal infections, cancerous skin lesions, etc.)
- Treatment with antiretroviral medications reduces the number of virus in the body and thereby decreases the destruction of CD4 cells. With successful treatment, CD4 cell counts increase, restoring immune function and patients experience fewer or no OIs. CD4 cell counts can rise anywhere from 50 to 150 cells to more with successful treatment. This rise may take several months as it depends on how severely the patient's immune system has been affected at the start of the treatment.
- Patients with CD4 cell counts at or below 200 cells/cm<sup>3</sup> are eligible to receive antiretroviral medications (these guidelines are subject to revision).

- Lower CD4 counts signify advanced HIV disease
- CD4 cell counts increase with treatment

Lower CD4 counts are associated with an increase in the number of episodes of OIs and continued disease progression. Higher CD4 counts indicate a lower risk of OIs and improved health status. Patients should know their CD4 cell count and monitor how it changes with treatment. Knowledge about the disease improves levels of adherence to treatment.

**Viral load**

NACO does not recommend viral load test among patients on ART. It is desirable to discuss the viral load with patients even when it may not be available for routine monitoring. The discussion should cover the following points:

- Viral load measures the amount of HIV in the blood
- Higher viral load levels signify increased risk of transmitting infection
- Treatment with ART results in viral load reduction
- Patients start to feel better when the viral load decreases

The patient should understand how viral load measurements change in response to effective treatment.

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#### **Viral load**

- Viral load tests measure the amount of HIV virus in the bloodstream. If the viral count is high, it means that the virus is in a period of greater activity, replicating (producing copies of itself) and further infecting new cells.
- Viral load tests, when available (they are very expensive and require advanced laboratory facilities), are used to determine the need for therapy and assess prognosis.
- Successful treatment with highly active ART (three-drug cocktail) should result in a reduction in the viral load. The viral load should/can go down 10-fold in the first eight weeks and then further to undetectable levels in 16–20 weeks.
- The rate of viral load decline is affected by the baseline CD4 cell count, initial viral load, potency of the regimen, adherence to treatment, prior antiretroviral medication use and the presence of OIs.
- Viral loads tend to be the highest during initial acute HIV infection (acute HIV syndrome) and in advanced disease.

## **SIDE-EFFECTS OF 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.

### **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 higher blood levels and maybe more side-effects.

Patients should be taught to deal with side-effects:

- 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 gotten 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 dose, without talking to the doctor. Doing so can allow the virus to develop, and might lose the use of some antiviral drugs

### **Which side-effects are the most common?**

Dealing with drug side-effects can be a challenge to every doctor. Every anti-HIV drug, as well as drugs that prevent and treat infections, has its own set of possible

effects. These may vary from one person to the next. Some people experience few or no side-effects at all, while some experience mild and manageable side-effects. Others have severe side-effects.

- **Fatigue** is tiredness that does not go away when the patient rests. It can be physical or psychological.
- **Depression** is more than just feeling sad. Chemical changes in the brain can cause fatigue and a lack of interest in daily activities.
- **Diarrhoea** is usually caused by an infection in the stomach or intestines. Bacteria, parasites, fungi, or viruses can cause the infection.
- **Lipodystrophy** is a condition when a collection of changes in body shape occur in people taking anti-HIV medications.
- **Skin problems:** Some medications cause rashes. Most are temporary, but in rare cases they indicate a serious reaction.
- **Peripheral neuropathy** is a disease of the nerves. The peripheral nerves are all the nerves except for the brain and spinal cord.
- **Anaemia** is low red blood cells.
- **Nausea and vomiting** are common symptoms found among patients on ARVs.
- **Weight loss** can be a serious problem in HIV disease. It can result from some of the side-effects discussed in this section such as vomiting, nausea, dry mouth, anemia or fatigue.
- **Dry mouth** can result from taking certain medications.

Before starting any therapy, discuss possible side-effects with the patients. 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.

## THE NEED FOR GUIDELINES ON ADHERENCE

Adherence is defined as a patient's ability to follow a treatment plan, take medications at prescribed times and frequencies, and follow restrictions regarding food and other medications. Both patients and health-care providers face significant challenges with respect to adherence to ART. Once initiated, ART is a life-long treatment that consists of multiple medications to be taken two to three times a day with varying dietary instructions. These medications have side-effects, some of which may be temporary while others may be more permanent requiring a change of treatment. Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of OIs and poorer health outcomes.

In the past one-and-a-half decades, lessons learnt have indicated an increasingly central role of adherence to the success of ART. Care and support services that have

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a component of ART have also included adherence support as part of their clinical services. While the importance of adherence to achieving success in treatment is acknowledged in treatment guidelines, our understanding of factors associated with high and low adherence seems to have lesser clarity.

#### **SIGNIFICANCE OF ADHERENCE TO ART**

Adherence has been rightly called the ‘Achilles’ heel’ of ART. The consequences of low adherence are serious for the individual, for public health and for the optimal use of limited health-care resources. For the individual, lower levels of adherence are associated with the development of viral resistance, treatment failure and increased risk of disease progression. The prognosis for individuals who have experienced multiple treatment failure is uncertain.

From a public health perspective, an increase in the prevalence of resistant virus as a result of low adherence is likely to result in an increased transmission of the resistant virus to newly infected individuals. Acquired resistance has a negative impact on subsequent ART response.

#### **CHALLENGES IN TAKING ART**

ART consists of three or more antiretroviral medications to be taken in combination. In addition to ARVs, patients also have to take medication for treatment or prevention of OIs. In addition, some ARVs also require specific food and fluid restriction.

Antiretroviral medication controls the replication or multiplication of HIV. Even when the virus becomes undetectable in the blood with successful ART, there are some sites in the body where drugs are unable to reach the virus. These sites are called sanctuary sites. Therefore, the virus cannot be completely eradicated from the body and continues to remain hidden in these sanctuary sites. The virus emerges when ART fails or is stopped. As the virus cannot be eradicated, ARVs have to be taken regularly, long-term, for the rest of the patient’s life. HIV infection can therefore be managed but not cured.

#### **IMPORTANT FACTORS THAT PREDICT HIGH ADHERENCE**

The optimal time to begin ART remains a controversial issue and expert opinion on the matter is divided. Various factors have a role to play in fostering and maintaining high adherence.

Patients themselves have the most fundamental role to play. Low adherence does not restrict itself to social class, age or gender but is widespread and largely unpredictable. Moreover, adherence rates vary not between individuals but also within the same individual over time. Cultural and socioeconomic factors influence

adherence to medication. Religious beliefs about illness and medication impact adherence. Processes of socialization and imbibed values often promote the idea of placing the health-care needs of others before one's own requirements. This is often seen in India, especially in cases where both partners may be infected.

The mental health status of the individual is an important factor determining the level of adherence. High levels of stress and depression negatively impact adherence. One's own perception of the disease is also a significant contributor. Experience indicates that people who believe that they have the ability to survive tend to show better adherence.

Given the fact that low adherence is widespread and largely unpredictable based on demographic characteristics, withholding treatment on the grounds of assumptions about an individual's adherence behaviour is highly unjustifiable. Access to ART and adherence support services need to be provided to all patients.

The move from the word 'compliance' to the word 'adherence' in the latter part of the 1990s relates to the recognition that successful therapeutic outcomes are reflections of an effective partnership between the clinician and the patient as opposed to expectations from the patient to submit to demands from their doctors. This fact has also given recognition to the multidisciplinary approach in HIV/AIDS therapeutics. The appropriate use of skilled professionals allied to medicine contributes significantly to successful therapeutic outcomes.

Requirements enforced by chosen regimens contribute to effective adherence to treatment. Regimens that fit in and around an existing lifestyle are more likely to be adhered to than regimens that require substantial changes in the daily routine. Additional adherence factors relating specifically to regimens include the potential for harmful drug interactions and side-effects. The influence of side-effects causes practical problems such as missed doses due to nausea, vomiting, diarrhoea or at times, even fatigue causes people to sleep through dosage timings.

### **ROLE OF COUNSELLORS IN PREPARING THE PATIENT FOR ART**

Patient preparation is an important step that goes a long way in getting patients to take treatment correctly as prescribed over a long term. Preparation includes the initial assessment of the patient and can be done over three to four visits before initiating ART.

The preparation process is important for both patients starting treatment for the first time (treatment-naïve) as well as those who may have used ARVs in the past (treatment-experienced).

For treatment-naïve patients, the preparation process helps patients

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- To understand the challenges of taking ART
- To think about the impact the treatment will have on their lives
- To make a commitment to long-term treatment

For treatment-experienced patients, the preparation process helps patients

- To re-evaluate their commitment towards treatment
- To identify potential and actual barriers
- To address these barriers and adhere to treatment

The Health Belief Model of behaviour change is based on the theory that patients usually perceive a threat to their health (in terms of severity and susceptibility) and expect certain outcomes before they adopt new behaviours and develop the self-efficacy to make the change. Based on this theory, the process of behaviour change in a person is thought to have five stages.

- Pre-contemplation:** When the patient is unaware or not interested in changing behaviour,
- Contemplation:** When the patient thinks about behaviour change,
- Preparation:** When a patient actively decides to change,
- Action:** When the patient works towards changing behaviour, and
- Maintenance:** When a person is able to sustain behaviour change for more than six months.

### PREPARATION OF THE PATIENT

The preparation process works on the principles described below. It gives patients the time to understand their disease and its severity, and to understand the need to take medications to gain health benefits. It helps the patient to make a commitment to take treatment regularly and correctly in order to achieve the desired health outcomes. The preparation process helps to empower patients before starting treatment.

#### Establishing trust between the patient and the provider

The first step in preparing the patient is to establish trust. This is an ongoing process that is strengthened over time. An assurance of confidentiality, a non-judgemental attitude, mutual respect and clear communication of information contributes greatly to developing a trusting relationship between the provider and the patient.

#### Introducing to the treatment and adherence programme

A discussion about the ARV programme, health facility, medication availability, laboratory facilities and support services helps to familiarize the patient with the treatment programme. An introduction to the staff providing services and

**Establishing a treatment plan**

- A discussion about the treatment regimen should cover the following points: medication names, dosing instructions, food and fluid intake requirements, and storage of medications. It is extremely important for the patient to know and understand their treatment regimen to enable them to take an active role in managing their HIV disease.
- A discussion about potential side-effects and ways to manage them; when to seek care and how to contact providers should be included. Preparing the patient in advance about the side-effects, that they might expect to see, removes the surprise or fear and prevents patients from stopping medications on their own.
- A discussion on the plan for routine follow-up should be included. Counsellors should establish a contact system so that patients can contact the provider in the case of need, medication side-effects, illness, psychosocial problems, etc. Providers may also need to contact the patient in case of missed appointments. Telephone numbers and addresses should be exchanged. Patients should be encouraged to discuss their travel plans in advance so that extra medications can be issued.

familiarizing the patient with the clinic layout are important steps in putting the patient at ease.

It is important to emphasize that disease progression can be delayed with treatment, if taken regularly. Patients should be given a positive message. Patients who have adhered well to their treatment are in good health more than a decade after they started treatment.

**Assessing the patient’s health status**

Learn about the patient’s health through a detailed medical history. This includes an assessment of the general health status, past illnesses and hospitalizations, and mental health. Patients who have experienced serious infections or hospitalizations may perceive their illness as serious and adhere better to treatment. Patients with severe mental illness may need help with taking medications regularly.

**Overall health**

A discussion on the overall physical and mental health status, ability to be in control of their lives, and ability to conduct routine daily activities sets the stage for a discussion on the importance of taking medications regularly. A detailed medical history forms the basis for understanding some of the barriers to adherence.

**What patients can expect to see with treatment**

A discussion on the changes in the CD4 counts and viral load measurements with successful treatment should be included. Emphasize the connection between regular

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and correct medication-taking with improving immune function, improvements in general physical conditions, weight gain, fewer OIs and slowed progression to AIDS.

#### **The importance of adherence**

Preparatory counselling should emphasize the importance of adherence to treatment to achieve viral load suppression and success in treatment. Patients should understand the link between regular intake of medication or higher adherence with a decrease in the viral load, increase in CD4 cell counts and success in treatment. Consequences of non-adherence, such as ongoing increase in the viral load, decrease in CD4 cells and immune function, and disease progression should be discussed. The counsellor should emphasize the need for taking every dose every day and correctly with respect to time intervals and dietary instructions. A twice-daily dose is to be taken 12 hours apart, a thrice-daily dose is to be taken eight hours apart, etc.

#### **Prior use of ARVs**

A discussion on prior use of ARVs and experience with adherence to treatment is important. Patients with prior adherence problems or irregular use of ARVs would need added support and counselling.

A counsellor should get information on other medications that the patient may be taking to assess drug interactions and side-effects.

#### **Patient's beliefs and attitudes**

Learn about the patient's beliefs and attitudes towards HIV and treatment. Positive attitudes and beliefs support adherence. Patients who believe that treatment is beneficial, are able to make a commitment to long-term treatment, and are confident that they will be able to take medications correctly and regularly, and tend to adhere to better treatment.

#### **Social support and socioeconomic situation**

The initial assessment and preparation should include a discussion on the sources of social support for the patient. Does the patient live alone or with their family? Have they disclosed their HIV status to the family? Does the patient have a friend or a family member that they expect support from? The discussion should include sources of support from outside the family such as non-governmental organizations (NGOs), people living with HIV/AIDs (PLHA) support groups, religious or faith-based organizations or workplace programmes, etc.

Learn about the socioeconomic situation of the patient: housing, employment and income, number of dependent family members, migrant status, living conditions—

factors that may influence regular and correct intake of medications.

It is important to discuss the patient's daily routine (employment, work timing, eating and sleeping patterns), HIV confidentiality issues at place of work and at home, medication storage and travel plans so as to identify areas where patients may have problems and need support. An understanding of the patient's daily routine and lifestyle helps to better integrate medication intake into the daily routine. Treatment reminder cues can be identified based on the patient's daily routine. Treatment reminder cues include typing medication intake to mealtime or specific routine activity such as leaving for work, notes written to oneself and placed at strategic points in the house, medication kept at a strategic location in the house.

## **PRE-ART ADHERENCE COUNSELLING**

### **First counselling session**

It is important to assess the patient's knowledge of HIV/AIDS, clear misconceptions and educate them and, if required, their families on HIV/AIDS. Information should be provided that HIV is a virus, that there are different routes of HIV transmission, immune system weakens over time, OIs can occur, how healthy living practices can strengthen the immune system (e.g., good nutrition, exercise, rest, social support, positive attitude toward life). This is similar to the pre-test information provided at the VCTC or PPTCT.

### **Issues relating to ART that need to be addressed are:**

- ART is not a cure but a treatment that suppresses the virus and improves the immune system
- ART does not prevent transmission of the virus hence behaviour change and safe behaviours need to be adopted
- Regular clinical follow-up and laboratory investigations would be required
- Adherence to the medication regime is important
- Potential barriers to adherence need to be identified
- General side-effects of ART and how to manage them
- Other health-related (physical or mental) aspects
- Issues related to substance use (alcohol, illicit drugs)
- Diet and Nutrition
- Financial difficulties
- Support services that may be required
- Answers to questions the client may have
- Follow-up visits need to be planned

Other important issues are disclosing the status to family and preparing the guardian to participate in treatment.

### **Follow-up counselling session**

Follow-up sessions at regular intervals help provide appropriate information, clarify misinformation, and re-emphasize the need to adhere to treatment. Review the topics discussed during the previous counselling session—HIV/AIDS, ART and the importance of adherence. It is important to discuss the role of family as the primary care-provider and its support in ART adherence.

It is important that patients understand names of each medication, dose and time of medication; dietary needs, and tests as prescribed by the doctor. Patients should be helped with developing strategies to adhere to medication such as using a monthly date calendar to mark medication intake, using symbols like the sun indicating morning and the moon night marked on the envelope with medicines to indicate time to be taken, or help identify time (e.g. using a title song of a TV serial) to indicate time to take medicine.

In families where one patient receives medication, patients may choose to share the same with their spouse or partner. Patients need to understand the importance of taking the complete dose prescribed to them.

Patients should be encouraged and instructed to report any serious adverse effects to the physician immediately. Emergency services and how to access them should also be explained. The preparation process should empower clients to understand the need to take medications to achieve health benefits. It helps the patient to make a commitment to take treatment regularly and correctly, to achieve the desired health outcomes.

The counsellor should maintain notes of each session by maintaining a diary, or by developing formats for the same. Counselling for adherence is an ongoing process and patients would require counselling throughout their life. Patients should be assessed on adherence to the medications, side-effects should be identified and if required appropriate referrals should be made. Obstacles or barriers to adherence and strategies to overcome them, emphasis on HIV prevention to reduce the risk of transmission or re-infection with the virus needs to be discussed.

### **STRATEGIES AND TOOLS TO ENHANCE ADHERENCE**

Perhaps the greatest way that adherence in HIV therapy differs from adherence in other chronic illness is the lack of immediate symptoms or consequences when adherence fails. This lack of rapid response places most of the responsibility for adherence on the mind and, less so, on the immediate reactions of the body. Multidisciplinary modalities and support systems are really the only feasible solution. The strategies and tools listed below are not exclusive and definitely do not function in isolation. Each individual patient will finally require a tailor-made strategy.

**a. Counselling**

Counselling forms the mainstay of any treatment programme. Counselling aims to improve patient's knowledge about the disease, the medications and its side-effects. Counselling helps the patient to set goals, to develop positive beliefs and perceptions and to increase self-efficacy. In addition to counselling, patients often need other forms of support to be able to adhere to treatment. Adherence tools are helpful for many patients.

Since the patients themselves are the fundamental factor influencing adherence, the involvement of the individual is of key significance.

- Patient education involves information about the disease itself and the need for ART.
- Reviewing written information with each patient, describing technical terms in simple language and asking patients to repeat instructions may be helpful. Efforts should be made to avoid uncomfortable situations where the patient's lack of or lower levels of literacy are revealed. This encourages a sense of trust in the provider and self-efficacy in the patient.
- It is essential to avoid promoting ART as the 'miracle' drug, especially in conditions that operate within the health framework of India.
- Initiating ART is not usually an emergency. It helps to give enough time for evaluation of the patient's knowledge, understanding and attitude towards therapy.
- Identifying concerns and misconceptions helps in the involvement of the individual in the treatment process.
- Initiation of ART must be preceded with evaluation of the motivation and commitment of the patients to treatment.
- Assessment and management of mental health factors before initiation and at regular intervals is essential. All care providers must be aware of and alert to signs of depression and/or psychological distress in patients.
- An understanding of the patient's lifestyle and daily routine are essential to help them plan drug timings, prompts, etc., e.g. a person's daily television programme could be an effective cue for medication.
- The manner in which environmental and social factors influence adherence should be assessed regularly. Such factors include housing, employment, relationships, and drug and alcohol use. It is important for health-care workers to obtain the wider involvement of local, non-government as well as community-based organizations to enhance support networks for PLHA.
- Wherever possible, undergoing a 'dry run' using placebos instead of medications may be useful in identifying possible barriers to optimal adherence.
- Every patient prescribed ART must have their adherence measured and recorded on regular clinic visits.
- Patients may require help in planning ahead for weekends, vacations, etc. Encourage patients to get a refill of their medication a few days before their

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medications are to get over. This ensures that the patient will not lose out on doses due to lack of stock.

- Patients will also need help in issues of self-disclosure. Privacy requirements in taking medication must be discussed and planned.
- Encourage patients to maintain a daily diary or journal in which they take notes of all that is important to them. For example, when was treatment initiated; feelings towards the disease; issues and routine difficulties, etc. Encourage patients to use recorders/planners for marking doses taken/missed, etc.

#### **b. Pillboxes**

Pillboxes are containers for storing medication with dividers for each day and each dose within the day. This makes it easy for patients to take doses correctly. Pillboxes with electronic reminders are also available. Some pharmacies in the west even distribute pre-loaded pillboxes. A possible disadvantage of the pillbox in developing country settings may be its visibility in situations where patients need to hide medications from others due to confidentiality reasons. Patients who are illiterate or very sick may need help to fill the pillboxes correctly.

#### **c. Electronic devices**

Many treatment programmes in developed countries use electronic devices to enhance adherence to medications. Devices range from beepers to alarms to watches that remind patients to take medications on time. Electronic pagers that are linked to the internet are used to send messages to patients. Electronic devices need to be discreet to avoid stigma and confidentiality related issues. These tools may not be practical in developing country settings. MEMS can be used both to measure adherence as well as a reminder tool for patients.

#### **d. Telephone reminders**

Telephone reminders are being tried out in some studies on adherence. There are several limitations to its use: it is labour intensive for staff, patients must have a telephone at all times and cost issues. Internet based confidential reminder services are also being used.

#### **e. Medication diaries**

These are diaries in which patients record the time and date of medication intake, missed doses and reasons for missed doses. These can serve as useful records of side-effects or other problems patients may experience. This is a useful tool to identify patterns of use and reasons for missing doses.

#### **f. Buddy system**

The Buddy system relies on a friend or family member to help the patient to take medications regularly—reminding the patient to take his medication on time, offering

encouragement to keep going, helping to keep hospital appointments, providing support, etc.

### **g. Pill charts**

Pill charts are used to visually display pills (colour and shape), names and dosage for each medication and are used by the nurse or health provider during counselling. This is a useful tool for patients with literacy problems. All the strategies outlined above serve as 'enablers' for patients, helping them to receive their treatment.

### **h. Directly Observed Therapy (DOT)**

DOT is an intensive strategy in which patients take their medication under the supervision of adherence staff. In TB DOTS, health workers observe the intake of all medication doses for the entire treatment period of 6–9 months. TB DOTS is more regimented and provides a tighter monitoring of medication intake. In the case of ART, it is not practical to observe all doses as most HAART regimens have multiple doses and treatment is lifelong. Therefore, only some doses are observed for a fixed period of time (a few months). In some countries, this is called modified DOT or directly administered antiretroviral therapy (DAART). Modified DOT can be done at health centres, in community-based organizations or even at patient's home. In the management of HIV infection, a modified DOT strategy, through frequent patient-provider contact, is used as a behavioural intervention that helps patients

- to develop an understanding of the treatment;
- to develop good treatment taking behaviour;
- to receive support during the first few weeks of ART when patients have short term side-effects; and
- to develop a trusting relationship with providers.

### **i. Incentives**

Several programmes in the USA use incentives such as telephone cards, transport and food coupons, shopping coupons, movie tickets, tickets to sports events, etc. to increase effectiveness of ART intake.

#### **Adherence is a dynamic behaviour**

- Adherence levels change over time.
- Adherence is determined by a matrix of inter-related factors that shift over time. No factor stands alone.
- Adherence requires an integrated, multidisciplinary approach: physicians, nurses, counsellors and pharmacists.
- Adherence requires a combination of adherence promoting strategies.

**Module 5 • Submodule 1**

Antiretroviral therapy: Counselling and medical aspects

**Adherence from pill counts**

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

Name of medication	Number of pills dispensed	Number of pills patient expected to have taken (A) (take into account whether patient has come early, on time or after the refill due date)	Number of pills patient actually took (take into account remaining pills and whether patient has come early, on time or after the refill due date)	Number of pills missed (B)	% Adherence $\frac{A - B}{B} \times 100$
E.g. d4T one tablet taken twice daily	60 (for 30 days)	54 (patient came in 3 days early)	50 (10 pills remaining when they should have been only 6)	4	$\frac{54 - 4}{54} \times 100 = 92.5\%$

Adherence could be <100% when patients have taken fewer pills than required or >100% when they have taken extra pills by mistake.

**Adherence from self-report**

Adherence measured using a self-report will only reflect the adherence over the period of recall, e.g. 3 days in the table below.

Patients should be asked about missed doses: How many doses of d4T did you miss yesterday, the day before that and the day before that (3 days ago)?

$$\% \text{ Adherence} = \frac{\text{Number of doses patient should have taken} - \text{number of doses missed}}{\text{Number of doses patient should have taken}} \times 100$$

Name of medication	Yesterday (missed doses)	Day before yesterday (missed doses)	The day before that (3 days back) (missed doses)	% Adherence $\frac{6 - \text{missed}}{6} \times 100$
E.g. d4T one tablet taken twice daily	0	1	1	$\frac{6 - 2}{6} \times 100 = 67\%$

**Antiretroviral drugs, main adverse reactions and follow-up action/tests**

Drugs	Adverse reactions	Follow-up action/test
<b>1. Nucleoside reverse transcriptase inhibitors (NRTIs)</b>		
(i) Zidovudine (3 azido-2, 3 dideoxythymidine)	<ul style="list-style-type: none"> <li>• Initial headache and nausea (usually temporary)</li> <li>• Anaemia, leucopenia (neutropenia)</li> <li>• Myopathy</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Blood count</li> <li>• CPK</li> </ul>
(ii) Didanosine (2,3 dideoxyinosine)	<ul style="list-style-type: none"> <li>• Gastrointestinal disturbance</li> <li>• Polyneuropathy (long-term treatment)</li> <li>• Pancreatitis</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Clinical examination</li> <li>• Amylase</li> </ul>
(iii) Lamivudine	<ul style="list-style-type: none"> <li>• Nausea, vomiting</li> <li>• Polyneuropathy</li> <li>• Ulcerative stomatitis</li> <li>• Pancreatitis</li> </ul>	<ul style="list-style-type: none"> <li>• Liver function tests (LFT)</li> <li>• Clinical examination</li> <li>• Clinical examination</li> <li>• Amylase</li> </ul>
(iv) Zalcitabine (2,3 dideoxycytidine)	<ul style="list-style-type: none"> <li>• Peripheral polyneuropathy (common)</li> <li>• Abnormal LFT</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Clinical examination</li> <li>• Amylase</li> </ul>
v) Stavudien (2,3 didehydrodidoxy- thymidine)	<ul style="list-style-type: none"> <li>• Pancreatitis (rare)</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Liver enzymes</li> <li>• Amylase</li> </ul>
<b>2. Non-nucleoside reverse transcriptase inhibitors (NNRTIs)</b>		
(i) Nevirapine	<ul style="list-style-type: none"> <li>• Skin rash (common)</li> <li>• Elevation of the level of liver enzymes</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Liver enzymes</li> </ul>
(ii) Delavirdine	<ul style="list-style-type: none"> <li>• Skin rash (common)</li> <li>• Abnormal LFT</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Liver enzymes</li> </ul>
<b>3. Protease inhibitors (PIs)</b>		
(i) Indinavir	<ul style="list-style-type: none"> <li>• Nausea, gastrointestinal disturbances, headache, dry skin</li> <li>• Elevation of the level of bilirubin</li> <li>• Kidney stones/flank pain</li> <li>• Diabetes mellitus (rare) (Glucose, erythrocytes)</li> <li>• Haemolytic anaemia (rare)</li> <li>• Liver dysfunction (rare)</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Bilirubin</li> <li>• Urinary dip tests</li> <li>• Clinical examination</li> <li>• Liver enzymes</li> </ul>
(ii) Ritonavir	<ul style="list-style-type: none"> <li>• Nausea, gastrointestinal disturbances</li> <li>• Paresthesias</li> <li>• Elevation of the serum levels of liver enzymes, urate— glutamyltranspeptidase (GT), creatine-kinase (CK), triglycerides</li> <li>• Gastrointestinal disturbances (around 20% of patients)</li> </ul>	<ul style="list-style-type: none"> <li>• Clinical examination</li> <li>• Clinical examination</li> <li>• Analysis of serum levels of: Liver enzymes, urate,</li> <li>• Analysis of glucose in the urine</li> <li>• Clinical examination</li> <li>• Analysis of glucose in urine</li> </ul>
(iii) Nelfinavir	<ul style="list-style-type: none"> <li>• Hyperglycemia and lipodystrophy</li> </ul>	<ul style="list-style-type: none"> <li>• Liver enzymes</li> </ul>



## **Module 5**

### **Submodule 2: The purview of counselling in HIV/AIDS home-based care**

#### **Session objectives**

At the end of session trainees will be able to:

- To understand the background and scope of home-based care as a methodology in the management of HIV/AIDS
- To understand the objectives of home-based care
- To understand the special counselling requirements in the spectrum of home-based care services
- To understand the outcomes of home-based care

#### **INTRODUCTION**

Home-based care as a methodology to health promotion was initially popularized in the mid-1900s. This approach has been widely used in the management of chronic health conditions. The magnitude and nature of the HIV/AIDS epidemic has made health-care providers, governments and international agencies consider home-based care as one of the most feasible and cost-effective systems for the management of HIV/AIDS.

Home-based care is an approach to care provision that combines clinical services, nursing care, counselling and social support. It represents a continuum of care from the health facility to the community, family and the individual infected with HIV/AIDS and back again. The component of counselling in this continuum is particularly important given the emotional and spiritual upheavals the disease causes. It is of utmost importance to remember that 'care' in the home-based care does not end when a person succumbs to the disease, and is extended to the survivors, especially children.

Home-based care as a methodology has a wide perspective. It helps change attitudes towards PLHA and towards the disease itself. Home-based care recognizes that a diagnosis of HIV does not necessarily mean that death is at hand. It helps reduce the stigma attached to the disease. Home-based care as a methodology helps provide the support that will help HIV-positive persons to extend their productive lives for many years.

The disease of HIV/AIDS as of today remains without a cure and without a vaccine,

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### The purview of counselling in HIV/AIDS home-based care

and is ultimately fatal. Prevention efforts are yet the backbone of the management of this epidemic. It is here again that home-based care has an important role to play. When an entire community is involved in the process of care, it increases not only the community's access to care but also enhances the process of involvement in prevention activities.

### THE RATIONALE AND MEANING OF HOME-BASED CARE

The worldwide increase in the number of people infected with HIV and number of people developing AIDS calls for partnerships among family members, health-care workers, local communities, community-based organizations (CBOs), NGOs and the persons themselves in providing care and support to those infected and affected by the HIV /AIDS epidemic. Home-based care systems are being developed the world over as the best options for PLHA. Home-based care is a holistic collaborative effort between the health-care facility, the family and the community to enhance the quality of life of PLHA and their families.

#### Objectives of home-based care

- To facilitate a continuum of care and support to PLHA extending from the health-care facility to the home and family
- To promote family and community awareness of HIV/AIDS prevention and care
- To empower PLHA, the family and community with the knowledge needed to ensure long-term care and support
- To reduce stigma and discrimination associated with HIV/AIDS within families as well as communities
- To create an effective network of referral services from institutional health-care facilities and into the community, and from communities to adequate health set-ups as required
- To develop home-based care as the vital link between prevention and care
- To mobilize both human and fiscal resources essential for the sustainability of the system

### THE INVOLVEMENT OF PLHA

Models that recognize the importance of the contribution made by PLHA are better able to respond to the epidemic and create a further space within society for the enhanced involvement of PLHA. Thus an active involvement of PLHA removes the long-held notion that they are passive recipients of care and support services. There are four levels of involvement of PLHA in community and home-based care programmes.

**(i) Access:** Use of the service

**(ii) Inclusion:** Working as support staff or volunteers, providing peer outreach or home visits.

- (iii) Participation:** Providing HIV/AIDS services either as volunteers or staff, using their experience and training
- (iv) Greater involvement:** Designing services and managing organizations, engaging in advocacy activities and public speaking

This kind of meaningful involvement helps in improving providers' attitudes and understanding of issues affecting PLHA and creates a more supportive environment.

### **THE COMPONENT OF COUNSELLING IN HOME-BASED CARE**

People with HIV/AIDS experience a variety of social support needs, psychological distresses and spiritual yearnings. These needs are felt in varying intensity throughout their lives. The phase when a person finds out his HIV status is a very difficult and sensitive stage. To a large extent, how the person will manage his life with HIV will depend on adjustments made during this stage. Support also needs to intensify during phases of illness. It has been seen that often, when people with HIV fall sick intermittently, it is not viewed as a phase of illness but rather as a progression of the disease which brings the end closer. Support needs are also very intense in cases when there is a loss of partner or one's child to the disease. Reduced income or employment comes as a major obstacle to the emotional and spiritual well-being as the HIV-positive individual may either be denied employment or be unable to generate income due to phases of ill health.

### **SPIRITUAL CARE**

Illness is a major life event that can cause people to question themselves, their purpose and meaning in life. It disrupts their careers, family life and the ability to enjoy life. Palliative care has long recognized that, in addition to physical and psychological symptoms, patients with chronic illness suffer existential distress with regard to the meaning of life, the fear of death and the realization of being separated from loved ones. These issues take on a larger significance in the context of HIV/AIDS due to the stigma and judgement that accompany PLHA. Clinical experience shows that people cope with suffering by finding meaning in it. Spirituality has a critical role to play, because the relationship with a transcendent being or concept can give meaning and purpose to people's lives.

Spirituality is recognized as a factor that contributes to health in many people. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family and humanism. All these factors can influence how patients and health-care professionals perceive health and illness and how they interact with one another. It is important that all members in a home-based care team accept and honour all approaches to existential concerns. This requires open-mindedness, cultural sensitivity and a willingness to learn from the life experiences of others.

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Much of medical training has to do with ‘finding a cure’ or fixing a problem. This may no longer be possible in chronic illnesses which have no known cures. To continue to care for patients when disease-specific therapy is no longer available is where spiritual care becomes so critical.

The basic principles of spiritual care are common to the principles of counselling and involve compassion and the ability to be present for the patient in the midst of their suffering. Although illness may disrupt a person’s life, it also offers an opportunity to see life in a different way. The role of counsellors is crucial in helping patients appreciate aspects of life they have never noticed before and to find new priorities that make life have a meaning and purpose.

It is important to include spiritual assessment or history as part of the overall clinical assessment of a patient. Doing so enables the provider to assess spiritual needs and resources, mobilize appropriate spiritual care and enhance overall care-giving. Assessment enables the inclusion of spiritual concerns into therapeutic plans. A high amount of vigilance is required on the part of health-care workers to avoid the imposition of their own beliefs. Once a spiritual assessment has been made appropriate interventions should be offered. While spiritual and religious interventions can be provided by clinicians and counsellors, including a pastoral care provider or religious leader into the health-care team ensures that the team becomes familiar with religious and spiritual issues. Some examples of spiritual practices are meditation, guided imagery, art, yoga, religious rituals and prayer.

### **SHARED CONFIDENTIALITY WITHIN THE LOCAL COMMUNITIES**

Home care is effective in reducing stigma. It builds the patient’s self-confidence, promotes involvement of the family, and enhances prevention. Successful home-care teams include not only professionals but also helpers and volunteers from the community and CBOs. Home-care teams are characterized by an expression of caring that is distinct from providing care. They are sensitive to the shared confidentiality that normally flourishes within close-knit local communities.

Shared confidentiality within groups frequently exists when potentially stigmatizing issues are at play, such as HIV, domestic violence and drug abuse. Matters of private significance to people, and their immediate family and friends, are often shared with other people in the immediate living environment. Confidential sharing is characterized by issue-centered confidentiality in this group context, rather than by person-centred confidentiality. Health-care workers in the field commonly come across such instances. The following case demonstrates this. The case is an excerpt from the home-based care team’s diary of the Kripa AIDS programme operating in the Vasai region of the Thane district in Maharashtra. The identifying details have been kept out of the case description.

Munshi, a young Koli (fisher community) man hails from a remote village in the Vasai region. The only way to access this village nestled within a fort is by boat. On the reference of his family physician, Munshi was brought to the centre by his family. The patient was examined and initial treatment was planned. In the following week, the team made its first visit to the home of the patient before officially registering him on the home-based care system. The community received them well and the team came back with the feeling that the community seemed to be aware of the patient's illness. However, no direct references were made. After a time, the patient did not turn up for his regular follow-up and the team went back to ascertain the health of the person and look into the cause of his failure to follow up. Even before the team reached the house of the patient they knew that the patient's lack of follow-up was due to his alcoholism. The community supported the patient through rehabilitation for his alcoholism and today he is back to fishing for a living along with the other men of his village. The Koli community is a close-knit community where secrets of a home are secrets of a village. Rapport-building here is not just with the patient and the family, but with the entire community.

### **DEALING WITH GRIEF AND BEREAVEMENT**

The experience of chronic, debilitating disease in loved ones and their death can be an experience of profound sadness and loss. The multidimensional responses to loss are all part of the grief process which is even more complicated with the association of HIV/AIDS to it. There are unique challenges and needs in the bereavement process for people coping with HIV/AIDS.

Grief is the normal dynamic process that occurs in response to any type of loss. This process encompasses physical, emotional, cognitive, spiritual and social responses to the loss. It is highly individualized depending on the person's personal perception of the loss and is influenced by context and concurrent stressors. PLHA and their caregivers often experience complicated grief reactions. There is usually a chain of reactions throughout the disease process right from the time the individual is informed about his seropositive status. Personal experience of symptoms, witnessing other people experiencing symptoms and societal and health-care worker responses all add to the complications in the grief process. Often enough, caregivers are also HIV-positive and are dealing with their own physical health issues as well as facing personal loss and witnessing the loss of loved ones.

When health-care professionals are trained to identify feelings of grief and bereavement in their patients, they are better able to facilitate this period by

- Identifying and legitimizing feelings of sadness, anger, guilt and anxiety
- Encouraging the expression of these feelings
- Redefining terms related to expressions of grief, such as 'lose control' or 'break

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### The purview of counselling in HIV/AIDS home-based care

down' can be reframed as 'emotional releases', which are normal expected aspects of coping with stress and grief

- Enabling people to complete unfinished business
- Encouraging people to live fully and enjoy life to the extent best possible

The process of going through grief is an active one and requires effort. It is a process of 'accommodation' and involves an adaptation to fit specific circumstances rather than a linear process with an endpoint. Thus, moving through grief requires the accomplishment of certain 'tasks' (for more information see Module 7 Submodule 11).

#### **1. Accepting the reality of the loss**

The first task of grieving is to acknowledge and accept the reality of the loss; the fact that the person is dead and will not return. This task takes times due to the numbness and shock often experienced by the grieving person. This also holds true when situations or death have been expected. Traditional rituals such as funerals or memorial services can help people accomplish this task. This public method of saying goodbye helps people confront the finality of the death. The primary aim of the facilitator is to help the grieving person accept the reality of their loss in their own time and at their own pace.

#### **2. Experiencing the pain of grief**

This is the second task in the mourning process and the expression may include emotional, physical, behavioural, cognitive, spiritual and social responses to the loss. In AIDS-related deaths, the survivors often may be positive and experience both normal physical responses to loss as well as symptoms of the disease of HIV itself. Appropriate medical attention in such cases will be crucial. Sleep disturbances and appetite changes are some of the most commonly noted behavioural responses and also warrant the health-care team's attention. An often-neglected aspect of grief in AIDS-related deaths is the social response. Survivors often experience social isolation and stigmatization which hinders the entire process of grief.

#### **3. Adjusting to the loss**

The third task refers to the work of developing the skills and filling the roles necessary to move forward without the lost person. Usually this task begins after some time and may include adjusting to living alone, being a single parent, getting a job, learning to manage finances and, at times, for PLHA it may also include the need to find other caregivers. Part of the coping process lies in dealing with all the 'firsts' without the person—the first holiday, first birthday. Grief responses can be triggered by the following factors:

- Cyclical precipitants—events that occur regularly such as holidays and birthdays

- Linear precipitants—one-time occurrences, such as the absence of the loved one on an important occasion
- Stimulus-cued precipitants—include reminder-inspired reactions and can be elicited by people, places, belongings, music, etc.

#### 4. Reinvesting energy from the deceased into new life

This refers to the ability to transfer the emotional energy invested with the lost person into new healthy approaches to life. Signs that a person is learning to accommodate their grief include

- Focusing on self-care,
- Acknowledgement of the reality of the loss,
- Redefining identity,
- Emergence of new skills or roles, and
- Establishment of or reconnecting with a support system.

It is important for the health-care team to maintain a therapeutic perspective in reaching out to the grieving. Remember that

- No one can take away the pain,
- A sense of helplessness should not stop the process of reaching out to the grieving,
- The value of ‘being present’ is recognized by the grieving.

In dealing with AIDS-related deaths, the health-care team has to face challenges in addition to dealing with grief. It is also important to address the concurrent stressors, substance abuse, mental health issues and the effects of racism and stigmatization. The team will also have to play a significant role in the advocating of accessible services and community resources.

#### CARING FOR THE CAREGIVER

People living with HIV are cared for by a variety of individuals including family members, community volunteers and health-care workers. It is these caregivers who are at the frontlines of the epidemic. A unique feature of the disease of HIV/AIDS is that often caregivers are also infected with HIV. Thus, they experience a parallel process of disease. Caregivers have special needs, which require attention, if not attended to there may be significant distress and burn-out issues.

Home-based care programmes require a component that attends to the caregivers. The kind of support offered depends upon the resources available, however, there exist wide modalities of support systems, which can be built into the programme.

- A caregivers’ group—to provide people the space to ventilate feelings and share experiences
- Training caregivers in basic care systems

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### The purview of counselling in HIV/AIDS home-based care

- Day care centres
- Counselling
- Respite care—a person who will sit in for the caregiver and allow time out

### **SUPPORT GROUPS AND NETWORKS**

Due to misconceptions and myths surrounding HIV/AIDS, PLHA often experience feelings of isolation, stigmatization and abandonment. In many settings, they fear rejection by friends and family, restrictions on travel, and exclusion from employment, housing and educational opportunities. These fears often lead individuals to hide their HIV status from loved ones and the community at large. In many countries, extreme isolation has led PLHA to form SHGs which give members support and strength.

Peer support groups and networks of PLHA provide individuals with a sense of solidarity and understanding that they might not gain with trained counsellors and medical professionals. These groups offer opportunities for members to share experiences and discuss problems openly, which counteracts feelings of isolation, fear and despair. The groups often have role models for ‘living positively’ with hope and purpose despite the unknown future. These groups also assist individuals to cope with HIV infection and empower them to engage in safer behaviours.

As there is relatively little start-up funding involved and because they contribute to the overall well-being and security of communities, support groups are extremely cost-effective. Formation of support groups, including groups with counsellors who themselves may be infected with HIV, should be encouraged. When counsellors living with HIV are involved, clients/members have a role model with whom they can identify.

It is now widely accepted that once clients know their HIV status, they can benefit from the support of other clients with similar concerns. To provide a context in which clients can continue to make positive life choices, it is recommended that counsellors help establish post-test clubs that include both negative and positive clients. Post-test clubs foster ‘healthy living’ attitudes and help members avoid sexual risk. They also help members maintain focus and motivation.

Note that counsellors might not play the main supportive role. Self-help support groups, whether comprising PLHA and/or their relatives, may be the primary source of support. There is some evidence that the benefits of support groups are occasionally greater than those of individual supportive counselling. There are support programmes for infected individuals, their families and orphans.

### **NUTRITION AND HIV/AIDS**

As nutrition can affect the morbidity and mortality of PLHA, nutritional intervention

is fundamental at all stages of illness. Weight loss, nutritional deficiencies, and malnutrition (particularly protein calorie malnutrition, or PCM) are common among PLHA. As HIV disease progresses, there is a simultaneous decrease in the lean body tissue and an increase in intracellular and extracellular water. Malabsorption, diarrhoea, oral/oesophageal complications, nausea/vomiting, and fever can compromise the nutritional status. The severe malnutrition that frequently accompanies AIDS can exacerbate the effects of the illness and compromise the quality of life.

Several factors may contribute to HIV-related weight loss (wasting), including inadequate dietary intake, malabsorption of nutrients, abnormalities in metabolism and energy expenditure, and OIs. Reduced intake often results from loss of appetite (due to nausea), diarrhoea, and oral, pharyngeal, and oesophageal sores. Other factors associated with weight loss include depression, dementia, anorexia, and adverse drug reactions or interactions.

Comprehensive nutritional intervention requires an experienced nutritionist or dietician. It is important that the counsellor identifies appropriate referrals for individualized long-term professional nutritional support and follow-up. However, before referring, the counsellor must discuss nutrition with his/her clients (for more information see Module 5 Submodule 3 on Nutrition).



## Module 5

### Submodule 3: The role of diet and nutrition in the management of PLHA

#### Session objectives

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

- To understand the importance of nutrition in management of PLHA
- To understand the counselling strategies needed to follow food and nutrition habits

#### INTRODUCTION

There exists a well-established link between infection control and good nutrition. Good nutrition is essential for achieving and preserving health while helping the body to protect itself from infections. Few crises have affected human health and threatened national, social and economic progress in quite the way that HIV/AIDS has. The pandemic has had a devastating impact on household food security and nutrition through its effects on the availability and stability of food, and access to food and its use for good nutrition.

Good nutrition cannot cure AIDS or prevent HIV infection, but it can help to maintain and improve the nutritional status of PLHA and delay the progression from HIV to AIDS-related diseases. It can therefore improve the quality of life of PLHA. Nutritional care and support are important from the early stages of the infection to prevent the development of nutritional deficiencies. A healthy and balanced diet will help to maintain body weight and fitness. Eating well helps to maintain and improve the performance of the immune system—the body’s protection against infection—and therefore helps a person to stay healthy.

#### HIV/AIDS AND NUTRITION

The HIV virus attacks the immune system. In the early stages of infection, a person shows no visible signs of illness but later, many of the signs of AIDS will become apparent, including weight loss, fever, diarrhoea and OIs (such as sore throat and tuberculosis [TB]).

Good nutritional status is very important from the time a person gets infected with HIV. Nutrition education at this early stage gives the person a chance to build up healthy eating habits and to take action to improve food security at home, particularly as regards to the cultivation, storage and cooking of food.

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### The role of diet and nutrition in the management of PLHA

Good nutrition is also vital to help maintain the health and quality of life of the person suffering from AIDS. Infection with HIV damages the immune system, which leads to other infections such as fever and diarrhoea. These infections can lower the intake of food because they not only reduce the appetite but also interfere with the body's ability to absorb food. As a result, the person becomes malnourished, loses weight and is weakened.

One of the possible signs of the onset of clinical AIDS is a weight loss of about 6–7 kg for an average adult. When a person is already underweight, a further weight loss can have serious effects. A healthy and balanced diet, early treatment of infection and proper nutritional recovery after infection can reduce this weight loss and reduce the impact of future infection.

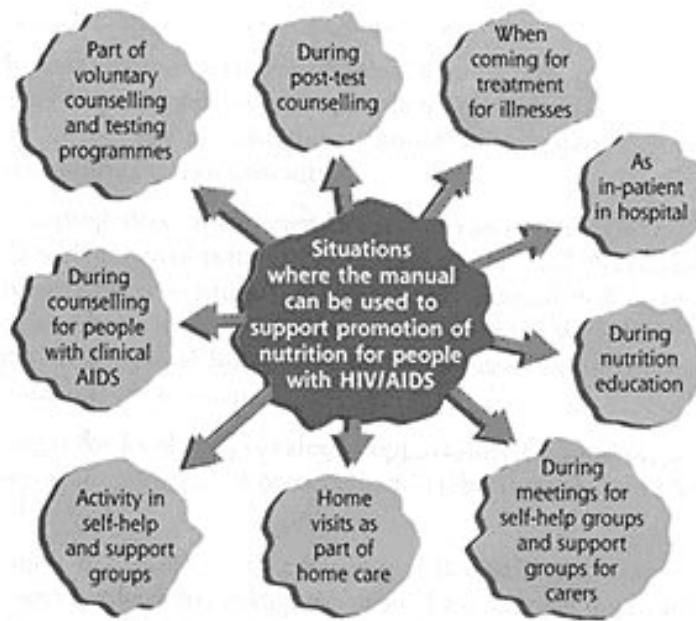
A person may be receiving treatment for OIs and also perhaps combination therapy for HIV; these treatments and medicines may influence eating and nutrition. Good nutrition thus reinforces the effect of the drugs taken.

#### **HIV and nutrition in the Indian context**

There are various stages and phases when nutritional counselling can be introduced. It is important to remember that nutritional counselling must span the entire spectrum of HIV/AIDS counselling. It needs to include not only the person infected with HIV/AIDS but also the entire family. In a country such as India, where nutritional requirements are still not well met among a major part of the population, prescribing specialized nutrition for PLHA may not be effectively implemented. There is a need to maximize resources and use culturally acceptable and low-cost nutritional resources to meet the needs of PLHA.

A healthy and balanced nutrition must be included as one of the goals of counselling and care for people at all stages of HIV infection. An effective programme of nutritional care and support will improve the quality of life of PLHA by:

- Maintaining the body weight and strength
- Replacing lost vitamins and minerals
- Improving the function of the immune system and the body's ability to fight infection
- Extending the period from infection to the development of the AIDS disease
- Improving the response to treatment; reducing the time and money spent on health care
- Keeping HIV-infected people active, allowing them to take care of themselves, their family and children
- Keeping HIV-infected people productive, able to work, grow food and contribute to the income of their families



**Fig. 5.1** Promotion of nutrition for people living with HIV/AIDS

### INCREASED NUTRIENT NEEDS OF PLHA

When infected with HIV, the body's defence system—the immune system—works harder to fight infection. This increases energy and nutrient requirements. Further, infection and fever also increase the body's demand for food. Once people are infected with HIV they have to eat more to meet these extra energy and nutrient needs. Such needs will increase even further as the symptoms of HIV/AIDS develop.

#### People with HIV/AIDS often do not eat enough because:

- The illness and the medicines taken for the disease may reduce the appetite, modify the taste of food and prevent the body from absorbing it
- Symptoms such as a sore mouth, nausea and vomiting make it difficult to eat
- Tiredness, isolation and depression reduce the appetite and the willingness to make an effort to prepare food and eat regularly
- There is not enough money to buy food

**HIV/AIDS reduces the absorption of food.** Food, once eaten, is broken down by digestion into nutrients. These nutrients pass through the gut walls into the bloodstream and are transported to the organs and tissues in the body where they are needed. One of the consequences of HIV and other infections is that since the gut wall is damaged, food does not pass through properly and is consequently not absorbed.

**Diarrhoea is a common occurrence in PLHA.** When a person has diarrhoea the

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### The role of diet and nutrition in the management of PLHA

food passes through the gut so quickly that it is not properly digested and fewer nutrients are absorbed.

**Reduced food intake and absorption lead to weight loss and malnutrition.** When a person does not eat enough food, or the food eaten is poorly absorbed, the body draws on its reserve stores of energy from the body fat and protein from the muscle. As a result, the person loses weight because body weight and muscles are lost. The weight loss may be so gradual that it is not obvious. There are two basic ways to discover whether weight is being lost.

- Weigh the person on the same day once a week and keep a record of the weight and date (see Activity 4). For an average adult, serious weight loss is indicated by a 10% loss of body weight or 6–7 kg in one month. If a person does not have weighing scales at home, it might be possible to make an arrangement with a chemist, clinic or local health unit to weigh them.
- When clothes become loose and no longer fit properly.

If a person loses weight, they need to take action to increase weight to the normal level. Weight is gained by eating more food, either by eating larger portions and/or eating meals more frequently.

#### **Some suggestions for gaining weight:**

- More staple foods such as rice, maize, millet, sorghum, wheat, bread, potatoes, sweet potatoes, yams and bananas should be eaten.
- The intake of beans, soy products, lentils, peas, groundnuts, peanut butter and seeds, such as sunflower and sesame should be increased.
- All forms of meat, poultry, fish and eggs can form a part of the diet as often as possible. Minced meat, chicken and fish are easier to digest. Offal (such as kidney and liver) can be the least expensive source.
- Snacks can be taken regularly between meals. Good snacks are nuts, seeds, fruit, yoghurt, carrots, cassava crisps, crab crisps and peanut butter sandwiches.
- The fat content of the food can be gradually increased by using more fats and oils, as well as eating fatty foods—oilseeds such as groundnuts, soy and sesame, avocados and fatty meat. If problems with a high fat intake are experienced (especially diarrhoea), the fat intake should be reduced until the symptoms are over and then gradually increase it to a level that the body can tolerate.
- More dairy products such as full-cream milk, sour milk, buttermilk, yoghurt and cheese should be introduced into the diet.
- Dry milk powder should be added to foods such as porridge, cereals, sauces and mashed potatoes. However, coffee and tea whiteners are not to be used as they do not have the same nutritional benefits as milk. Note that some people may find milk difficult to digest. It should be avoided if it causes cramps, a feeling of being full or skin rashes.
- Sugar, honey, jam, syrup and other sweet products can be added to the food.
- Meals should be made as attractive as possible.

## DEALING WITH DIET-RELATED PROBLEMS IN PLHA

### Diarrhoea

#### **General recommendations**

PLHA need to drink more than eight cups of fluid, particularly water, every day. It is also good to take fluid in other forms to replace the salts that have been lost and provide energy. Some suggestions are given below for easily digested foods and drinks that will help to rehydrate the body and provide salts, energy and vitamins.

#### **Recommended foods and drinks**

- Soups, fruit juices diluted with water or an oral rehydration solution.
- Soft, mashed, moist foods such as soft vegetables and fruit, porridge from cereals, rice, bananas, potatoes and stews with refined maize meal, rice, barley or potatoes. Soft vegetables also include squash, pumpkins and carrots, and vegetable soup.
- To replace the lost minerals, soft vegetables and fruits, particularly bananas, mangoes, papaya, watermelon, pumpkins, squash, potatoes and carrots can be eaten.
- Refined foods (soluble fibres) such as white rice, maize meals, white bread, noodles and potatoes.
- Vegetables and fruits need to be peeled and cooked so that they can be better tolerated.
- Food should be eaten warm, rather than very hot or very cold.
- Small and frequent meals should be eaten.

#### **Foods and drinks to limit or avoid**

Some foods can make diarrhoea worse. It is advisable to remove one food at a time from the diet and see if it makes a difference.

- Fats can make diarrhoea worse and cause nausea. Fat intake should then be reduced, adding less or no cooking oil, cutting off visible fat or skin from meat and boiling food rather than frying it. However, fat is an important energy source and should not be omitted from a diet unless really necessary.
- Green, unripe and acidic vegetables and fruit such as tomatoes, pineapple and citrus fruit sometimes may not be tolerated.
- Milk sometimes may not be tolerated, so it needs to be seen whether heated milk or yoghurt is digested better.
- Coffee, tea and alcohol can worsen dehydration. They should be replaced by other fluids such as water, herbal tea and soups.
- Very spicy foods such as chillies and pepper may sometimes make diarrhoea worse.
- Foods such as beans, broccoli, cauliflower, cabbage, brussels sprouts, onions and green peppers that produce gas should be avoided.

**When not hungry, the best way to regain appetite is to eat**

- To eat different foods until a person finds those that is liked and can try to have a mixed diet
- To eat smaller meals more often. A person can eat whenever the appetite is good—and should not be too rigid about fixed times for meals
- It helps to try to drink a lot of water, milk, yoghurt, soups, herbal teas or juices throughout the day—mainly after, and in between meals—and should not drink too much before or during meals
- To add flavour to food and make it look and taste interesting, a person can squeeze some lemon juice over it or add spices such as, cardamom, fennel, coriander and cinnamon
- Fizzy drinks, beer and foods such as cabbage, broccoli and beans that create gas in the stomach and can make a person feel bloated
- A person may try rinsing one’s mouth out before eating as it might make food taste fresher
- Light exercise such as walking outdoors, and breathing plenty of fresh air can stimulate an appetite
- To eat in a well-ventilated room away from cooking or unpleasant smells also helps
- Eating with family and friends can also help a person regain their appetite. If the person has to stay in bed, they can also join at the bedside
- Alcohol should be avoided. It reduces the appetite, weakens the body and interferes with medicines
- If the reason for lack of appetite is diarrhoea, nausea and vomiting, or a sore mouth, the guidelines to be followed are given later in this HO

**Nausea and vomiting**

***General recommendations***

- To avoid nausea and vomiting, it helps to sit up when eating. Also, one should not to lie down until one or two hours after eating.
- To drink plenty of fluids after meals.
- One should try not to prepare food by themselves. The smell of preparing or cooking food may worsen the feeling of nausea. Someone else can prepare food or foods that require little preparation can be eaten.

***Recommended foods to eat and drink***

- If vomiting occurs, drinking small amounts of water, soups and spice teas helps. One can eat soft foods and go back to solid foods when the vomiting stops.
- Smelling fresh orange, lemon peel, or by drinking lemon juice in hot water or a herbal or ginger tea helps relieving the feeling of nausea.
- Eating dry and salty foods such as toast, crackers and cereal also helps.

**Foods to avoid**

- Fatty, greasy and very sweet foods can make nausea worse. It is better to remove one food at a time from the diet to see if it makes a difference. If so, that food should be avoided. What affects one person may not affect others. People need to find out what suits them best.
- There are medicines that can reduce nausea. These can be discussed with a doctor or a health worker.

**Below is a 7-day meal plan that may be easier to follow**

Everything else is the same, except for the lunch and dinner choices, But when you choose snacks or fruits, try to choose different ones each time.

Breakfast: 1 glass milk + 3 teaspoons skim milk powder + 1 katori poha/daliya/chapatti

Snack 1: 1-2 Pieces of fruit: 2 bananas or other sweet fruit (Either citrus or sweet, never both at the same time). If having severe diarrhoea (can still drink fruit juice but strain it)

Lunch: See list below

Snack 2: 1 cup tea + 1 katori poha/daliya/chapatti

Dinner: See list below

Bed time: 1 glass milk + 3 teaspoons skim milk powder

Each day, you can always choose to have the full meal with rice, dal, vegetable, and chapatti. But the selections have mixed some of these categories, so you do not necessarily have to prepare the full meal if you are feeling tired.

**Day 1**

Lunch: Rice, tuar dal with sarso bhaji, fansi (green beans) vegetable, tomato, cucumber and carrot salad, 1 katori curd

Dinner: Kichri with spinach, cabbage, potatoes, and whole moong and rice in equal parts, curd curry, white and red radish salad

**Day 2**

Lunch: Dudhi chana dal, chapatti, sprouted moong salad with onion and kothmir, 1 katori curd

Dinner: Rice, soya dal, potato/peas/tomato vegetable, raita with onions, cucumber, and sprouted moong

**Day 3**

Lunch: Rice, udad dal, potato/spinach vegetable, carrot, beet and cucumber salad with lime, 1 katori curd

Dinner: Ragi chapatti, matki dal, green tomato, stuffed parval vegetable, sprouted soya salad with onion and cabbage, buttermilk

**Day 4**

Lunch: Missi roti (chana flour + wheat flour) with ambadi bhaji or bhakri (bajra,

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### The role of diet and nutrition in the management of PLHA

jowar or nachni) with ambadi bhaji, bhindi masala, sprouted soya salad with tomato and onions, 1 katori curd

Dinner: Rice, tuar dal, chowdi vegetable/chapatti, sprouted matki, red radish, jaggery, carrot and cabbage salad, buttermilk

#### Day 5

Lunch: Ragi chapatti, green tomatoes/brinjal vegetable, channa dal, sprouted chowli salad with carrots and sweet lime, 1 katori curd

Dinner: Moong daal kichri, curd curry, sweet potatoes with chawli bhaji, green salad leaves, cucumber, tomato and onion salad

#### Day 6

Lunch: Bajra bhakri, vaal and parval vegetable, carrot, tomato and spinach salad, 1 katori curd

Dinner: Rice, tuar dal with amaranth chapatti, gavar vegetable, beets and red and white radish salad, buttermilk

#### Day 7

Lunch: Potato/methi stuffed chapatti, chana dal with sahijan kepatte (drumstick leaves), cucumber, onion and tomato salad, 1 katori curd

Dinner: Rice, tuar dal, tendil + rajma vegetable, cabbage, tomato and kothmir salad with sweet lime, buttermilk

#### BOTTOM LINE

- The above is only a guide. If you feel tired, you can put the vegetables in the dal or put everything in a kichri mix. You can mix and match the foods listed above
- You can also try to make simple foods such as upma or poha more nutritious by adding vegetables such as peas, carrots, onions, etc.
- USE ONLY SEASONAL FRUITS AND VEGETABLES as they are both cheaper and better for you
- Make sure you wash the raw vegetables thoroughly or even slightly cook them in order to reduce the number of microorganisms they contain
- When choosing pulses or vegetables, try to vary the colors so that you get a variety of nutrients. Foods of different colors contain different vitamins and minerals

*Source:* Easy way to living healthy. Hamsafar Trust, Mumbai.

#### Sore mouth or when eating is painful

- Soft, mashed, smooth or moist foods such as avocados, squash, pumpkins, papaya, bananas, yoghurt, creamed vegetables, soups, pasta dishes and minced food should be eaten.
- Liquids should be added to foods or dry food should be softened by dipping in liquids.

- Drinking soups, cold drinks, vegetable and fruit juices also help.
- A straw can be used for drinking fluids.
- If the gums are painful and brushing the teeth is not possible, rinsing the mouth with bicarbonate of soda mixed with water will make the mouth feel fresh.
- Chewing small pieces of green mango, kiwi or green papaya may help to relieve pain and discomfort.
- Drinks such as spice teas, fermented sour cabbage water or yoghurt may help to ease a sore mouth when eating is painful.

### ***Foods and drinks to avoid***

- Very spicy and salty foods such as chillies and curries.
- Acidic or very sour foods such as oranges, lemons, pineapple, vinegar and tomatoes.
- Food and drinks that are too hot or too cold should be avoided. Food and drinks should be kept at room temperature.
- Foods that need a lot of chewing such as raw vegetables, or are sticky and hard to swallow such as peanut butter.
- If candida (oral thrush) is diagnosed, sweet foods such as sugar, honey, and sweet fruit and drinks should be cut down on because sugar may make the condition worse.

### **Other digestive problems**

#### ***General recommendations***

- Chewing food well will make it easier to digest.
- Chopped papaya added to meat acts as a tenderizer and helps digestion.
- Fermented foods such as sour cabbage water, sour porridge, yoghurt and sprouts can be easier to digest and help the digestion of other foods.
- Recommended foods should be used as if they were medicine, particularly during and after antibiotic treatment. It should be eaten three times a day before or with meals and continued for two weeks.

#### ***Foods to avoid***

- People can experiment by omitting a particular food and see if it makes them feel better. Some people find fatty foods such as fried foods, chips, hard cheese, peanut butter and cream difficult to digest. However, they can go back to a normal mixed diet once they feel better.

### **How to stop constipation**

- Eating insoluble fibre, contained in foods such as raw vegetables and fruit, dried fruit, wholemeal dark bread, whole-grain cereals, nuts and seeds helps

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### The role of diet and nutrition in the management of PLHA

- Eating frequent and small meals regularly throughout the day
- Drinking plenty of fluids throughout the day
- Being active and exercising regularly helps to stimulate bowel movement and improve digestion

#### ***How to prevent a bloated feeling***

- People should not drink too much with food.
- Foods such as cabbage, beans, onion, broccoli, brussels sprouts and cauliflower, and cold fizzy drinks that create gas in the stomach should be avoided.
- Some people find it difficult to digest whole-meal foods and foods rich in dietary fibre, particularly when the diet also contains sugar and sugary foods. They should try to exclude sugar and sugary foods from the diet for a while.

Most of us work in low-resource areas where a nutritionist may not be a part of the team. It is therefore important for counsellors to include in their tool box of counselling skills a set of relevant and low-cost recipes which could help meet the nutritional requirements of PLHA.