

Adherence to Treatment for HIV A Training Curriculum for Counselors



Participant Manual



ENGENDERHEALTH SOCIETY

Improving Women's Health Worldwide

Adherence to Treatment for HIV A Training Curriculum for Counselors

PARTICIPANT MANUAL



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This publication was made possible through the Global Fund to Fight AIDS, Tuberculosis and Malaria, Round IV supported Access to Care and Treatment project. The opinions expressed herein are those of the publisher and do not necessarily reflect the views of the funder.

Cover Design : Geetha Venugopal and Shishir

Printing : Impression Communications

Illustrations : Crossway Communications

Printed in India.

**This curriculum is dedicated to all the counselors
who are reaching out to people living with
HIV, with information on positive living and treatment**

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PREFACE

With funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) Round IV - the National AIDS Control Organization (NACO) aims to provide Antiretrovirals (ARV) for 1,37, 000 people living with HIV/AIDS (PLHA) in India. As part of this program, the Global Fund awarded a grant to an NGO Consortium to complement NACO's efforts in six HIV high prevalence states by providing care and support services to clients who will be receiving Anti-retroviral therapy (ART). The NGO consortium aims to increase the number of NGO sector providers capable of delivering high quality care and support services in accordance with the National Treatment Guidelines, this will help clients achieve and sustain adherence to treatment for effective antiretroviral therapy. In order to achieve this aim, the NGO consortium supports the program through improving the capacity of existing Indian health care training institutions to provide training and follow-up support to service providers. The NGO consortium is comprised of the Population Foundation of India (PFI), Indian Network for People Living with HIV/AIDS (INP+), EngenderHealth Society (EHS), Confederation of Indian Industry (CII) and Freedom Foundation (FF).

EngenderHealth Society recognizes access to treatment education as one of the key component for improving the quality of life of a person living with HIV. Our work aims to build the confidence and skills of individuals to make small changes in their lives and become key actors in managing and integrating their treatment in their life styles in ways that maximise the overall care and support that these individuals and their families can access. EngenderHealth Society recognizes that people living with HIV are critically important partners and that their meaningful involvement is essential to strengthen prevention, care and support and to remove barriers to access to information and services. We work closely with people living with HIV to assert their rights to health and to be treated with dignity and respect.

EngenderHealth Society also recognizes that adherence to treatment is a life long process requiring ongoing support and a variety of skills and strategies to enable clients to overcome the many challenges they may face to continue treatment effectively. Our work aims to build the capacity of service providers and of grass roots support systems to respond to these needs and to adapt experiences and learning to continue to innovate and improve services for people living with HIV .

This four-day curriculum expresses our commitment to achieve these aims. It engages the counselors in a meaningful dialogue with their clients to engender a sense of ownership of their health and their well-being and motivate them to sustain treatment adherence. The curriculum makes complex information understandable and accessible to the audience, and this helps to remove a critical barrier to personal empowerment around what are often perceived to be daunting treatment issues. The curriculum focuses both on counseling involved in adherence to therapy and self care, as well as on providing guidance on health seeking behavior and ways of accessing support. This curriculum also recognizes the critical role of a person living with HIV in the prevention of further HIV transmission, in preventing the development of ART resistance and in reducing the transmission from parent to children.

The enormous effort of the scientific community to understand the HIV virus and to find a cure for the disease is bringing about rapid changes in the body of knowledge in this field. We hope that these efforts will soon result in a cure for the disease. We are aware that over time new research may make some of the content in this edition outdated or irrelevant. Therefore we encourage the users of this manual to proactively complement our materials with technical updates from other sources, as necessary.

We hope that this curriculum will equip the counselors to support people living with HIV in their efforts to access quality ART services and the necessary care and support that will enhance their quality of life and their right to health.

Jyoti Vajpayee
Country Director
EngenderHealth Society

ACKNOWLEDGEMENTS

We acknowledge with gratitude **Fabio Saini**, EngenderHealth the primary writer of the manual assisted by Dr. Vijayabhaskar Reddy Kandula and Geetha Venugopal. Our special appreciations are due to Charlotte Storti for her detailed editorial review of the English version of the curriculum.

The manual follows National AIDS Control Organization (NACO) and World Health Organization (WHO) guidelines on HIV treatment and its contents are adapted from **WHO's Integrated Management of Adult Illnesses for HIV Treatment - WHO Basic ART Clinical Training Course 2004**. We acknowledge WHO for allowing us to adapt the IMAI Manual and their continued support during the curriculum development process.

We thank Family Health International for allowing us to use concepts and illustrations from the 'ART Basics Flip Chart' and 'ART Side Effects Flip Chart' developed by them. We thank the International Training and Education Centre on HIV (ITECH) for allowing us to use concepts and illustrations from their brochures 'Tips for ART Adherence' and 'HIV and ART' in some sessions.

A series of three consultative workshops were conducted for assessing training needs in August 2005 by EngenderHealth Society in consultation with Anjali Gopalan and her team from Naz Foundation, we acknowledge their contribution in content development. We appreciate the participation and inputs of representatives from Tamilnadu State AIDS Control Society (TNSACS), Karnataka State AIDS Control Society (KSACS), Andhra Pradesh State AIDS Control Society (APSACS), Maharashtra State AIDS Control Society (MSACS), Nagaland State AIDS Control Society (NSACS), Manipur State AIDS Control Society (MSACS), Mumbai Districts AIDS Control Society (MDACS) and NGOs from the GFATM ACT project states in content development.

EngenderHealth Society gratefully acknowledges the contribution of the partner organizations of Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) Round IV NGO consortium: Indian Network for People Living with HIV/AIDS (INP+), Population Foundation of India (PFI), Confederation of Indian Industry (CII) and Freedom Foundation for their assistance in content development and pre-testing of the manual. Our special thanks to all the members of the State and District Level Networks of people living with HIV of INP+ from Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka, Nagaland and Manipur, for participating in the content development, pilot testing of the manual and master trainings and for providing valuable feedback.

We thank the National AIDS Control Organization (NACO), World Health Organization (WHO) India office, Centres for Disease Control (CDC), India office, International Training and Education Centre on HIV (ITECH), India and the NGO Consortium partners for being an active part of the Technical Advisory Group for the curriculum development and for critically reviewing the curriculum.

A number of EngenderHealth Society staff and consultants have contributed to the research, concept, writing, development, translation and production of this curriculum. We appreciate their substantial contribution and special thanks to Dr. Vijayabhaskar Reddy Kandula, Geetha Venugopal, Vaibhavi Bhalekar, Chandramouli Peyyala, Dr. Sethuramashankaran, Thepuphi Kapuh, Meenu Ratnani and Shishir Seth for their contribution to this manual. We are grateful to Dr. Jyoti Mehra and Susmita Das for providing overall guidance and support throughout the process. We thank Dr. Jyoti Vajpayee, Country Director for her leadership and guidance in this endeavour.

We are thankful to the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) Round IV Access to Care and Treatment (ACT) project for providing financial support to this pioneering initiative.

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ABBREVIATIONS

ART	Antiretroviral therapy
CD4	A type of white blood cell used to monitor HIV disease state
GFATM	Global Fund to Fight AIDS, Tuberculosis, and Malaria
IVDU	Intravenous drug user
MSM	Men having sex with men
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NRTI	Nucleoside reverse transcriptase inhibitor
PLHA	People Living with HIV/AIDS
PPTCT	Prevention of parent-to-child transmission
STI	Sexually transmitted infection
TB	Tuberculosis

ABOUT THE COUNSELORS CURRICULUM

Adherence to Treatment for HIV – A Curriculum for Counselors has been developed for training people who handle HIV/AIDS counseling and build their capacity to reach out to their clients with information on living healthy with HIV, with a special focus on antiretroviral therapy (ART), adherence to ART, positive living and prevention among HIV positive people. “HIV Treatment Education and Counseling” empowers people living with HIV/AIDS by making them understand the role of ART in leading a healthy life so they can adhere successfully to their ART regimen and followup visits to clinic and laboratory. This prevents development of resistance by HIV virus against ART and ensures success of antiretroviral therapy both for the individual and for the national ART roll out program.

Written in a simple, non-technical language, this curriculum can be used with people in a training setting of groups of 15-25 participants. The training curriculum has been designed in such a way so as to provide ample opportunities for participants to interact in a supportive environment through a variety of exercises and activities. The curriculum can be used as a whole or in parts, but for sake of completeness and to ensure quality of training it is crucial that all the sessions be covered adequately and the suggested duration for each session adhered to.

The Counselor’s curriculum consists of a **‘Facilitator Guide’** and a **‘Participant Manual’**.

The Facilitator Guide consists of:

- Trainer’s Notes: provides instructions for the facilitator on how to conduct the sessions.
- Trainer’s Resources: provides important technical information that the trainer will need to refer to before or during sessions

The Participant Manual consists of:

- Handouts: contain important technical information for the participants to use as they participate in the sessions and also for them to refer to later.
- Participant Resources: contains important information about the topics that are covered in the training program.

The Participant manual contains only the handouts and Information resources.

About the Participant Manual

The Participant’s manual complements the Facilitator’s guide and its sections correspond to the sections detailed in the Facilitators guide. For the participants, the manual functions as a workbook during the training and as a reference after the training. Participant’s manual contains

all the essential learning points that is required to understand HIV treatment and adherence. It includes simplified visual representation of medical information in the form of pictures charts and graphs from the curriculum. Participants who complete the training will receive the copy of the participant manual. Although the curriculum is designed to provide complete information about HIV treatment, participants are encouraged to seek more knowledge of the subject and update their information.

How to use a Participant's manual

Participant's manual is organized as handouts and participants resources.

1. Handouts contain information to be used in the process of the workshop for group discussion and group learning. Handouts are to be used as per the instruction in the counselors manual.
2. Participant's resource contains information, which is imparted in the training program. It has been presented either in a question and answer format or listed as bullet points for easy learning and recall.


SECTION 1

FACTS ABOUT HIV, AIDS AND ART

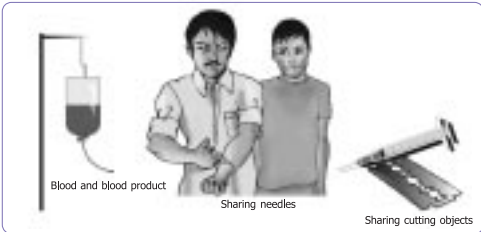
SESSION 1.4 : The Impact of HIV on Immune System

Handout A : Routes of HIV Transmission

Source: World Health Organization, Retrieved January 25, 2006, from <http://ftp.who.int/ntm/IMA1/Firstlevel/flipchart.pdf>



1. **Unprotected sex**



2. **Transfusion with blood or blood products or sharing unsterilised needles, syringes and cutting objects with blood**

Participant Manual

1

Adherence to Treatment for HIV

13

This symbol indicates the trigger question to be asked in the session

This symbol indicates the significant points for the particular topic

This box contains a definition

Participant Manual

1

Adherence to Treatment

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.8 : Resistance to ART

Information resource 'A'

1. One of the main problems we face in ART is that the drugs may stop working and the HIV virus in that person's body develops what we call **resistance to treatment**.
Resistance is the ability of HIV virus to multiply (replicate) even when ART is taken regularly. Resistance occurs because of changes in structure of HIV virus.
2. ART resistance occurs when the HIV in a person's body is no longer affected by medication, and the HIV is therefore able to multiply and destroy CD4 cells. ART resistance occurs when people do not take their medication regularly.
3. To help people understand the concept of resistance, refer to Handouts A, B and C.
4. When HIV virus develops resistance to ART it leads to 'treatment failure'. At this point the person will become sick again. Sometimes a new regimen of a different medicine can be provided that can battle the HIV that is resistant to other drugs. However, there are only a few drug regimens, so HIV can eventually become resistant to all drugs.
5.
When a person does not adhere there will be treatment failure and the person becomes sick again. If two or more pills are missed in a month resistance is likely to develop.

Key Messages :

- Resistance is a change in the virus that makes the virus protected and ARV drugs ineffective.
- ART resistance occurs when people do not take their medication regularly.
- The best way to prevent resistance and treatment failure is to help and support people on ART to achieve and sustain at least 95% adherence to treatment.

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SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.2 : Overview of the HIV Epidemic

Handout A : Global Estimates of HIV

Source : UNAIDS Website www.unaids.org, 2005 December

According to UNAIDS as of the end of 2005, 4.03 crores people were estimated to be living with HIV/AIDS worldwide. An estimated 43 lakh people became newly infected with HIV in 2006. Twenty Nine lakhs people died of AIDS-related causes in 2006. Women represent a growing proportion of people living with HIV/AIDS and now comprise nearly half (46%) of adults estimated to be living with HIV/AIDS worldwide. Young people under the age of 25 are estimated to account for half of all new HIV infections worldwide.

Number of people living with HIV in 2006 : 3.95 crores (39.5 million)



- Adults : 3.7 crores
- Women : 1.77 crores
- Children under 15 years : 23 lakhs

People newly infected with HIV in 2006 : 43 lakhs



- Adults : 38 lakhs
- Children under 15 years : 5.3 lakhs

AIDS deaths in 2006: 29 lakhs

- Adults : 26 lakhs
- Children under 15 years : 3.8 lakhs

Although access to antiretroviral (ARV) treatment has increased over the last few years, only 15% of people living with HIV in need of ARV in low and middle income countries were estimated to be receiving treatment as of June 2005. This represents only 9.70 lakhs of the estimated 65 lakh people in need of antiretroviral treatment in these countries.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.2 : Overview of the HIV Epidemic

Handout B : The epidemic in India

India Estimates of HIV/AIDS

Source : National AIDS Control Organization, India.

Number of people living with HIV in India as of 2006 : 53 lakhs



- Women living with HIV : 19 lakhs
 - Children living with HIV : 1.2 lakhs
-

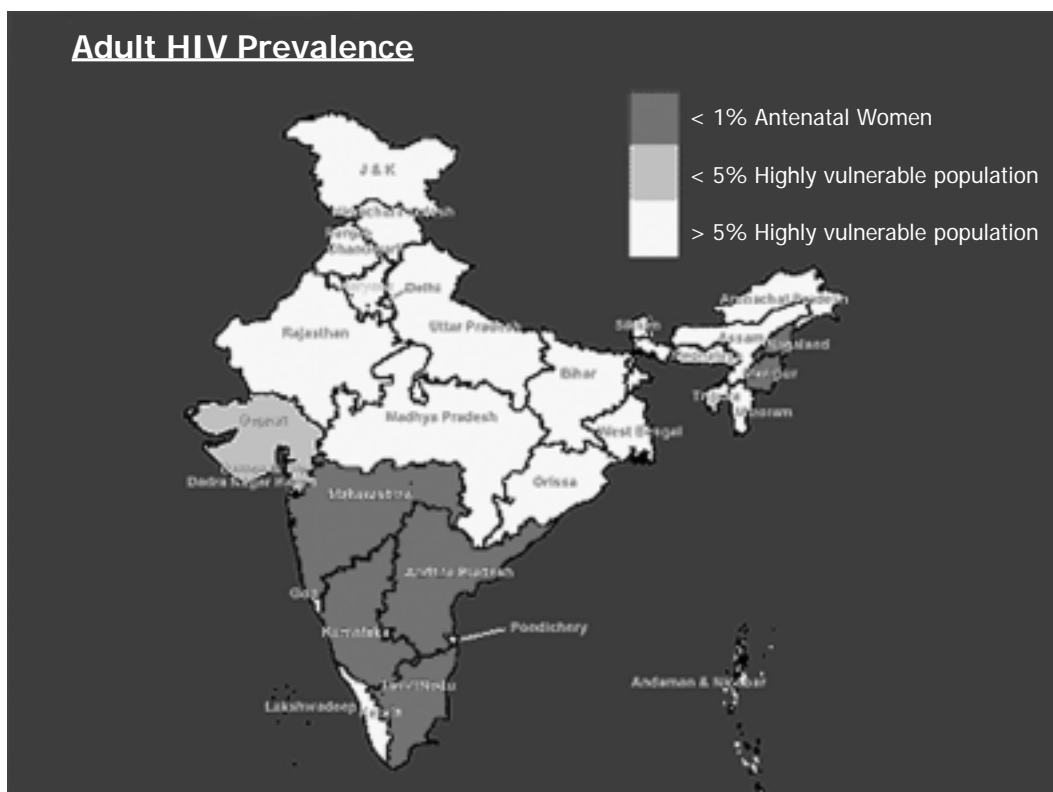
India accounts for almost thirteen percent (13%) of the world's HIV positive people



- It is difficult to count every person with HIV infection in a country as big as India.
 - Therefore NACO uses estimated numbers based on monitoring HIV at selected locations. Refer to map on page 6.
 - States are classified based on HIV in general population and among people with high-risk behaviors
 - HIV estimates in women attending prenatal clinic is used as an indicator for estimating the HIV prevalence among adults in the general population.
-

1. Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur, and Nagaland are most affected by HIV. In these states more than one percent of women attending prenatal clinics are HIV positive. More than five percent of people in the population with high-risk behavior are HIV positive.
2. In Gujarat, Goa, and Pondichery, the three states adjacent to states with high HIV prevalence, less than one percent of women attending prenatal clinics are HIV-positive. In these states too, more than five percent of population with high-risk behavior are HIV positive.

3. In the remaining states that are categorized as less affected, less than one percent of women attending prenatal clinics are HIV-positive and also less than five percent of population with high-risk behavior (sex workers, intravenous drug users, etc) are HIV positive.
- HIV/ AIDS prevalence among adults in India is still relatively low at just below 1%. Because of the large population size a small increase in the percentage of people with HIV will translate into huge numbers.



SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.3 : The Government of India's HIV Treatment Initiative

Information resource 'A' :

1. Government of India through National AIDS Control Organization (NACO) has several programs for HIV/AIDS and one of them is providing ARV treatment for people living with HIV.
2. All the service providers; doctors, nurses, pharmacists, field workers, counselor and Peer Educators (who are people living with HIV) need to work as a team to make HIV treatment with ART a success.
3. This is where counselors can play an important role in making this national initiative a success. This training is an effort towards building human capacity to provide HIV treatment and offer support to people living with HIV/AIDS.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.3 : The Government of India's HIV Treatment Initiative

Handout A : HIV in India and the need for ART :



- As of December 2005 India has 51.3 lakh people living with HIV/AIDS.
- This accounts for an estimated 13% of HIV infections globally.
- India has an estimated 7,00,000 people urgently in need of antiretroviral therapy but less than 30,000 are currently receiving it.

Government of India National AIDS Control Organization HIV Treatment Initiative:



- In 2003, WHO/UNAIDS estimated India's total treatment need to be 7,10,000 people, and the WHO "3 by 5" treatment target was calculated as 3,55,000 people by the end of 2005 (based on 50% of estimated need). In 2004, WHO/UNAIDS estimated that India's total treatment need had risen to 7,00,000* people.
- In November 2003, India declared a national target of providing antiretroviral therapy free of charge through the public sector to 1,00,000 people by 2007. Implementation of the programme began in April 2004. By the end of April 2005, the government reported that 7333 people were receiving free antiretroviral therapy through the public sector. Initiated in eight government health centers and was expanded to 54 centers in the country in 2005 and would be increased to 100 centers in 2006. The government plans to provide treatment in 188 centres across the country by 2007.
- Overall, an estimated 35,000* people were receiving antiretroviral therapy as of April 2005, including people enrolled through private facilities.
- Some treatment is provided through the private not-for-profit and the corporate sectors. The Employees State Insurance Scheme in the public sector and the Central Government Health Scheme also provide antiretroviral therapy services to employees.
- The Round II grant from the Global Fund aims to provide antiretroviral therapy to nearly 4500 women and their partners and children. The Round IV grant of Global Fund Round aims to provide 1,37,000 adults and children with antiretroviral therapy through public services by the end of 2009.
- The Government of India has further reduced the cost of the ARV medication through its budget in 2006.

*Number subject to change depending on situation.

How does ART help in controlling HIV epidemic :



- ARV medicines are not a cure for HIV
 - It reduces death rates, prolongs lives, improves quality of life, rekindles hope in communities and has transform HIV/AIDS to a manageable condition.
 - ARV treatment can add many years of healthy life to HIV positive person.
 - Availability of HIV treatment encourages people to volunteer for HIV testing as they now see a hope.
 - If diagnosed early people can seek care and initiate treatment at the right time and not wait until they are sick with symptoms.
 - Stigma and discrimination are also likely to reduce since more people will be able to be open about their status, work and contribute to the community.
-

Factors that support the National rollout of ARV :



- Favorable Government policy, with the National AIDS Control Organization (NACO) coordinating HIV/AIDS activities with the State AIDS Control Societies (SACS).
 - Involvement of People living with HIV
 - A strong indigenous pharmaceutical industry which has reduced cost of ART
 - Involvement of NGO's
 - Availability of doctors, nurses, counselors and other member of team
-

Challenges in National initiative of ARV rollout :



- Training program managers, health care workers and others in the implementation of National ARV rollout program
 - Training health care workers to provide ART and adherence counseling
 - Reaching information about ARV to people living with HIV, so they will be able to access the same
 - Ensuring equitable access to antiretroviral therapy (ART) for all those who need it
 - Ensuring adherence to drugs through treatment education.
 - Addressing the need for **long-term support** for people on ART – including the resources for procurement of drugs, second line drugs, pediatric formulation etc.
 - With a high prevalence of TB infection in India, TB related to HIV infection also poses a major public health challenge, particularly in the high HIV burden states.
 - Addressing treatment failure.
 - Preventing transmission of ARV resistant HIV
-

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.4 : The Impact of HIV on Immune System

Information resource 'A' :

1. The basic messages in the Information resource and handouts can be used with clients to explain the impact of HIV on the immune system.
2. As the CD4 levels decline, the risk of getting opportunistic infections increases. Review WHO adult HIV clinical stages in Handout C.
3. The purpose of this session is not to provide an in-depth clinical understanding of these conditions; rather, you are asked to keep yourself updated with this basic information because counselors, as members of the team managing a client, need to be aware of these clinical stages.
4. Please read these handouts in your own time because these materials contain simple messages to explain complex clinical issues to clients. In addition, participants should familiarize themselves with the signs and symptoms for WHO adult HIV clinical stages included in these handouts.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.4 : The Impact of HIV on Immune System

Information resource 'B' : Find Your Match Exercise

HIV is a retroviral that attacks....	...the immune system.
AIDS is a syndrome. A syndrome is...	...several conditions or illnesses. In the case of HIV infection, this happens because the virus weakens the immune system.
Every healthy person has a strong body defense against diseases called...	...the immune system, of which the white blood cells are an important part.
A lymphocyte is a type of white blood cell. Some types of lymphocytes have...	...a tag/mark on its surface called CD4.
HIV attacks mostly CD4 cells and this is why...	...the number of CD4 cells is a good way of checking how much of the immune system is still working.
When a person gets infected with HIV...	...the virus will start attacking the immune system.
During the first few (approximately five) years of HIV infection...	...the immune system still functions well.
During the first few (approximately five) years of HIV infection...	...the person will have no symptoms, or only minor symptoms like skin diseases or a little weight loss.
During the first years of HIV infection...	...a lot of people do not know that they are HIV-positive.

After many years HIV infection usually causes.	... the immune system to become weak and the person will be vulnerable to diseases that normally would be resisted by the body.
These diseases are called...	...opportunistic infections (OI) because they take advantage of a weakened immune system.
Usually, it takes about 7-10 years after HIV infection...	...before the person becomes very sick (AIDS), if he/she is not on ART.
One of the most common opportunistic infection associated with HIV is TB...	...because "sleeping" or latent TB can be reactivated due to a weak immune system.
Pulmonary TB symptoms usually include...	...persistent cough, fever, and loss of weight.
More than 50% of people with pulmonary TB...	...will not have a positive sputum test. A negative sputum result for TB in an HIV+ person does not exclude TB. Further tests would be needed.

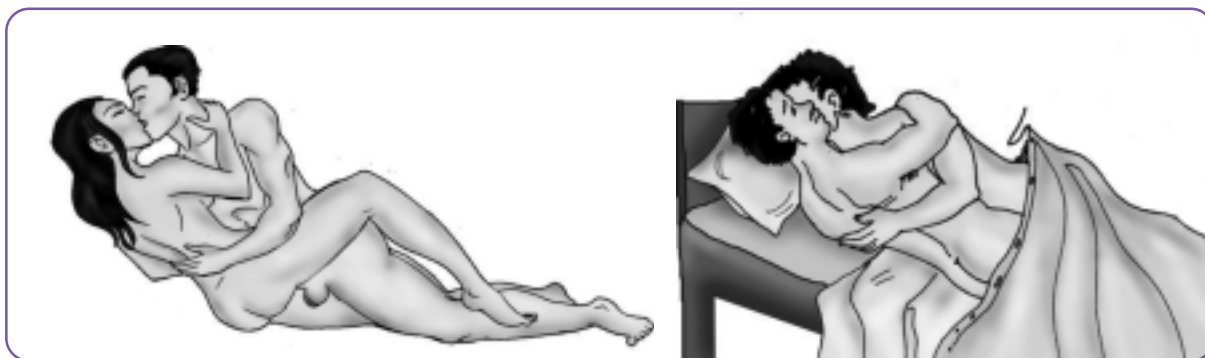
SECTION 1

FACTS ABOUT HIV, AIDS AND ART

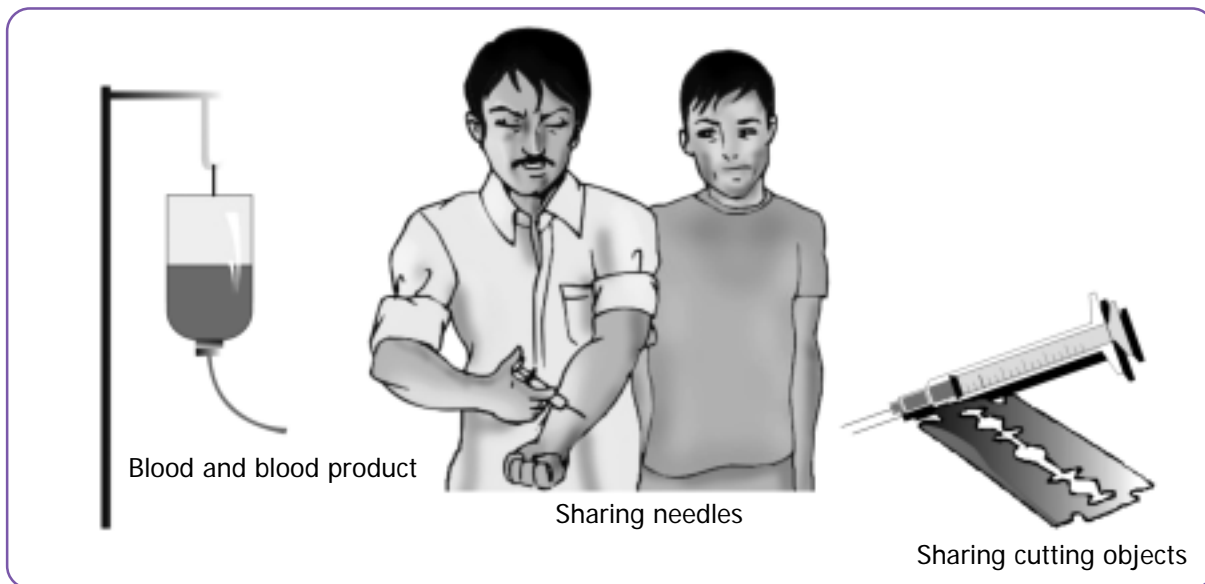
SESSION 1.4 : The Impact of HIV on Immune System

Handout A : Routes of HIV Transmission

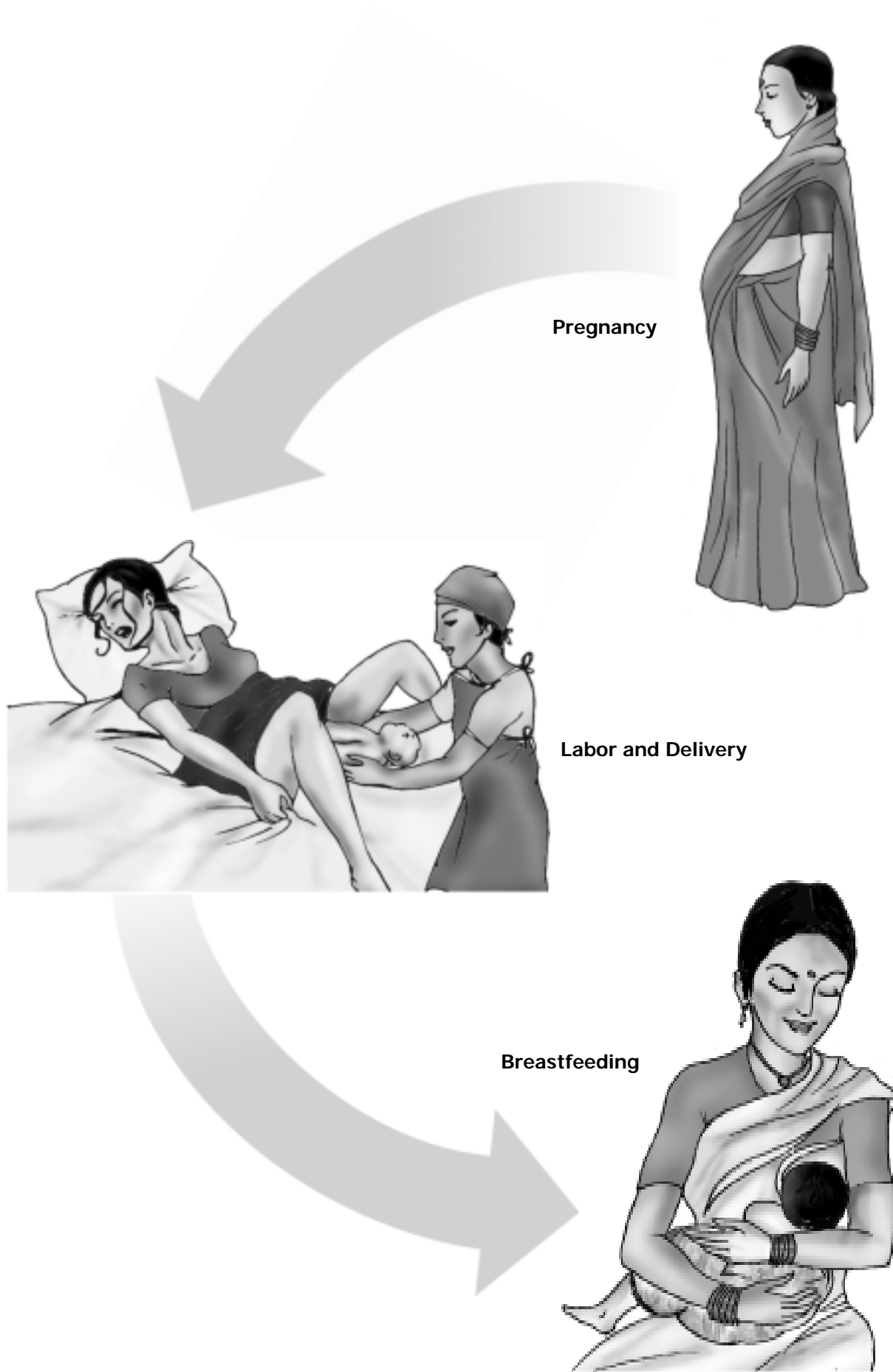
Source: World Health Organization. Retrieved January 25, 2006, from <http://ftp.who.int/htm/IMAI/Firstlevel/flipchart.pdf>



1. **Unprotected sex with unknown partner or multiple partners**



2. **Transfusion of blood or blood products or sharing unsterilised needles, syringes and cutting objects containing blood**



3. Transmission of HIV from parent-to-child.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

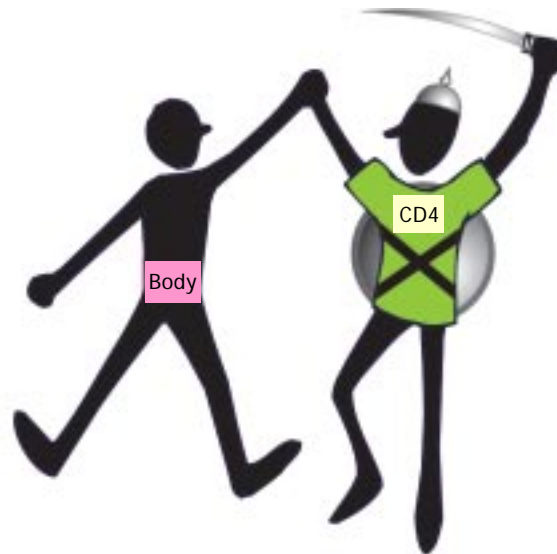
Session 1.4 : The Impact of HIV on Immune System

Handout B : How HIV Affects Our Health

Source: World Health Organization (WHO). 2004. Chapter 2: Introduction to HIV/AIDS and Opportunistic Infections. In *Participant Manual for the WHO Basic ART Clinical Training Course*. Geneva: World Health Organization.

HOW HIV ATTACKS OUR HEALTH

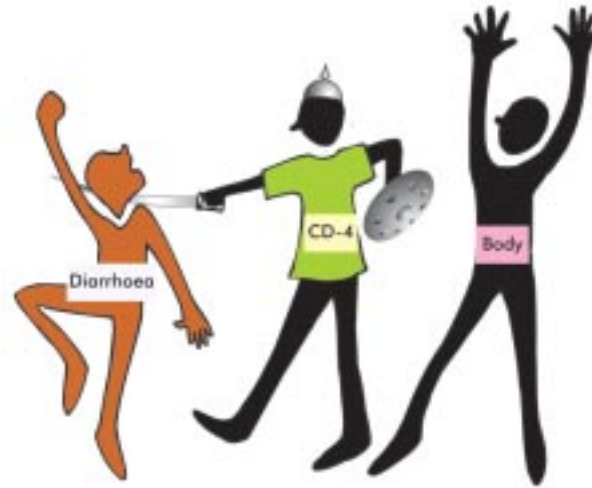
1. The CD4 cell is a kind of white blood cell. The CD4 is the friend of our body.



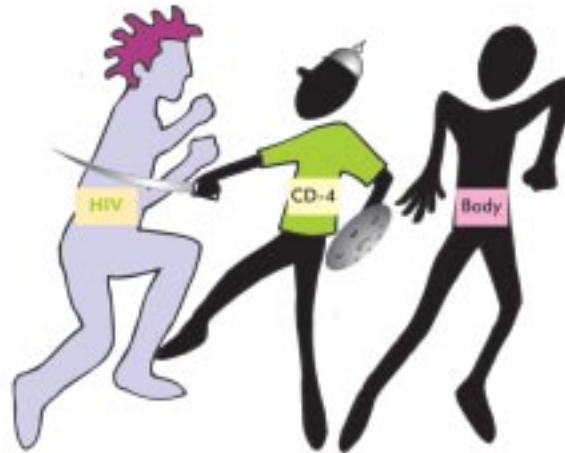
2. Problems like cough try to attack our body, but the CD4 fights them to defend the body, it's friend.



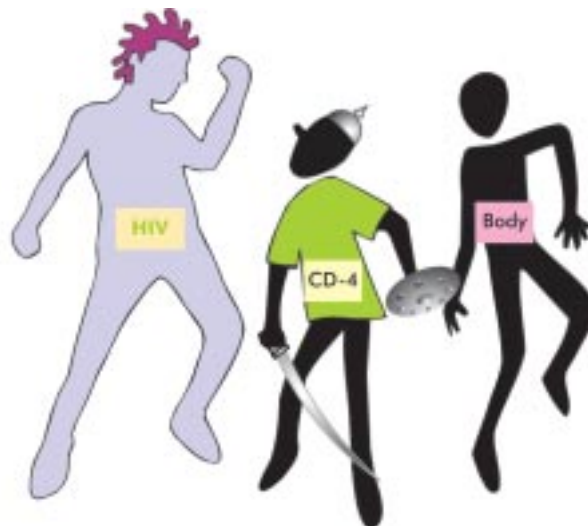
3. Problems like diarrhoea try to attack our body, but the CD4 fights them to defend the body.



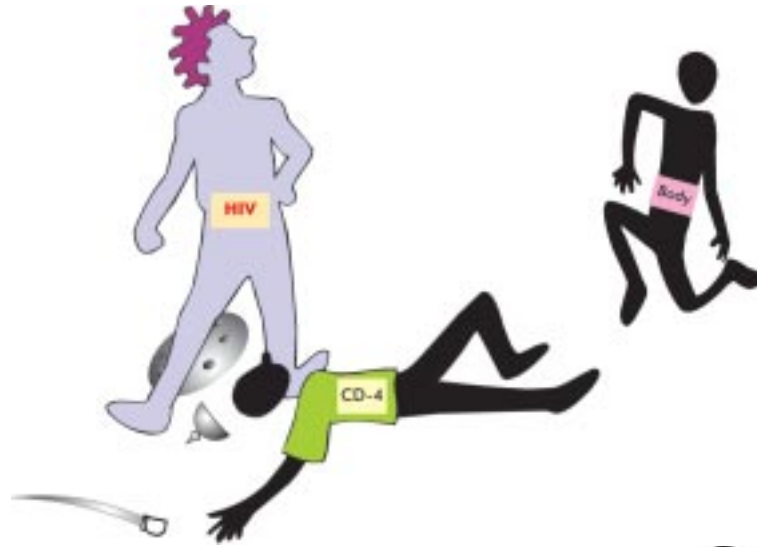
4. Now, HIV enters and starts to attack the CD4.



5. The CD4 notices it cannot defend itself against HIV.



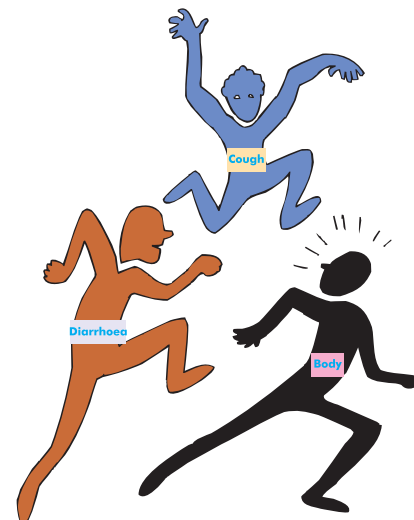
6. Soon, CD4 loses it's force against HIV.



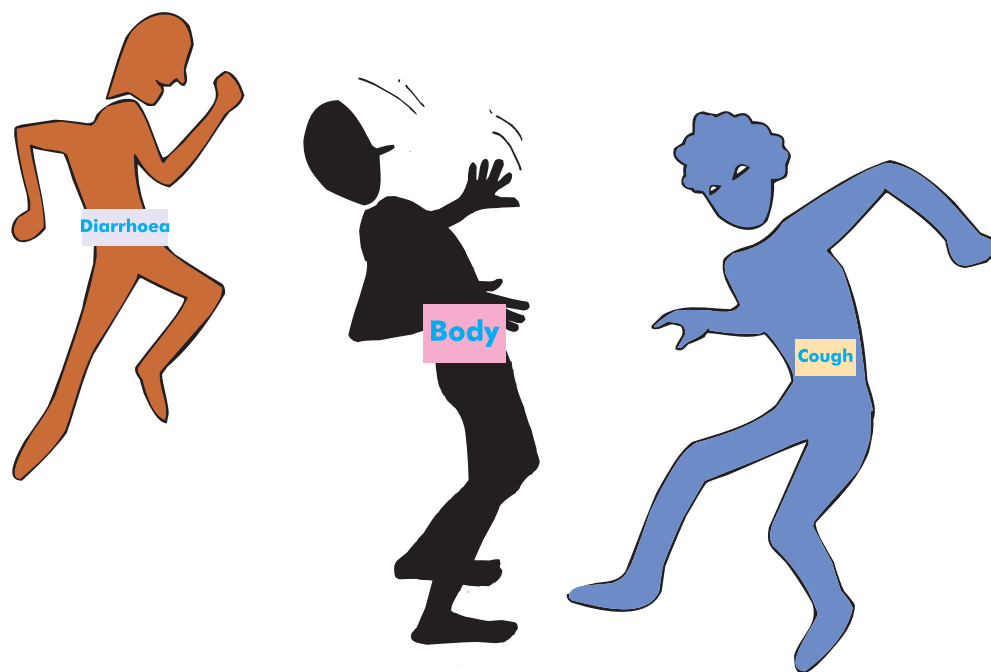
7. CD4 loses the fight.
The body remains without defence.



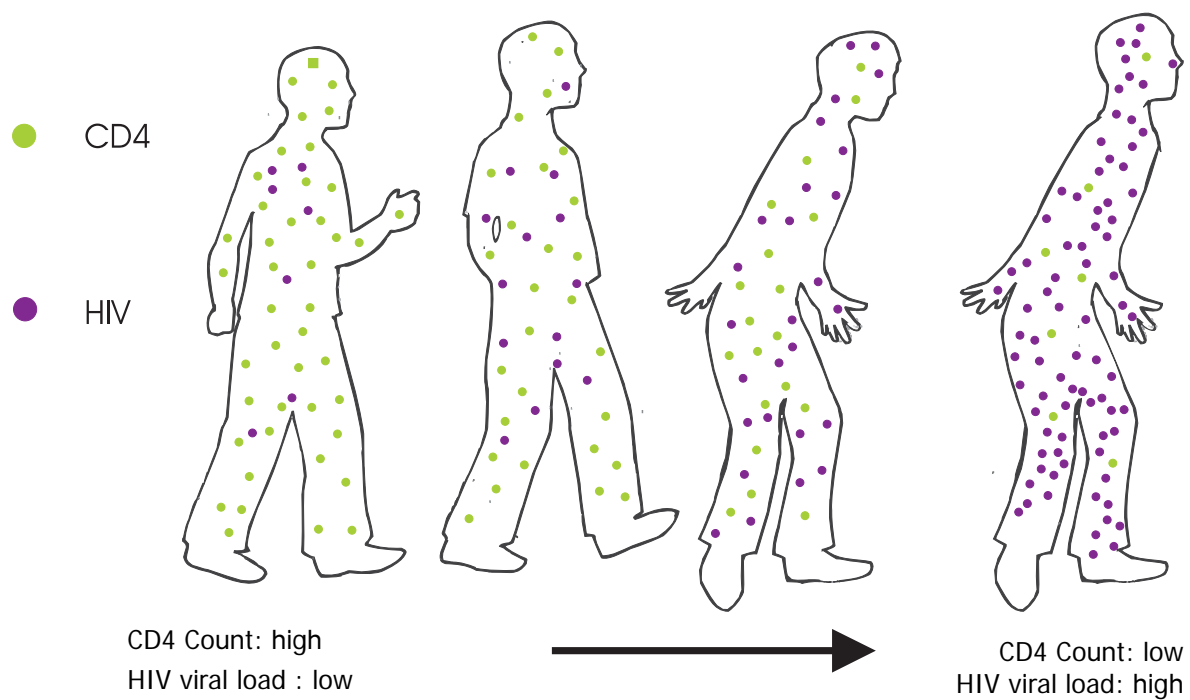
8. Now, the body is all alone, without defence.
All kinds of problems, like cough and diarrhoea
take advantage and start to attack the body.



9. In the end, the body is so weak, that all diseases can attack without difficulty.



Therefore, as HIV infection progresses, a person's CD4 count gets lower and a person's viral load gets higher. This concept is illustrated below:



SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.4 : The Impact of HIV on Immune System

Handout C : WHO Adult HIV Clinical Stages

The signs and symptoms for WHO adult HIV clinical stages

WHO Clinical Stage 1 Asymptomatic	WHO Clinical Stage 2 Mild Disease
<ul style="list-style-type: none">• No symptoms or only• Persistent generalized lymphadenopathy: Multiple, small, painless lymph nodes	<ul style="list-style-type: none">• Weight loss 5-10%• Sores or cracks around lips (angular cheilitis)• Small lesions at the corners of the mouth• Scaly skin eruption on the border between face and hair and side of the nose (Seborrhea)• Itchy skin eruption on the arms and legs (Prurigo)• Herpes zoster: painful blisters on a region of one side of the body, face, or extremities• Recurrent upper respiratory infections: repeated throat infections, sinusitis, or ear infections• Recurrent mouth ulcers

WHO Clinical Stage 3 Moderate Disease	WHO Clinical Stage 4 Severe Disease
<ul style="list-style-type: none"> • Weight loss >10% • Oral thrush: White patches covering areas in the mouth • Oral hairy leukoplakia: Non -painful, white vertical lines on the side of the tongue, which cannot be scraped off • More than one month of: <ul style="list-style-type: none"> - Diarrhoea, sometimes intermittent - Unexplained fever • Severe bacterial infections: <ul style="list-style-type: none"> - Pneumonia, - Muscle infection, etc. • Pulmonary TB • TB lymphadenopathy • Acute necrotizing ulcerative gingivitis/periodontitis (gum inflammation and bleeding) 	<ul style="list-style-type: none"> • HIV wasting syndrome: extremely thin with chronic fever and/or chronic diarrhoea • Esophageal thrush: severe pain when swallowing • More than one month of herpes simplex ulcerations: large and chronic painful wounds on the genitals and/or anus • Some kinds of blood cancer (Lymphoma) • Kaposi's sarcoma: dark (purple) lesions on the skin and/or mouth, eye, lungs, intestines, often accompanied by a hard edema(swelling) • Invasive cervical cancer • <i>Pneumocystis</i> pneumonia: severe pneumonia with shortness of breath on exertion and dry cough • Extrapulmonary TB: for example, in the bone or meningitis • Cryptococcal meningitis: meningitis which can present without neck stiffness • <i>Toxoplasma</i> brain abscess (collection of pus) • Kaala Azaar Infection (Visceral leishmaniasis) an infection accompanied by fever and abdominal pain • HIV encephalopathy (damage to brain) significant neurological impairment interfering with independent functioning and not due to other cause, will sometimes improve on ART

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.5 : Introduction to HIV Care and Support

Information resource 'A':

1. List of behaviours that HIV-positive people can adopt that will help them live longer.

The list may include the following:



- Eat well at regular intervals
- Get plenty of rest
- Stop smoking and drinking alcohol
- Exercise regularly
- Keep a positive mental attitude
- Start taking antiretroviral drugs when needed

2. Important points to remember



- There are a lot of important things HIV-positive people can do both before and after they begin receiving ART.
- Healthy behaviours such as a good diet, exercise, adequate rest, and abstaining from drugs/smoking/alcohol are important habits to begin adopting before a person begins ART and can help delay the need for taking ART medications.
- Just because a person is HIV-positive does not mean he or she needs ART immediately.
- However, over time, HIV diminishes a person's ability to fight off diseases. When this occurs, a person will need to start taking ART for the rest of his or her life.

3. Advantages of starting ART :



- You can live longer and have a better quality of life.
- You won't get sick as often.
- You will have more time to fulfill your dreams and goals.
- If you have children, you will see them grow up and go through life.
- You will have the opportunity to continue earning a living because you are well.
- You have more time to do things that you enjoy.



4. Challenges of starting ART :

- ART is a lifelong treatment that must be taken every day at the same time and in the same way.
- In the beginning ART seems complicated.
- Sometimes you have to adjust what you eat and when you eat it according to the drugs you take.
- Some types of ART require that you take several pills each day.
- Some types of ART may be harmful if taken with other drugs or during pregnancy.
- ART can give side effects. Some of them will go away after a few weeks, while others will need to be addressed by the health worker.
- If you do not take your ART regularly, the medicine will not work anymore. This means that you will have fewer options for ART in the future.
- It is difficult to start taking ART when one has TB.
- Only limited regimens are available in the government roll out .
- There is a lack of clarity about when to really start the ARV medication and who should make the decision: the person taking it or the doctor.

5. Benefits ART bring to families and communities :



- Households can stay intact
 - Decreased number of orphans
 - Reduces parent-to-child transmission of HIV
 - Increased number of people who accept HIV testing and counselling
 - Increased awareness in the community since more people do the test
 - Decreased stigma surrounding HIV infection since treatment is now available
 - Less spent to treat opportunistic infections and provide palliative care
 - Increased motivation of health workers since they feel they can do more for HIV positive people
 - Businesses can stay intact
-

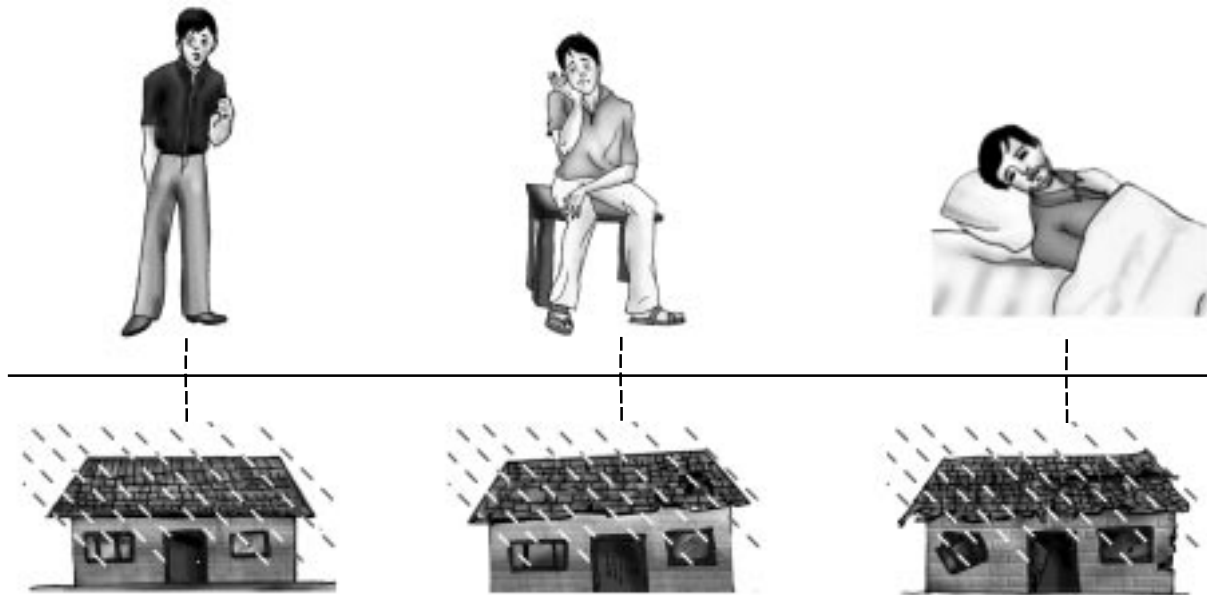
SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.5 : Introduction to HIV Care and Support

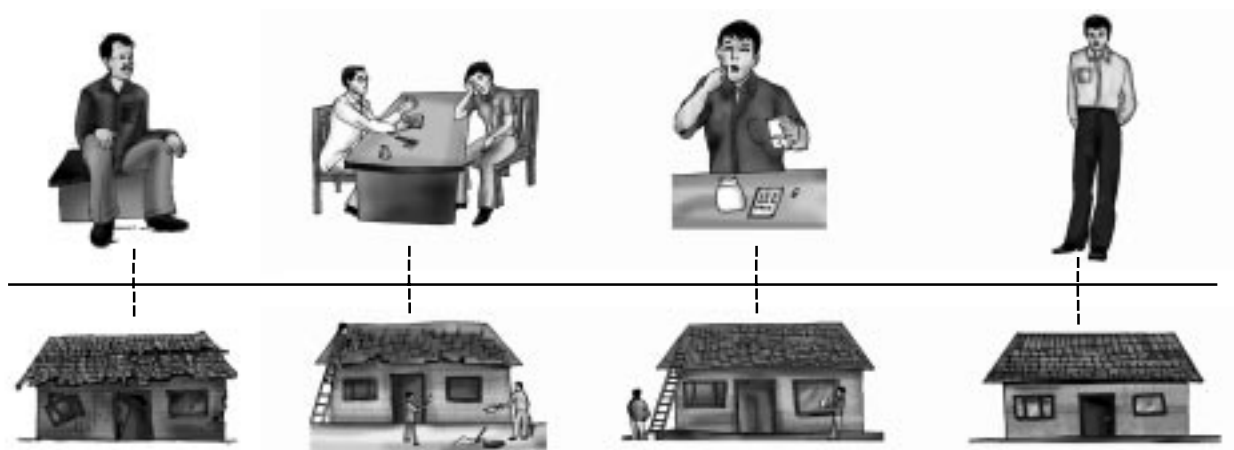
Handout A : Antiretroviral Treatment

Source: Family Health International (FHI): ART Basics Flip Chart

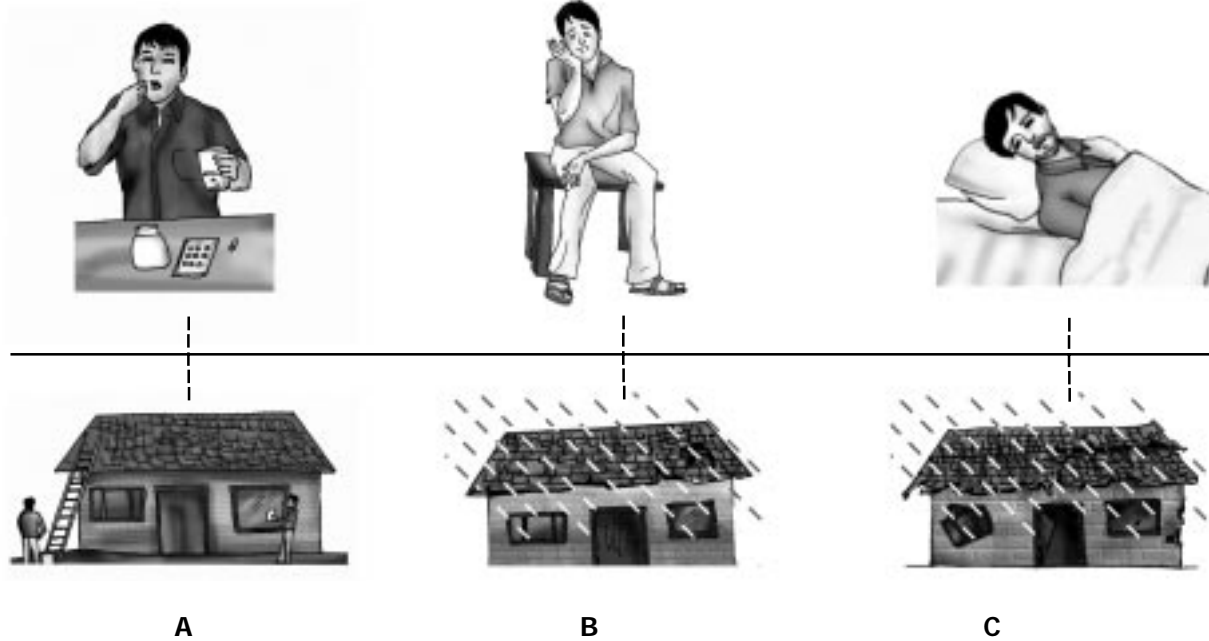


Our body has an immune system that protects us from getting sick, just like a house protects us from the rain and cold.

If left untreated over time, the HIV virus will take over a body's immune system, leaving a person ill with opportunistic infections, just like a house that is left uncared for.



If a person is sick from HIV, he or she can begin taking medicines called anti-retroviral treatment. These medicines reduce the amount of HIV in the body. As a result the body's immune system can fight off disease and the person can become healthy again. Therefore taking ART is like repairing a house. Based on several factors including the CD4 count, a doctor prescribes ART to such people.



- A. ART is several different medications. A person must take all of them, every time, every day for the rest of his or her life for the treatment to be effective.
- B. ART does not cure HIV. Therefore the body will need the medications every day in order to stay healthy. Going without medications, even for a short time, is like not repairing the house.
- C. If a person does not take his/her medicine, HIV will multiply in the body and continue to damage the immune system and taking ART in the future will not be able to stop it.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.6 : Basics of Antiretroviral Therapy

Information resource 'A':

1. The virus that causes AIDS; a virus that attacks the human immune system; a virus for which there is not a cure yet. The answer you want to elicit is that HIV is a type of virus which attacks CD-4 cells. Viruses are very small organisms that are not easily visible to the eye. They are difficult to see even with a microscope. HIV is a type of virus called retro virus that replicates (reproduces itself) and also mutates (changes itself) once it enters a person's body. The drugs that are used to fight HIV are antiretroviral drugs, shortened to ARV, because they interfere with HIV virus in order to stop it from replicating and changing.

2. **Definition of antiretroviral therapy :**

- *Antiretroviral Therapy (ART): Giving ARV drugs in the correct combination, with adherence support, is called ARV therapy, shortened to **ART**.*
- *The powerful combination of three different antiretroviral drugs is called **ART regimen**. This is the standard of good therapy, and has the greatest benefits for the longest time.*
- *ARV means "Antiretroviral" drugs. ART means "Anti-Retroviral Therapy". It is a combination of at least three ARV drugs. However, on many occasions ARV and ART may be used interchangeably.*



3. **What is the goal of ART?**



- To reduce the concentration of the HIV virus in the blood as much as possible.
- To increase the number of CD4 cells (i.e., to boost the immune system) as much as possible.

4. ART drugs reduce the HIV concentration in the blood, the immune system recovers and the number of healthy CD4 cells increases.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.6 : Basics of Antiretroviral Therapy

Information Resource 'B' : The ART Quiz

Questions	Answers
What are the 3 main groups of ARV? (Must respond in full, e.g., not just NRTI but Nucleoside Reverse Transcriptase Inhibitors)	The NRTI – Nucleoside Reverse Transcriptase Inhibitors The NNRTI – Non-Nucleoside Reverse Transcriptase Inhibitors The PI: Protease Inhibitors
Which groups or class of ARV prevent HIV from entering the infected cells' center, so HIV can't start making new copies?	NRTI and NNRTI
What do Protease Inhibitors do to HIV?	They prevent the new copies of HIV from "assembling" and from leaving the infected cell to go to infect other cells.
How many different drugs do we need to take in order to have an effective ARV regimen? What is such a combination called?	3 drugs. This combination is called a regimen.
Can any 3 ARV drugs be combined in ART regimen	No. Only specific drugs can be combined to form an ART regimen. This is decided by the doctor.
What are the commonly used NRTI drugs?	Stavudine (d4T) Lamivudine (3TC) Zidovudine (ZDV or AZT) Didanosine (ddl) Abacavir (ABC) Tenofovir (TDF)

What are the commonly used NNRTI drugs?	Nevirapine (NVP) Efavirenz (EFV)
What are the commonly used PI drugs?	Saquinavir (SQV) Ritonavir (RTV) (it is used as booster or helper with PI to make the effect of other PI stronger) Indinavir (IDV) Nelfinavir (NFV) Lopinavir (LPV)
What is a first-line regimen?	A combination of ARV used in a client who has never taken ARV before
What classes of ARV are most commonly included in a first-line regimen?	Two ARV from the NRTI group and one from the NNRTI group
What is the most common first-line regimen?	1. Stavudine (d4T)+ Lamivudine (3TC)+, Nevirapine (NVP) 2. Zidovudine (AZT)+ Lamivudine (3TC)+, Nevirapine (NVP)
What is the ARV drug common to most first-line regimens?	Lamivudine (3TC)
What is a second-line regimen?	A combination of drugs used when there is treatment failure of a first-line regimen
What happens if a client does not take ARV properly?	Often this leads to failure of therapy, i.e., the drugs become ineffective.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.6 : Basics of Antiretroviral Therapy

Handout A : The ART Information Sheet

Antiretroviral Drugs Interfere with the HIV Lifecycle.

There are 3 main groups of antiretroviral drugs :

1. NRTI or Nucleoside Reverse Transcriptase Inhibitor
2. NNRTI or Non-Nucleoside Reverse Transcriptase Inhibitor
3. PI or Protease Inhibitor



How they work?



Both the **nucleoside and the non-nucleotide reverse transcriptase groups of ART** work in a similar fashion. After the HIV virus enters the CD4 cell, it replicates by attaching itself to the center of the cell. These two groups of drugs **prevent HIV from entering the infected cell's center so HIV cannot make new copies.**



After entering the CD4 cell's center, parts of the HIV virus are produced. These parts then get assembled before they come out of the CD4 cell and go to other cells. **Protease inhibitors prevent the assembly of the HIV parts and thus prevent the HIV virus from coming out of the infected CD4 cell.** Since they are trapped and cannot come out of the CD4 cell, they cannot attack other CD4 cells.

The important point to remember is that protease inhibitors and NRTI and NNRTI work at different steps in the process that HIV goes through when it makes new copies of itself inside CD4 cells.

The Different Antiretroviral Drugs

The table below lists commonly used ARV drugs. In this manual emphasis is on Zidovudine (AZT), Stavudine (d4T), Lamivudine (3TC), Nevirapine (NVP), and Efavirenz (EFV) as these are the ARV drugs currently used in the first-line regimens in the National ARV rollout.

Table of Commonly Used Antiretroviral Drugs

Nucleoside (or nucleotide) Reverse Transcriptase Inhibitors (NRTI)	Non-nucleoside Reverse Transcriptase Inhibitors (NNRTI)	Protease Inhibitors (PI)
Stavudine (d4T) Lamivudine (3TC) Zidovudine (ZDV) Didanosine (ddI) Abacavir (ABC) Tenofovir (TDF)	Nevirapine (NVP) Efavirenz (EFV)	Saquinavir (SQV) Ritonavir (RTV), as booster* Indinavir (IDV) Nelfinavir (NFV) Lopinavir (LPV)

* Ritonavir is used as a 'helper' for another PI in adults, to make their effect stronger.



Why Do We have to use the Combination of Three Antiretroviral Drugs?

It takes a lot of force to stop HIV.

HIV makes new copies of itself very rapidly. Every day, many new copies of HIV are made, and every day many infected cells die. One drug, by itself, can slow down this fast rate of infection; two drugs can slow it down more; and three drugs together have a very powerful effect.



Antiretroviral drugs from different drug groups attack the virus in different ways. Earlier we learned how different anti-HIV drugs attack HIV at different steps of the process of copying itself (first when entering the cell's center, and then when new copies want to leave the cell). Attacking the virus at both steps increases the chance of stopping HIV and protecting new cells from infection.



Combinations of anti-HIV drugs may prevent or delay resistance.

Resistance is what happens when the virus changes itself and is capable of fighting the effects of ART and ART drugs can no longer attack it. HIV has to make small changes in its structure to become resistant to a particular ART. For HIV to be resistant to two or three ARV drugs, it has to make more changes. When only one or two ARV drugs are used, then the chances that the virus will make a change in its structure are higher. When this happens the ARV drugs fail to work against HIV. When three ARV drugs are used in combination as an ART regimen, the chances that HIV will make changes to its structure are less likely.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.7 : Antiretroviral Specifics

Information resource 'A'

1. *CD4 cells are white blood cells that play important roles in the immune system. Doctors use a test that "counts" the number of CD4 cells in a cubic millimetre of blood. A normal count in a healthy, HIV-negative adult can vary but is usually between 600 and 1200 CD4 cells/mm.³*



It is useful to have your CD4 count measured regularly for two reasons :

- To monitor your immune system and help decide whether and when to take anti-HIV drugs and treatments to prevent infections.
- To help monitor the effectiveness of any anti-HIV drugs.

2. *Viral load is the term used to describe the amount of HIV in a person's blood. The more HIV in the blood, the faster you lose CD4 cells.*



3. CD4 count and viral load are crucial indicators of the condition of a person's immune system and how far along a person's HIV infection have progressed. Doctors use this information to help determine when a person needs to begin ART. Doctors also use this to monitor how a person is responding to ART

4. **Doctors determine when a person should begin ART based on National Guidelines:**

After the doctor has made a detailed study of the person's past and present medical history, it will be decided whether the person requires antiretroviral therapy (ART).

The decision will be based on the following :



- Identification of current and past HIV-related illnesses
- Identification of other medical conditions that might influence the timing and choice of ART
- Current symptoms and physical signs of other medical conditions, such as TB or pregnancy
- The CD4 count of the person
- The NACO treatment guidelines explain that the criteria to begin ART for a person is that he or she has a CD4 cell count less than 200/ mm³.
- Cost incurred to a person for ART is around Rs 700-1000 for the first-line drugs consisting of NRTI and NNRTI. The cost is higher for second-line ART, and they generally have more side effects. This is especially true of PI class of ART drugs.
- CD4 count testing is only available in selected centers in the country.

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.7 : Antiretroviral Specifics

Handout A : ART Regimens

Source: World Health Organization (WHO). 2005 March. *Chronic HIV Care with ARV Therapy. Integrated Management of Adolescent and Adult Illnesses: Interim Guidelines for Health Workers at Health Center or Clinic at District Hospital Outpatient.* Draft Rev 1.

1. TREATMENT EDUCATION CARD

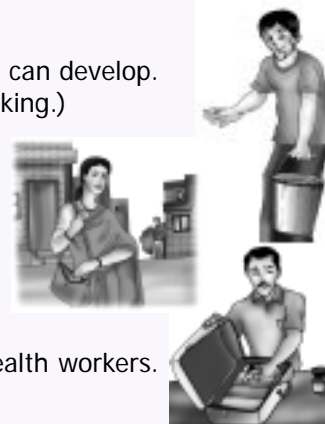
Now you are on ART



	Stavudine	Lamivudine	Nevirapine
	d4t-3TC-NVP		
Week 1-2	Week 3-on		
Morning: Stavudine Lamivudine Nevirapine	Morning: Stavudine Lamivudine Nevirapine		
Evening: Stavudine Lamivudine	Evening: Stavudine Lamivudine Nevirapine		

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.)
- Drugs must be taken twice daily, **and miss no doses.**
- This 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.



It is common to have side effects. They usually go away in 2-3 weeks.

If you have:	Do the following:
Nausea →	Take the pill with food.
Diarrhoea →	Keep drinking and eating little at regular intervals.

If nausea or diarrhoea persist or get worse, or you have any of the following, report to the health worker **AT THE NEXT VISIT.**

- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become **THIN.**
- Breasts, belly, back of neck become **FAT.**

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
- Fatigue and shortness of breath



SECTION 1

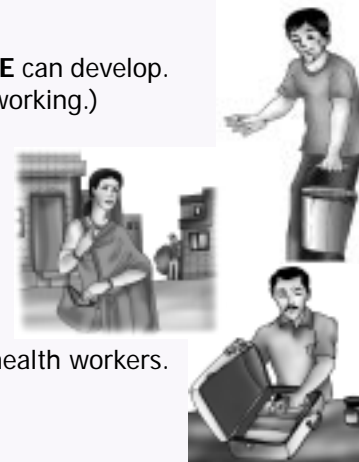
FACTS ABOUT HIV, AIDS AND ART

2. TREATMENT EDUCATION CARD Now you are on ART

	Zidovudine	Lamivudine	Nevirapine
	ZDV-3TC-NVP		
	Week 1-2		Week 3-on
	Morning: Zidovudine Lamivudine Nevirapine		Morning: Zidovudine Lamivudine Nevirapine
	Evening: Zidovudine Lamivudine		Evening: Zidovudine Lamivudine Nevirapine

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.)
- Drugs must be taken twice daily, **and miss no doses.**
- This is very important to maintain blood levels so ART can work.
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- 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.



It is common to have side effects. They usually go away in 2 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 little at regular intervals.
Muscle pain, fatigue →	These will go away.

If nausea or diarrhoea persist or get worse, report to the health worker **AT THE NEXT VISIT.**

SEEK CARE URGENTLY if:

- Severe abdominal pain
- Yellow eyes with high fever, headache running nose and body ache
- Skin rash, along with fever and ulcer in the mouth and lips
- Pale or do not have enough blood
- Fatigue AND shortness of breath

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

3. TREATMENT EDUCATION CARD

Now you are on ART

**Daily**

Morning: Zidovudine
Lamivudine

Evening: Zidovudine Lamivudine
Efavirenz

Zidovudine

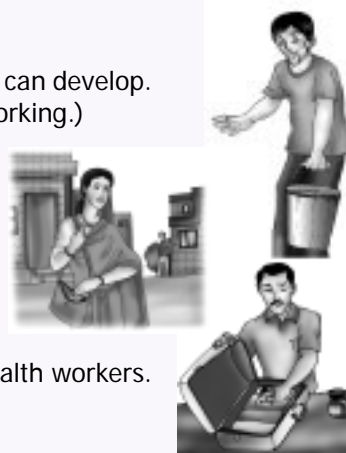
Lamivudine

Efavirenz

ZDV-3TC-EFV

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.)
- Drugs must be taken twice daily, **and miss no doses.**
- This 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.



It is common to have side effects. They usually go away in 2 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 little at regular intervals.
EFV can cause brain effects such as sleepiness, dizziness, bad dreams, or problems with sleep or memory →	These side effects usually go away. Taking the efavirenz at night is important. Do not take Efavirenz immediately after eating, it is best when taken before sleep.
Muscle pain, fatigue →	These will go away

If nausea or diarrhoea persist or brain effects get worse, report to the health worker **AT THE NEXT VISIT.**

SEEK CARE URGENTLY if:

- Bizzare thoughts/confusion
- Pale or do not have enough blood
- Yellow eyes with high fever, headache running nose and body ache
- Skin rash, along with fever and ulcer in the mouth and lips
- Fatigue and shortness of breath
- Missed period/possibility of pregnancy

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

4. TREATMENT EDUCATION CARD Now you are on ART



Stavudine	Lamivudine	Efavirenz
d4t-3TC-EFV		

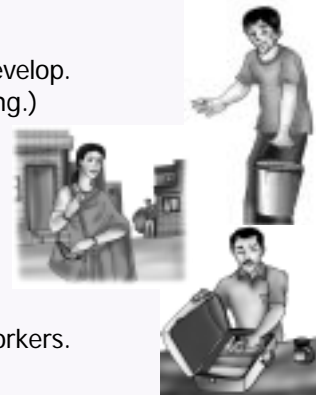
Daily

Morning: Stavudine
Lamivudine

Evening: Stavudine Lamivudine
Efavirenz

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.)
- Drugs must be taken twice daily, **and miss no doses.**
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If nausea or diarrhoea persist or get worse, or you have any of the following, report to the health worker **AT THE NEXT VISIT.**

- Tingling, numb or painful feet or legs or hands.
- Arms, legs, buttock, and cheeks become **THIN**.
- Breasts, belly, back of neck become **FAT**.

SEEK CARE URGENTLY if :

- Bizzare thoughts/confusion
- Severe abdominal pain
- Fatigue **AND** shortness of breath
- Yellow eyes with high fever, headache running nose and body ache
- Skin rash, along with fever and ulcer in the mouth and lips



SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.8 : Resistance to ART

Information resource 'A'

1. One of the main problems we face in ART is that the drugs may stop working and the HIV virus in that person's body develops what we call **resistance to treatment**.

Resistance is the ability of HIV virus to multiply (replicate) even when ART *is taken regularly*. Resistance occurs because of changes in structure of HIV virus.

2. ART resistance occurs when the HIV in a person's body is no longer affected by medication, and the HIV is therefore able to multiply and destroy CD4 cells. ART resistance occurs when people do not take their medication regularly.
3. To help people understand the concept of resistance, refer to Handouts A, B and C.
4. When HIV virus develops resistance to ART it leads to 'treatment failure'. At this point the person will become sick again. Sometimes a new regimen of a different medicine can be provided that can battle the HIV that is resistant to other drugs. However, there are only a few drug regimens, so HIV can eventually become resistant to all drugs.
- 5.

When a person does not adhere there will be treatment failure and the person becomes sick again. If two or more pills are missed in a month resistance is likely to develop.

Key Messages :

- ***Resistance is a change in the virus that makes the virus protected and ARV drugs ineffective.***
- ***ART resistance occurs when people do not take their medication regularly.***
- ***The best way to prevent resistance and treatment failure is to help and support people on ART to achieve and sustain at least 95% adherence to treatment.***

SECTION 1

FACTS ABOUT HIV, AIDS AND ART

Session 1.8 : Resistance to ART

Handout 'A' : Questions About Resistance

Questions about resistance



1. **Have you ever taken any medications in the past? If yes, did you miss any doses? For example when you had a cold and the doctor asked you to take the medicine thrice a day for five days and the other medicine twice a day for four days, did you take all of them?**

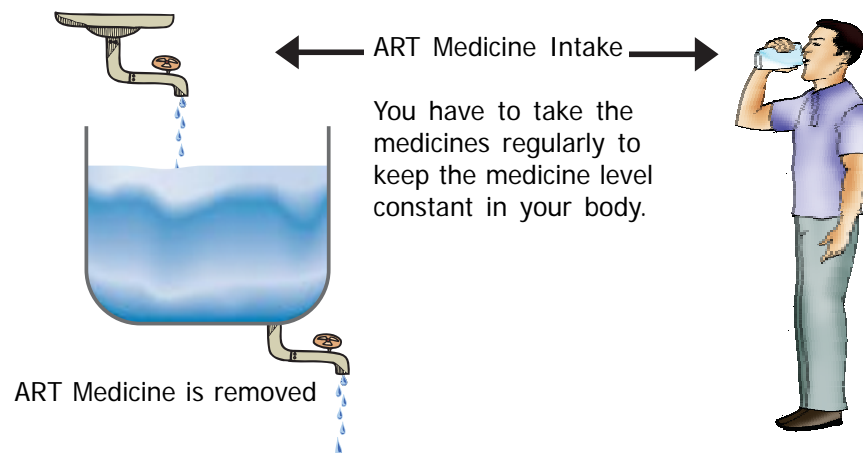
If you took your medicines right on time, good for you. But if you did not, you should know that most people tend to miss out medicines. For many diseases, like diabetes or hypertension (blood pressure), if the medicines are stopped and then restarted, they will continue to work. But this may not be true for HIV.



2. **What if doses are missed?**

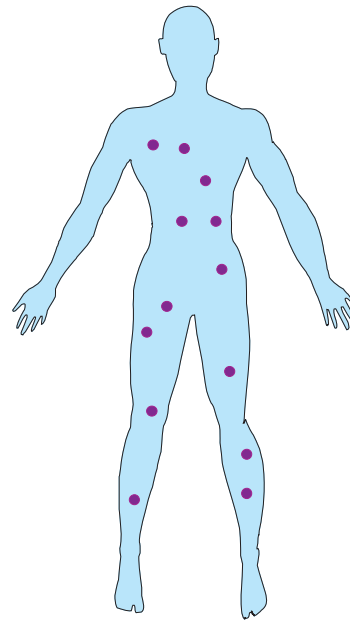
Resistance to ART medicines develops and the medicines will not work against the HIV virus. Then HIV continues to grow in the body and will destroy CD4 cells (the soldier), leading to weakening of the immune system, opportunistic infection, weight loss, diarrhoea, cough.

Think of your body as a pot with a tap. When you take ART medicine regularly, the body has enough medicine to fight the virus. After a while, however, usually about 12 hours, the level of medicines decreases. Therefore, you have to continuously take the medicine (usually every 12 hours, but it depends on the medicine and recommended dose) to keep the medicine in the blood.

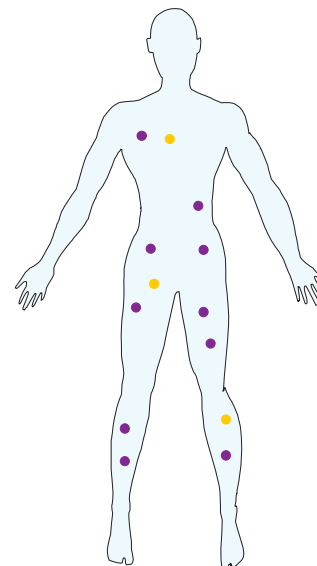


But medication only stays in our bodies for a short time, like a bottle that has a leak in the bottom. Therefore, we must continue to take medication to keep enough of it in our body at all times.

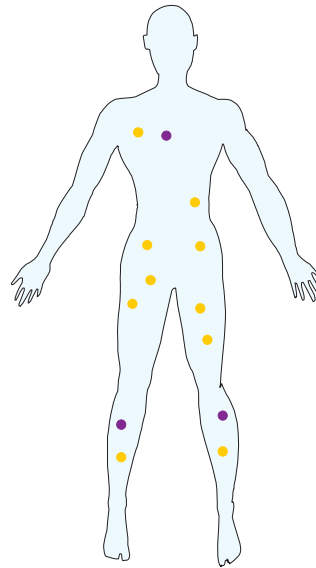
When a person is infected with HIV, there are viruses that live inside the body. The virus can be seen in the body in the figure below as purple dots. As long as we keep enough medication in our body, the medicine can keep the virus from reproducing.



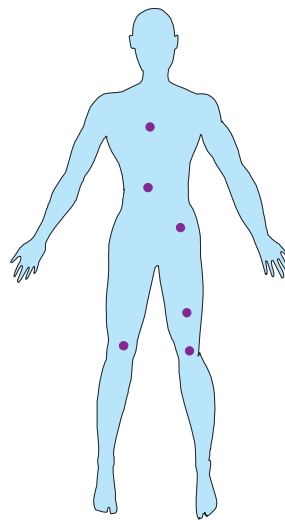
But if we don't take medicines on time, the HIV virus gets an opportunity to develop resistance against HIV medicine. Resistance is the ability of the virus to oppose the effect of the medicine. If you miss the medicine more than two times, the chances of HIV viruses developing resistance to HIV medicine are very high. These resistant viruses can be seen in the body as yellow dots.



These resistant viruses then reproduce in our bodies. When a person returns to taking medicine on time, the drugs cannot kill the resistant virus. So the medicine no longer works, and HIV takes over the body.



So the only way to keep the viruses from reproducing is to take the medicine at the same time, every day. If a person does that, he/she can stay healthy for a long time.



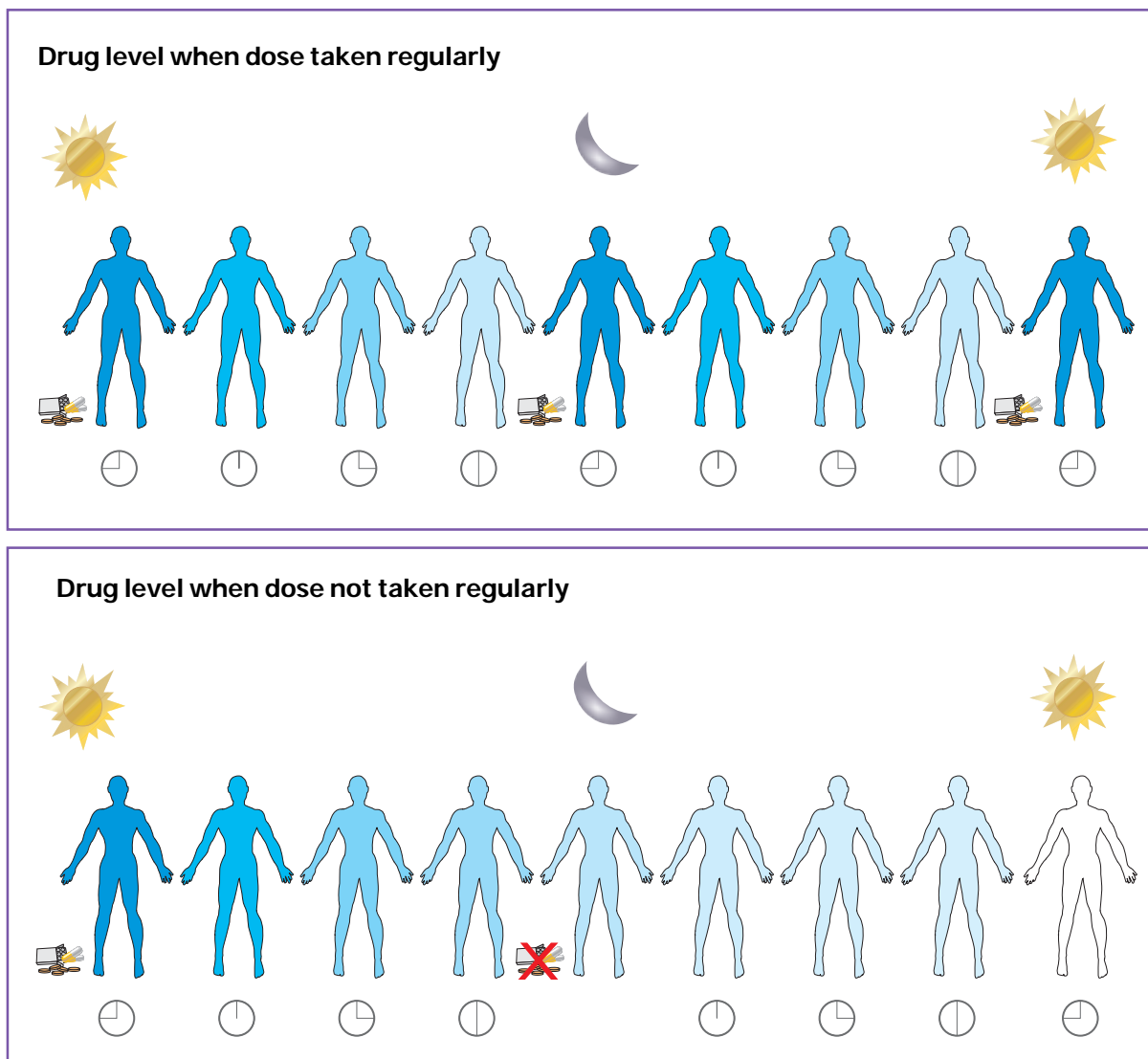
3. **If a person with HIV is not taking ART medicine, is it possible for the HIV virus in his body to become resistant to medicines?**

The answer is no because there is no ART medicine at all in the person's blood. The HIV virus in a person who is not taking ART medicine will not develop resistance to HIV medicine.



4. If a person with HIV is taking ART medicine regularly every 12 hours without fail as suggested by the doctor, will the HIV virus in his body become resistant to ART medicine?

The answer is no because the person has taken the medicine correctly; thus there is an adequate level of medicine in the blood, which is able to control the virus completely.



In order for ART to work properly it must remain in our body at all times. However, over time, the level of medicine decreases in our body. Therefore we need to continue taking ART medicine every twelve hours to keep enough in our body.

Resistance does not occur in a person who is not taking ART medicine or in a person who takes it regularly.



5. Then when does the HIV virus in the body become resistant to ART medicine?

If medicines are not taken regularly. If we forget to take our tablets, there will be no medicine in our body to fight HIV, and this causes serious problems. Whenever a dose is missed, the drug levels are not enough to kill the virus, and the virus gets an opportunity to develop resistance to ART medicine.

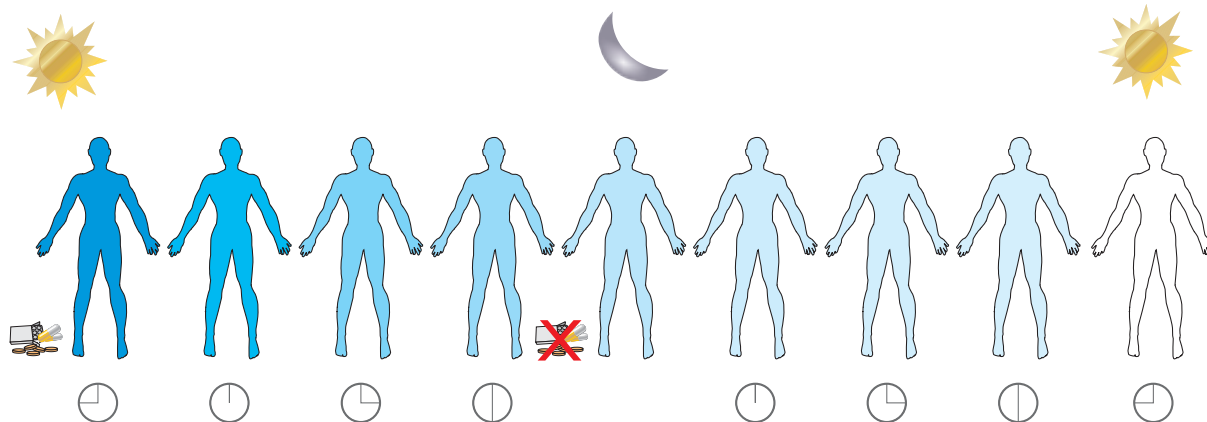
Think of this opportunity as if the virus purchased a lottery ticket against the medicine.



6. What if one dose is missed?

The virus gets one opportunity (compare it to buying a lottery ticket) to develop resistance to ART medicine.

Drug levels when a dose is missed



One missed dose is one opportunity for virus



JANUARY						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
✓ 1	✓ 2	✓ 3	✗ 4	✓ 5	✓ 6	✓ 7
✓ 8	✓ 9	✓ 10	✓ 11	✓ 12	✓ 13	✓ 14
✓ 15	✓ 16	✓ 17	✓ 18	✓ 19	✓ 20	✓ 21
✓ 22	✓ 23	✓ 24	25	26	27	28
29	30	31				

Two missed doses are two opportunities for the virus



7. **What are the chances of the HIV virus becoming resistant to the ART medicine?**

The more often you miss the drug (the more lottery tickets the virus has with it) the more likely resistance will develop.



8. **Even if I miss once, will the HIV virus develop resistance to ART medicine?**

It may. However

if you don't take it MORE THAN TWO TIMES in a month (more than two lottery tickets in a month), then resistance is very likely to occur.



9. **What happens if resistance occurs?**

As described above, the medicine will stop working and you will get sick.



10. **But aren't there other medicines for HIV as mentioned above?**

Yes, there are alternatives. They are very expensive and not available for free in the government hospitals, or they have more side effects and/or are more complicated to take. For example, you will have to take 2-3 pills more than one time a day as compared with the current regimen (assuming you are taking the first-line regimen), which is only one pill twice a day.



11. What if I miss a dose then? Can I take it if I remember it later or should I take it with the next dose?

It depends on when you find out you missed the dose. For example, if you realize at 11AM that you missed your 8AM dose, you can take it then. However, if you remember it in the evening when it is time for the next dose, DO NOT double the dose; just take the next dose and continue. Missing a dose should be avoided.

If you forget a dose, do not take a double dose.

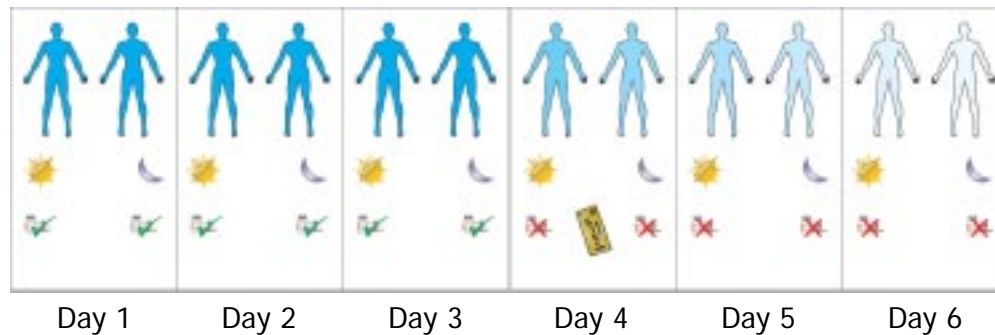


12. Now let us imagine that you went out of town and have with you only six tablets of medications, but you won't get back to your home where you have your medicines for the next six days. How will you take your medicines?

The choices are: Take the pills as prescribed twice a day x 3 days and stop. Or take 1 tablet x 6 days, go back home and continue twice daily.

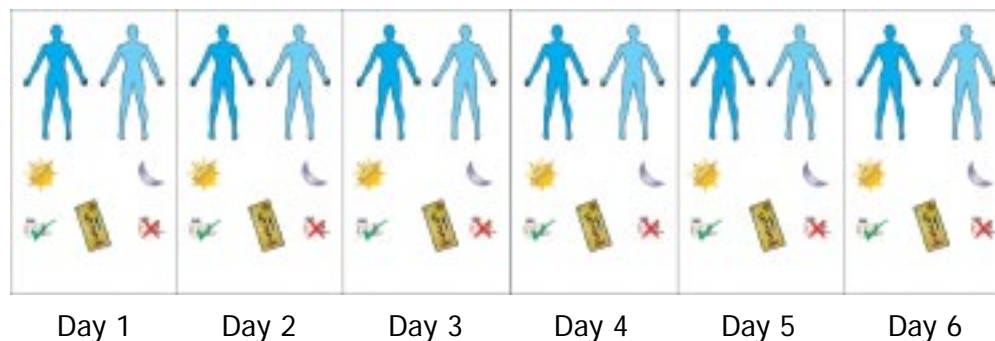
If you take the tablets twice a day x 3 days and stop, the virus will get only **one** opportunity (only one lottery ticket) to develop resistance.

2 tablets 3 days and then no tablets until back home.



If you take the tablets once a day x 6 days, the virus will get **six** opportunities (six lottery tickets) to develop resistance. And we have already discussed before that if you miss two or more doses the chances of resistance developing are very high.

One tablet a day for 6 days until back home.



SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.1 : The Role of Antiretroviral Therapy in the Context of Chronic HIV Care

Information resource 'A'

1. Over the last few years, the gradual expanding availability of and access to antiretroviral drugs has increased care options for people living with HIV and AIDS. We have witnessed a gradual but consistent shift from an almost exclusive focus on *acute care*—i.e., primarily dealing with opportunistic infections—to expanding access to lifelong treatment and care for people living with HIV and AIDS. Thus there has been a transition to a more comprehensive framework that looks at integrating acute and chronic care, as both are necessary, as well as prevention in care settings and linkages with home-based care. The expansion of ART services is a key acute care. Common diseases like cold, diarrhoea, skin infections, and most opportunistic infections like Candida and cryptococcal meningitis last for a short period of time, usually less than 1-2 weeks. Such diseases are called “acute,” and managing them usually involves a one-time prescription and no follow - up visit to the clinic.
2. Chronic care. Diseases like diabetes, hypertension, and joint diseases persist for long periods of time, usually several decades or even for life. Several infections like tuberculosis are also “chronic,” as they persist for months or years. HIV infection being life-long is also a chronic condition. Chronic disease, unlike acute disease, requires repeated visits to the doctor and life-long treatment with medicines.
3. Difference between acute and chronic diseases.

Acute diseases :

- Usually requires only onetime treatment.
 - There is a cure.
 - There is no need for follow up.
-

Chronic diseases :

- There is usually no permanent cure (There are a few exceptions like tuberculosis).
 - There is a need for regular follow-up
 - The treatment with medicine is for years or lifelong as in HIV, diabetes and hypertension.
 - Hence adherence to medicines becomes an issue.
 - Treatment needs to be tailored to the individual's life.
-

4. Successful ART program involves far more than getting pills into the mouth of the client. ART is not a cure; for optimal outcomes, ART must always be linked strongly with prevention and care efforts, as these interventions are complementary.



5. What does client-centered care mean in the context of ART?

Good client-centered chronic care recognizes that the client has a right and a responsibility to understand and learn to manage his or her own chronic condition. Good chronic care is based on developing and supporting a partnership with the client in order to address the client's concerns and priorities.

6. HIV infection and its slow progression to AIDS require much education and support to give clients the skills to self-manage (manage their own condition).
 - Although the clinical team and others at home and in the community can help, it is the client that need to learn to cope with their infection, to disclose to those that they trust in order to get further help, to learn to practice prevention and positive living, and to understand and use ART and other treatments. This requires much education and support.
 - Rapid treatment scale-up in resource-constrained settings requires a public health approach. This includes implementing simplified and standardized services that make the best use of existing network systems.
 - People living with HIV and others can play a very important role in strengthening and expanding limited human resources. This requires involving people living with HIV as peer educators and family members of those infected with HIV.

Key Messages

- ***The gradual scaling up of ART reflects and contributes to a shift from an almost exclusive focus on acute care to a view of HIV infection as a chronic condition, requiring an expanded framework of access to life-long treatment and care for people living with HIV . This process aims to better integrate acute and chronic care, prevention in care settings, and linkages with home-based care.***
- ***A successful ART program involves far more than getting pills into the mouth of the client. ART is not a cure; for optimal outcomes, ART must always be linked strongly with prevention and care efforts, as these interventions are complementary.***
- ***Good client-centered chronic care recognizes that the client has a right and a responsibility to understand and learn to manage their chronic condition. Good chronic care is based on developing and supporting a partnership with the client in order to address the client's concerns and priorities.***
- ***Rapid treatment scale-up in resource-constrained settings requires a public health approach. This includes implementing simplified and standardized services that make the best use of existing network systems, and especially people living with HIV groups.***
- ***People living with HIV and other providers can play a very important role in strengthening and expanding limited human resources. People living with HIV contribute an essential understanding of what it means to live with HIV and AIDS at personal and social levels.***

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.2 : Adherence to HIV Treatment

Information resource 'A'

1. Adherence to HIV treatment means “to stick, to remain loyal to HIV treatment.” The success of HIV treatment requires a partnership in which the client, the doctor, the counselors and other team members, and the social environment interact constructively. This means addressing clinical, personal, and social factors that may impact a client’s ability to achieve and maintain the necessary level of treatment adherence.



2. **What does adherence mean? A very simple definition is :**

- *“Adherence means to stick to something.” In HIV treatment it means the necessary conditions to achieve successful outcomes. In order to achieve this aim the person with HIV has to*
- *Regularly follow up with the doctor for check-ups and for lab tests.*
- *Take the ART medicines as prescribed.*

- It is not enough if the person is taking ART daily. It is equally important to follow up with the doctor and get periodic lab tests including a CD4 count test as suggested by the doctor.
- Theoretically, full adherence to ART medicines should be defined as the client taking 100% of prescribed doses each day, at scheduled times when prescribed, and with the necessary dietary requirement for each of the medications. However, real life has shown that even doctors are unable to stick to such a rigid definition of adherence.
- In the context of ART, experiences have shown that clients must take over 95% of the necessary doses. Therefore, as counselors our aim is to support clients to achieve and sustain at least 95% rate of adherence to ART regimens. Counselors play a very important role in helping clients identify challenges to adherence and offering possible solutions to overcome these challenges.



3. **“Why do you think that over 95% of the doses are necessary to treat a person with HIV?”**



The aim of ART is to suppress the replication of the HIV virus in the body. We know that there is a direct relationship between the level of ART drugs in the body and the suppression of the virus. If adherence rates drop below 95%, levels of ART in the body are low and not enough to control HIV. In such a situation the HIV virus gets an opportunity to develop resistance to ART.

4. Adherence to treatment requires a client-centered partnership in which the client is encouraged and supported to understand the factors for therapeutic success and identify challenges and possible solutions to achieving this goal. Therefore, it is not sufficient to define adherence only from a clinical perspective.
5. The regimens currently available require a client to take HIV treatment for life. This in turn means that a client has to sustain adherence to HIV regimens for life. Many clients may not be equipped to face such a daunting commitment without understanding the requirements of ART and without access to support on a regular basis, and even in the best-case scenarios adherence often presents different challenges for different clients.
6. There are several factors that may impact adherence *from a client's point of view*. (Refer to the list provided below in the Information Resource.)



-
- **Client-centered factors impacting adherence.**
 - **Providers' attitudes and behaviors impacting adherence.**
 - **Environmental and social factors impacting adherence.**
-

7. One needs to remember that *ART is based on managing HIV as a chronic condition*. Clients affected by other chronic conditions may face similar challenges in sustaining their ability to stick to complex and/or challenging therapies. However, the nature of

The HIV virus and its ability to mutate and become resistant to treatment is an additional and very serious threat to therapeutic success, and this is why adherence plays a critical role.

Key Messages :

- ***“Adherence means to stick to something”. In the context of ART, studies have shown that clients must take over 95% of the necessary doses in order to achieve the conditions for therapeutic success, i.e. clients should “stick” to at least 95% of their drug schedule. Therefore, as counselors our aim is to support clients to achieve and sustain this rate of adherence to their regimens.***
- ***Not taking the medicines properly may lead to “drug resistance.” This happens because the antimicrobial agents in the HIV medicines do not tolerate frequent lapses in adherence since these lapses result in suboptimal concentrations of the drugs in the body. This in turn contributes to resistance to ART. Then it becomes difficult for the drugs to suppress the multiplication of the HIV virus. The drugs stop working.***

- *The ART regimens currently available require a client to take HIV treatment for life. This in turn means that a client has to sustain adherence to HIV regimens for a long time. Many clients may not be equipped to face such a daunting commitment without understanding the requirements of ART and without access to support on a regular basis, and even in the best-case scenarios adherence often presents different challenges for different clients.*
- *Therefore in a client-centered approach to care the word adherence is used to communicate that the success of a complicated medical regimen requires a partnership in which the client, the counselors, and the social environment interact constructively to achieve a goal, namely the success of the treatment or therapy. This means addressing clinical, personal, and social factors that may impact a client's ability to achieve and maintain the necessary level of treatment adherence. We need to consider adherence as the result of the complex interactions of many issues affecting the quality of life of clients.*
- *Counselors play a very important role in helping clients identify possible challenges and solutions to managing treatment as successfully as possible and maintaining quality of life. Establishing a good client-counselor rapport is a critical factor to help clients maintain treatment adherence. In order to achieve this aim, counselors should focus on the clients' concerns and priorities and help them to develop knowledge and skills to self-manage their chronic condition as effectively as possible.*

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.2 : Adherence to HIV Treatment

Information resource 'B' : Factors Impacting Adherence

Client-centered factors impacting adherence

- Feeling that health providers do not consider and respect the client's concerns and priorities
- Misunderstanding of prescribing instructions
- Frequent changes to drug regimens
- Multiple health care providers prescribing medicines
- Limited faith in the effectiveness of medicines and/or in health providers
- Inability to read written instructions
- Forgetfulness or confusion
- Denial of the illness or its significance
- Anger
- Depression
- Not feeling motivated
- Stress
- Fear of having to disclose one's HIV status
- Fear of consequences of disclosure of HIV status, e.g., gender-based violence
- Concerns about the impact of medicines on one's sexual life
- Lack of skills to communicate/negotiate with partners and families
- Lack of skills to communicate own needs and concerns with health providers
- Concerns about taking medicines at work
- Reduction, disappearance, or fluctuation in disease symptoms
- Concerns about medicines, e.g., side effects, toxicity, bad taste, etc.
- Inability to afford medicines



- Inability to afford regular and proper nutrition
- Physical difficulties limiting access to or use of medicines, e.g., problems swallowing tablets, opening containers, or handling small tablets
- Inability to distinguish colors or markings on medicines
- A history of non-adherence with regimens in the past
- Concurrent substance abuse
- Lack of information and understanding about the illness
- Lack of information and understanding about the need for medicine
- Lack of information and understanding about the importance of adherence for therapeutic success of ART
- Lack of information about possible side effects and ways to manage them
- Drugs with similar names or similar in appearance
- Precautions that are perceived as inconvenient or restrictive, e.g., exclusion of certain foods or herbal remedies in conjunction with medicines
- Unpleasant administration, e.g., injections
- Complex regimens, e.g., multiple drugs or frequent dosing
- Lack of family and social support
- Cultural beliefs about disease, death and dying
- Stigma and discrimination against people living with HIV

Providers' attitudes and behaviors impacting adherence

- Stigmatizing or discriminatory attitudes to HIV-positive people in general
- Stigmatizing or discriminatory attitudes to people perceived to be “bad” or deserving to be ill because of their lifestyle
- Lack of understanding of clients' personal and social circumstances
- Incorrect assumptions about clients' levels of understanding of their illness and the need for medicine
- Perceiving clients only as passive recipients of instructions
- Incorrect assumptions about clients' motivation to manage complex treatment regimens
- Gender biases, e.g., women are not expected to make their own decisions



- Lack of knowledge and skills to provide good counseling
- Lack of understanding of and respect for clients' rights, especially informed decision making
- Lack of understanding of the impact of stigma and discrimination on clients' lives
- Lack of skills to help clients assess their options to manage ART as successfully as possible
- Misconceptions about becoming infected with HIV through contacts with HIV-positive clients
- Lack of understanding of ART in the context of managing HIV as a chronic condition

Environmental and Social Factors Impacting Adherence

- Social stigma and discrimination against people living with HIV
 - Insufficient attention to clients' rights and clients' empowerment
 - Lack of social support networks integrated into the HIV/AIDS continuum of care
 - Lack of meaningful participation of people living with HIV in the HIV care continuum
 - Unaffordable medicines
 - Lack of appropriate and functioning referral systems
 - Poor or inadequate policy commitment and leadership
 - Lack of effective program strategies to increase access to ART
 - Insufficient focus on prevention, treatment, and care as mutually supportive
 - Lack of human resources
 - Inadequate strategies and investments to strengthen capacity (e.g., people living with HIV)
 - Inadequate supply and demand systems
 - Poor data collection, monitoring, and supervisory support
 - Restrictive national and international requirements and obligations that may limit access to medicines, e.g., patent issues and trade agreements
 - Cultural beliefs about disease, death, and dying
-

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.2 : Adherence to HIV Treatment

Handout A : Adherence Do's and Don't

Source : International Training and Education Center on HIV (ITECH), India.

Do's



Take your ART in the morning and evening without fail everyday.



Schedule doses before routine daily activities. For example, take medicines while watching favorite TV shows or at the time of the breakfast, dinner or bedtime.



Use reminders like alarms daily calendar, punch card, watch or cell phone for timely intake of medicines.



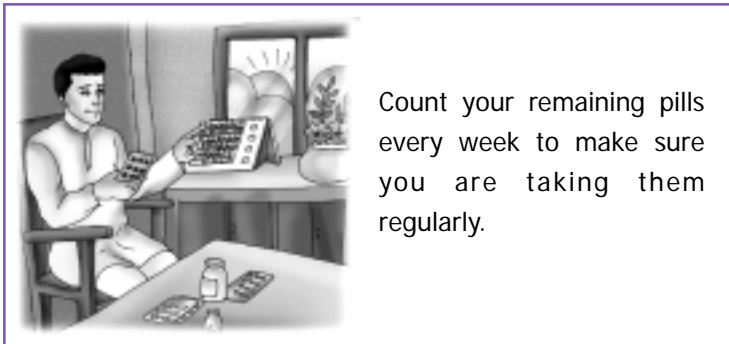
Carry the medicines required for the day in a small pill box or in the hand bag or purse when going out.



Take your medicines at same time everyday (for example 8 o'clock in the morning and 8 o'clock in the evening)



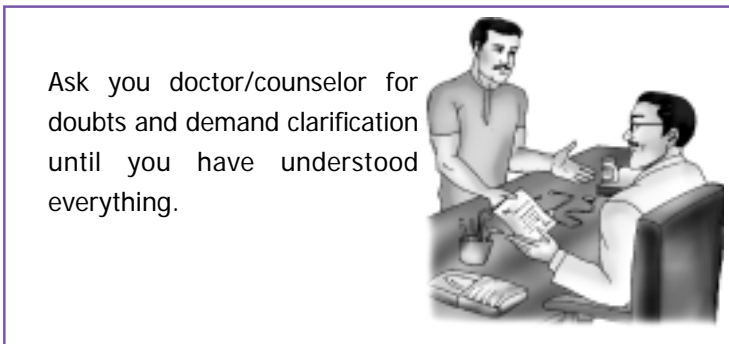
Plan early for the changes in your routine such as vacations, festivals or family celebrations and carry the medicines with you always for regular intake.



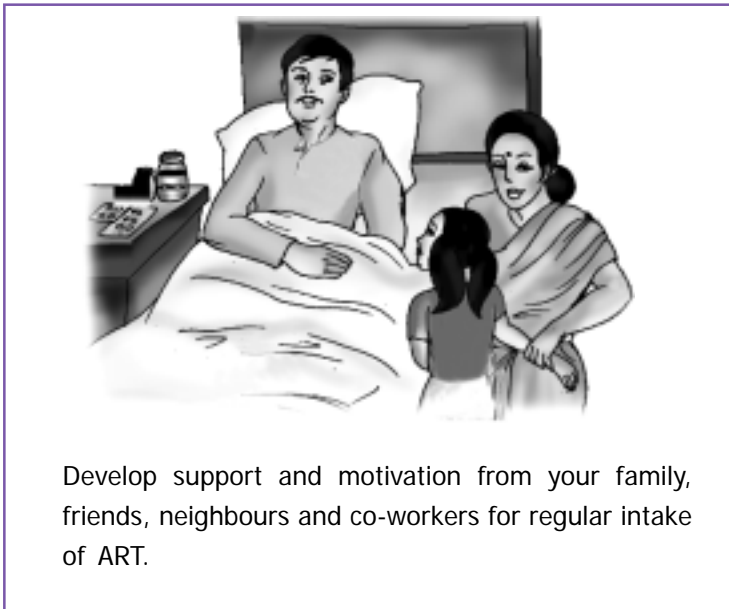
Count your remaining pills every week to make sure you are taking them regularly.



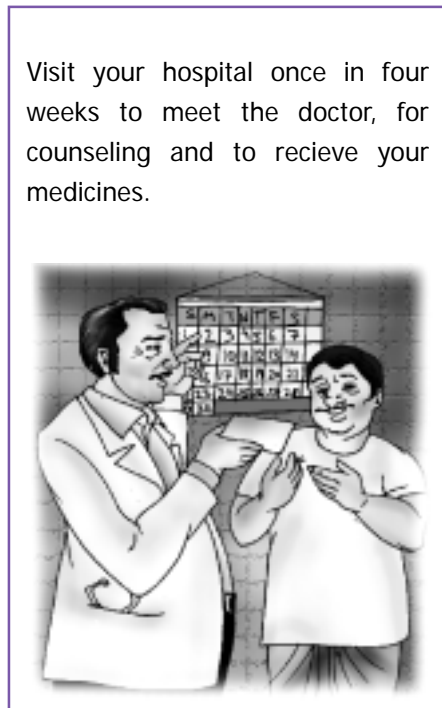
Consult your doctor immediately if you have serious side effects or illnesses.



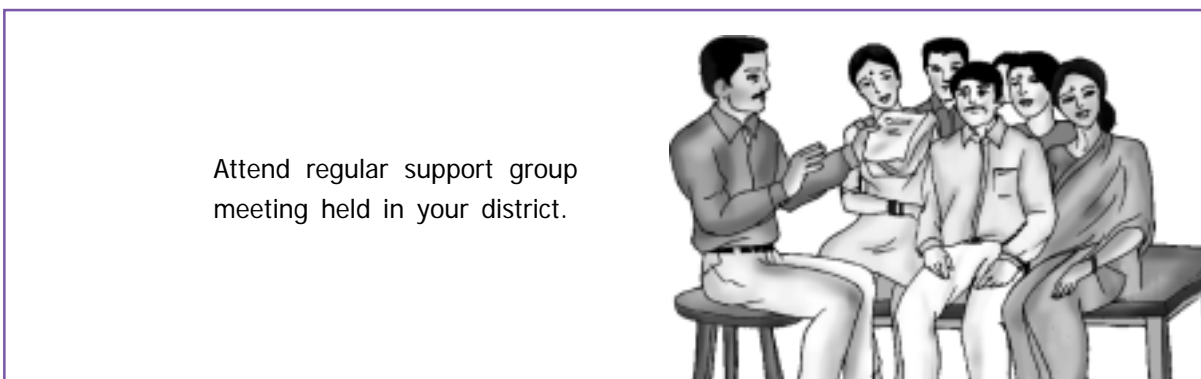
Ask your doctor/counselor for doubts and demand clarification until you have understood everything.



Develop support and motivation from your family, friends, neighbours and co-workers for regular intake of ART.



Visit your hospital once in four weeks to meet the doctor, for counseling and to receive your medicines.



Attend regular support group meeting held in your district.

Don'ts



Do not share your medicines with your spouse, partners or children.



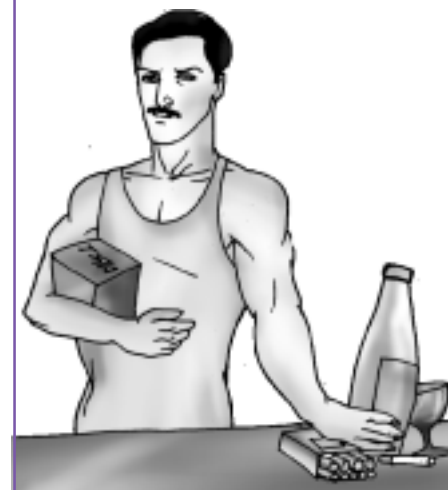
Avoid taking over dosage of ART.

Do not send your family or friends to collect your ART for you.



Be honest with your doctor or counselor if you miss a dose and then follow their suggestion.

Avoid self-medication. Use only medicines prescribed by your doctor while you are on ART.



Avoid smoking, liquor, tobacco, addictive drugs and injection while on ART as they are known to interact with the immune system thereby making ART less useful.

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.3 : Principles of Chronic Care in the Client-Centered HIV Context

Information resource 'A'

1. A few general principles that apply to the provision of good chronic care, including chronic HIV care are :

 - a. Develop a treatment partnership with your client.
 - b. Focus on your client's concerns and priorities.
 - c. Use the 5 A's: Assess, Advise, Agree, Assist, Arrange.
 - d. Support client self-management.
 - e. Organize proactive follow-up.
 - f. Involve "expert clients," peer educators, and support staff in your health facility.
 - g. Link the client to community-based resources and support.
 - h. Use written information—registers, treatment plans, and treatment cards—to document, monitor, and remind.
 - i. Work as a clinical team.
 - j. Assure continuity of care.
 - k. Remember that the person with HIV is the center of all our activities.

2. All these general principles of good chronic care are important, but that as providers and especially as Counselors we need to focus attention in particular on a,b,c,d,f and i.
3. The remaining principles may be considered as crosscutting issues applying to all the stages of good chronic care. For example, h. Use written information, is an essential element of good care in general, not just of chronic care, as is j. Assure continuity of care.
4. This session will deal in more detail the six principles listed below (which does not include the 5 A's because these will be discussed in greater detail later :
 - A. Develop a treatment partnership with your client.
 - B. Focus on your client's concerns and priorities.



- C. Support client self-management.
 - D. Work as a clinical team.
 - E. Involve “expert clients,” peer educators, and support staff in your health facility.
5. It is very important to have basic understanding of client-counselor partnership, the members of the team providing HIV care including ART service, roles and responsibilities of the team members and importance of involving people living with HIV and AIDS in this effort. (Refer to the Information Resource for more information)

Key Messages :

Managing any chronic condition requires the clients’ informed and active participation, especially when the client has to make potentially difficult decisions such as disclosure of the disease, the need to change behaviors, and commitment to long and complex treatments, such as in the case of HIV/AIDS.

It is very difficult for anybody to make and sustain commitments like these without knowledge, skills, and support to feel in charge of their own health care.

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

A critical issue for successful client self-management is to establish a partnership between the care team and the client that the client trusts and believes in.

Provision of good HIV chronic care requires teamwork.

Clinical teams may work together differently depending where they are located in order to ensure adequate compliance with national guidelines, supervision, case review, and accountability for overall clinical responsibility for the chronic HIV care delivered by the team.

Refer Annexure 1 - Coordinated approach to Chronic care to understand the roles of a care team.

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.3 : Chronic Care Concepts

Information resource 'B'

A simple definition of partnership : An agreement between two or more people to work together in an agreed way toward an agreed goal. This implies shared responsibility and commitment, clear expectations and roles, and mutual respect.

Advantages of focusing on clients' concerns and priorities : Often we focus only on the obvious signs or symptoms of illness and may miss the real reasons behind the client's visit to the clinic. It is important to find out these reasons and make sure that they are addressed. Failure to achieve this aim can seriously compromise rapport building with the client. You may refer to the Notes in the Adherence to HIV Treatment session (2.3) for examples of clients' concerns.



What does client self-management mean?

Self-management means clients taking responsibility for their own health care.

A critical issue for successful client self-management is to establish a relationship between the care team and the client that the client trusts and believes in.

Supporting client self-management : Whenever talking about how the client can have his/her needs met and who can support him/her, health workers should always try to leave the client as much in charge of his or her own care as possible. This is very important for adolescents and adults. A client with a chronic condition such as HIV/AIDS has a vital role in the management of his/her own care. This is called Self-Management.



- Self-management recognizes that the client takes responsibility for the daily treatment of his/her condition.
- The client takes responsibility for taking medicine. He or she makes choices about diet, exercise, and other lifestyle issues that protect or damage their health; this is often called positive living.
- When he or she makes choices on how to practice safer sex, use condoms, and prevent sexually transmitted infections and unintended pregnancies; this is called prevention.
- The care team helps clients understand their options and the consequences of their decisions. The client is the one who, on a daily basis, makes lifestyle choices and chooses to follow the plan of care.

- The client is responsible for doing what the care team recommends.
- Clients need to be educated, motivated, and supported to take care of themselves. This gives them a better sense of control and makes them feel better about their situation. It has been shown that this approach makes them more successful in caring for themselves.
- Promoting self-management includes developing a relationship between the care team and the client that the client trusts and believes in.

Advantages of supporting client self-management :

Managing any chronic condition requires the client's informed and active participation, especially when the condition may require the client to make potentially difficult decisions, such as disclosure of the disease, the need to change behaviors, and commitment to long and complex treatments, such as in the case of HIV disease. It is very difficult for anybody to make and sustain commitments like these without knowledge, skills, and support to feel in charge of their own health care.

A clinical team to provide ART :

Provision of good chronic care requires teamwork. This principle applies to chronic HIV care too. In order to deliver ART, ideally clinical teams should include a nurse, a clinical officer, an ART educator/ counselor (for education, psychosocial support, adherence preparation and support), and a medical officer or doctor. Providing good chronic care requires teamwork. They can consult with each other easily every day.

Why is involving “expert clients,” peer educators and support staff—and especially people living with HIV—in your health facility for good chronic care?

There is a growing consensus that a public health approach is the way forward for scaling up access to ARV treatment in resource-limited settings. This aims to provide treatment for as many people as possible, while working towards universal access to ARV treatment. A key element of the public health approach for scaling up ARV treatment is the involvement of a range of stakeholders, including people with HIV and other community members, to help human resources and increase access to and use of services.



SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.4 : Good Chronic Care : Stages in Counseling Using 5A's

Information resource 'A'

1. The Stages in Counseling, 5 A's are a key element of good chronic care. They provide practical steps to use in caring for clients.
 2. There are different types of Clients on ART with whom Counselors should make sure to cover the detailed steps of the 5 A's.
(Note: this categorization applies only in the context of this exercise for learning purposes):
Clients who are preparing for ART. These clients have NOT yet started treatment, but have been assessed to be eligible to go on ART.
Clients who are initiating ART. These clients are actually starting treatment.
Clients who are on ART and to whom we need to monitor and support for adherence.
 3. Not all of the elements of 5 A's would apply to all the three types of clients. For example, "Checking if client is interested in receiving therapy" in ASSESS applies only to clients who are preparing for ART. There may well be elements of the 5 A's that apply to all categories of clients.
 4. Refer to the handout for this session for further explanations and considerations for each of the elements in the 5 A's. It is important to remember that providers should not consider the 5 A's as rigid boxes in which to become "caged" during the counseling process. Even in the same counseling session, counselors may be in the AGREE step and realize that the client still is unclear about some aspects of the treatment being discussed, and therefore counselors must be able to revisit the ASSESS and ADVISE steps to be sure that the client can make an informed choice.
 5. Some elements of certain A's could also be classified as important elements of other A's, e.g. #14 in ASSESS could also be seen as an important aspect of ASSIST.
 6. In order to implement this counseling framework with Clients on ART, counselors must be able to have not only knowledge about ART and HIV/AIDS, but also equally importantly the necessary counseling skills to be able to use the right questions and key messages at the right time with clients.
- The 5A's express a key general principle of good chronic care. In the context of ART for HIV disease, the 5 A's provide a counseling framework that can be applied to key groups of clients, namely :

- A Clients who are preparing for ART.** These clients have NOT yet started treatment, but have been assessed to be eligible to go on ART.
 - B Clients who are initiating ART.** These clients are actually starting treatment.
 - C Clients who are on ART** and to whom we need to monitor and support for adherence.
- Counselors have a tendency to skip the AGREE step. In emergency situations, or when clients are too ill to go through a discussion, it may be justifiable to skip. However, most of the time HIV care is not emergency care. In chronic care, AGREE is a critical step—without it, there is no partnership with the client and no good self-management. For young children, this step has to be undertaken with parents or guardians.
 - Counselors should consider these five steps as a continuum through which they need to assist clients in their treatment journey. This means that Counsellors must have not only knowledge about ART and HIV/AIDS, but equally importantly the necessary counselling skills to be able to use the right questions and key messages at the right time with different types of clients at different times in their treatment journey.

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.4 : Good Chronic Care : Stages in Counseling Using 5 A's

Information Resource 'B' : Stages in Counseling : The 5 A's

Assess



1.	The purpose of today's visit is, i.e., the immediate concern/priority of the client
2.	Listening to the answer – paraphrasing if necessary to make the client feel that you heard his/her concern.
3.	Asking further questions to find out any other major issues for the client's visit.
4.	The knowledge of the person regarding HIV, : treatment, side effects
5.	The person's interest in HIV treatment
6.	Obstacles to adherence.
7.	Behavioral risks that might interfere with adherence to care and treatment; e. g., drug and alcohol abuse
8.	Expectations of ART, whether the person thinks it is a cure for HIV
9.	Asking questions respectfully and nonjudgmental manner. Ask in a way that makes it easier for clients to be truthful.
10.	Role of stigma related to taking the pills
11.	Family and community support
12.	Counting pills (to help check if the client is taking them according to the treatment schedule)
13.	How many pills the person has forgotten yesterday, in the last three days, in the last month
14.	The daily schedule (which activities the person does every day) of the person so as develop an appropriate plan to take medicines regularly



Advise

1.	Explain HIV is a chronic disease and it progresses over time.
2.	Explain that the various benefits of ART outweigh the negatives like side effects, stigma.
3.	Explain the possibility of side effects and drug interactions.
4.	Explain the critical importance for complete adherence to daily treatment.
5.	Explain what resistance is and when it may happen.
6.	Explain the options for treatment—not just “telling” what to do—so that the client feels that he/she is more motivated and better prepared for self-management.
7.	Advise on diet.
8.	Explain the importance of limiting or stopping alcohol consumption.
9.	Discuss the importance of disclosure of HIV status.
10.	Discuss the importance of testing for other people involved, e.g., spouses, partners, and children.
11.	Reinforce messages on safer sex.
12.	Ask questions to make sure that the person understood important information.
13.	Refer to doctor (e.g., changes to treatment plan, managing side effects, client stopping treatment).

Agree

1.	That the person is a partner in his/her treatment plan.
2.	That the person understands that his/her life depends on taking the medicines every day.
3.	That the person wants the treatment before initiating ART.
4.	That the person is willing to come for the required clinical follow-up.
5.	On the plan for support, e.g., treatment buddy or peer support group.
6.	On any changes in treatment and solutions to adherence problems.
7.	Check that the client understands the agreements reached and his/her commitment.

Assist

1.	In preparing a plan of action on how to adhere to medicines e.g., when to take pills, how to make it a habit.
2.	In developing the resources (pill box)
3.	Support (support groups) and other arrangements needed for adherence.
4.	In developing skills to overcome barriers that have been identified.
5.	The person in developing links with community-based support/peer groups/treatment buddies.
6.	In ensuring that the client knows how to link taking medicines with daily events, e.g., meals.
7.	In getting help
8.	Call for advice or refer sooner to clinician, but do not simply refer ; provide support.

Arrange

1.	Arrange to schedule follow-up visits at the clinic.
2.	Arrange the next visit with district clinician or other centers (if required)
3.	Making sure that the client understands where/when he/she will see a health worker.
4.	Arrange a home visit if feasible.
5.	Help with accessing help between visits, e.g., by phone.
6.	Arrange for picking up of medicines at periodic refills (usually monthly).
7.	Record adherence estimate on client card and reasons for non-adherence
8.	Making sure that the client and treatment buddy/supporter understand how to contact the clinic team if there is a problem.

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.4 : Good Chronic Care: Using the 5 A's

Handout A : Elements of the 5 A's As Applied to Different Categories of Clients

ASSESS

Elements	Category of client
1.	All
2.	All
3.	All
4.	A, and B in particular . Also C if there is any change in treatment.
5.	A.
6.	C.
7.	A, very important in B , but needs reinforcing with all.
8.	B, but needs reinforcing with all.
9.	All
10.	B and very important with C
11.	All but especially C
12.	All
13.	C
14.	C

ADVISE	
Elements	Category of client
1.	A and B
2.	A. Needs reinforcing with all
3.	A, B in particular, but also C especially if there's any change in regimen.
4.	Critical with B
5.	Very important with B.
6.	Critical in B.
7.	B. Also C especially if any change in treatment.
8.	B. Also C especially if any change in treatment or side effects
9.	A, but critical with B.
10.	A, but critical with B
11.	All
12.	All

13. B and C

AGREE	
Elements	Category of client
1.	A, and critical with B
2.	A, and critical with B
3.	Critical with B
4.	Critical with B
5.	Critical with B, but also very important with C
6.	C
7.	All, but critical with B.

ASSIST	
Elements	Category of client
1.	B, and may need consistent reinforcing with C , e.g., transport, taking pills at home/work, regular supply of medicines without stigma, supportive family/community, treatment buddy
2.	B and C
3.	B, Critical with C
4.	B and C
5.	B, needs reinforcing with C
6.	B and C
7.	Critical with C
8.	Critical with C

ARRANGE	
Elements	Category of client
1.	B and C
2.	B and C
3.	B
4.	B and C
5.	B and critical with C
6.	B and C
7.	Critical with C

SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.5 : Home-Based Care

Information resource 'A'



What is home-based care?

- Home based care means any form of care given to sick people in their own home instead of in a hospital.
 - It can mean the things people might do to take care of themselves or the care given by family members, health-care workers, Counselors or other care providers.
 - Home-based care includes physical, emotional, spiritual, and social aspects.
-



Why is home-based care effective and important?

- Many illnesses and infections associated with HIV and AIDS can be managed at home if people have some basic information.
 - Home care is less expensive and can be given with compassion and dignity in a familiar environment rather than in a hospital.
 - A caregiver (spouse, parents, children, neighbor, health worker, or a friend) can attend to other responsibilities if the person living with HIV is at home.
 - The person living with HIV doesn't have to travel long distances to seek care at a hospital.
 - It protects the person from acquiring any new infection or OI from other patient who are admitted in hospital
-



SECTION 2

HIV, AIDS AND CHRONIC CARE

Session 2.5 : Home-Based Care

Handout A : Preventive Home-Based Care

Source: World Health Organization (WHO). 2004. *Palliative Care: Symptom Management and End-of-Life Care. Integrated Management of Adolescent and Adult Illnesses (IMAI)*. Geneva

1. PREVENT BEDSORES IN ALL BEDRIDDEN PATIENTS

Remember that prevention of bedsores is better than cure, therefore :

- Help the bedridden person to sit out in a chair from time to time if possible.
- Lift the sick person up the bed-do not drag as it breaks the skin.
- Encourage the sick person to move his or her body in bed if able.
- Change the sick person's position on the bed often, if possible every one or two hours-use pillows or cushions to keep the position.
- Keep the beddings clean and dry.
- Look for damaged skin (change of colour) on the back, shoulders and hips every day.
- Put extra soft material such as a soft cotton towel under the sick person.



Instructions for bathing :

- Provide privacy during bathing.
- Dry the skin after bath gently with a soft towel.
- Oil the skin with cream, body oil, lanolin or vegetable oil.
- Use plastic sheets under the bed sheets to keep the bed dry when one cannot control urine or faeces.
- Massage the back and hips, elbows, ankles with petroleum jelly.
- If there is leakage of urine or stool, protect skin with petroleum jelly applied around private parts, back, hips, ankles and elbows.
- Support the sick person over the container when passing urine or stool, so as to avoid wetting the bed and injury.

2. TO PREVENT PAIN, STIFFNESS AND CONTRACTURES IN MUSCLES AND JOINTS

Exercise to Help Prevent pain stiffness and Contractures

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



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



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



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



3. MOVING THE BEDRIDDEN PERSON

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

When transferring from the bed to a chair :

1. Roll the person on one side



2. Move the person to the side of the bed, Ask the person to bend legs and to prop on the same side elbow



3. Hold on the person's pelvis, ask to raise his/her buttocks. Sit person on the edge of the bed with feet flat on the floor



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



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



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



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




SECTION 2



HIV/AIDS AND CHRONIC CARE



Session 2.5 : Home-Based Care

Handout B : Managing Symptoms

Source: World Health Organization (WHO). 2004. Palliative Care: Symptom Management and End-of-Life Care. Integrated Management of Adolescent and Adult Illnesses (IMAI). Geneva: WHO/CDS/IMAI2004.4 REV. 1.

<p>Weight loss</p> 	<ul style="list-style-type: none"> • Encourage the sick person to eat but do not use force as the body may not be able to accept food and he or she may vomit. • Offer smaller meals frequently of what the sick person likes. • Let the sick person choose the foods he or she wants to eat from what is available. • Accept that intake will reduce as person gets sicker and during end-of-life care. • Seek help from a trained health worker if you notice rapid weight loss or if the sick person consistently refuses to eat any food or is not able to swallow.
<p>Painful mouth ulcers or pain in swallowing</p> 	<ul style="list-style-type: none"> • Remove bits of food stuck in the mouth with cotton wool, gauze, or soft cloth soaked in salt water. • Rinse the mouth with diluted salt water (a finger pinch of salt or ½ teaspoon sodium bicarbonate in a glass of water) after eating and at bedtime. • Mix 2 tablets of aspirin in water and rinse the mouth up to 4 times a day. • Seek help from a health worker for persistent sores, smelly mouth, white patches or difficulty in swallowing.
<p>Constipation</p> 	<ul style="list-style-type: none"> • Offer drinks often. • Encourage any fruits, vegetables, porridge, and locally available high-fiber foods. • Take a tablespoon of vegetable oil before breakfast. • If constipated, gently put petroleum jelly or soapy solution into the rectum. If the person cannot do it, the caregiver can help—always use hand gloves. • Seek help from a trained worker if there is pain or no stool is passed in 5 days.

<p>Incontinence of urine</p>	<ul style="list-style-type: none"> • Change cloth pads regularly. • Keep the person dry. • Protect the skin with petroleum jelly.
<p>Incontinence of stool</p>	<ul style="list-style-type: none"> • Use cotton cloth pads and plastic pants. • Keep the person clean; change cloth pads as needed.
<p>Bed sores</p> 	<p>You can do the following to soothe the pain of bedsores and quicken healing:</p> <ul style="list-style-type: none"> • For small sores, clean gently with salty water and allow drying. • Apply ripe papaya flesh to bedsores that are not deep and leave the wound open to the air. • If painful, give painkillers such as paracetamol or aspirin regularly. • For deep or large sores, every day clean gently with diluted salt water, and cover with a clean light dressing to encourage healing. • Seek help from a trained health worker for any discolored skin or bedsores getting worse.
<p>Confusion</p> 	<p>People living with HIV with confusion will show the following signs:</p> <ul style="list-style-type: none"> • Forgetful • Lack concentration • Trouble speaking or thinking • Frequently changing mood • Unacceptable behavior such as going naked and using bad language <p>What to do:</p> <ul style="list-style-type: none"> • As far as possible, keep in a familiar environment. • Keep things in the same place, easy to reach and see. • Keep familiar time pattern to the day's activities. • Remove dangerous objects. • Speak in simple sentences, one person at a time. • Keep other noises down (such as TV, radio). • Make sure somebody he/she trusts is present to look after the sick person and supervise the medication.

<p>Cough</p> 	<p>For simple cough:</p> <ul style="list-style-type: none"> Local soothing remedies such as honey and lemon or steam, plain or with eucalyptus leaves or neem tree oil. Help the sick person sit in the best position. Use extra pillows or some back support. Open windows to allow in fresh air. Give person water frequently (it loosens sputum). <i>If the person has a new productive cough more than 2 weeks, it may be tuberculosis. Arrange with the health worker to send 3 sputums for examination for TB.</i> <p>Safe handling and disposal of sputum:</p> <ul style="list-style-type: none"> Handle sputum with care to avoid spreading infection. Use a tin with ash for spitting, and then cover it. Empty container in a latrine and wash with detergent or clean the tin with liquid bleach or boiled water.
<p>Fever</p> 	<ul style="list-style-type: none"> The sick person will lose a lot of water through sweating; therefore encourage him or her to frequently drink water, diluted tea, buttermilk or fruit juices. To cool the body temperature, wipe the body with damp cloth or give a bath. Encourage him or her to wear only light clothes. Give paracetamol, aspirin, or ibuprofen to reduce fever. Treat the sick person with recommended anti-malarial medicine if it is the first time in the last two weeks. <i>Seek help if the fever does not improve or comes back after treatment. Also if the fever is accompanied by cough, diarrhoea, severe pain, confusion, night sweats, rigors, stiff neck, or unconsciousness, or fever in pregnancy or after birth.</i>

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.1 : Introduction to Counseling and Communication Skills

Information resource 'A'



1. Definition of counseling :

Counseling is a process to help an individual identify problems, examine potential solutions, and help make decisions that are best for the individual.



2. Some issues where counsellors can offer counselling to PLWHA :

- Helping clients develop strategies to take pills regularly
 - Encouraging clients to practice safer sex
 - Helping clients disclose their HIV status to their partner
 - Helping clients make decisions about starting ART
 - Helping clients manage side effects
 - Challenging misconceptions about ART
-
3. There are certain key concepts of interpersonal communication that are the foundation for effective counselling.
4. Major part of communication does not involve any words at all. This is called nonverbal communication. There is positive nonverbal communication and negative nonverbal communication. Some examples of both positive and negative nonverbal communication. nclude the following:

Positive nonverbal cues

- Leaning towards a client
- Smiling
- Avoiding nervous mannerisms
- Presenting interested facial expressions
- Maintaining eye contact
- Making encouraging gestures such as nodding one's head





Negative nonverbal cues

- Reading from a chart
 - Glancing at one's watch
 - Yawning
 - Looking out the window
 - Fidgeting
 - Frowning
 - Not maintaining eye contact
-

5. Good relationship with a client is often based not only on what the clients hear, but also on what they observe and sense about the Counselor.
 6. Another effective communication skill is **verbal encouragement**. This lets the client know that the provider is interested and paying attention. Examples of things that providers can say to encourage a client while talking include:
-



- Yes.
 - I see.
 - Right.
 - OK.
 - Really? Tell me more about that.
 - That's interesting.
-

7. Another part of **verbal encouragement involves asking questions**. These require that the person answering the question must reply with a full answer rather than a simple "yes" or "no." Questions that only require a "yes" or "no" are called closed questions. An example of the difference:
-



Closed question: Have you taken your ART medicines today?

Open-ended question: Please tell me about the problems you face in taking your ART?

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.2 : Characteristics of a Good Counselor

Information resource 'A'

This session will attempt to elaborate on specific characteristics of counselors that affect counseling.

Characteristics of an Effective Counselor

- Genuineness: Reliable, actual source of information
- Creates an atmosphere of privacy, respect, and trust
- Good communicator: Engages in a dialogue or open discussion
- Nonjudgmental: Offers choices and does not judge the person's decisions
- Empathy
- Comfort with sexuality
- Patience
- Makes client comfortable, including offering privacy
- Talks in moderate pace and appropriate volume
- Presents a message in clear and simple language (language clients can understand)
- Asks questions of the listener to make sure that he/she understands
- Demonstrates patience when the client has difficulty expressing or understanding
- Identifies obstacles and removes them



Characteristics of a Poor Counselor

- Interruption in conversations (meeting other people, telephone)
- Provides counseling in the presence of other people (without consent)
- Makes decisions for clients
- Breaks confidentiality
- Poor nonverbal communication (looks away, frowns, etc.)
- Lacks knowledge on reproductive health issues
- Uncomfortable with sexuality
- Difficult to understand
- Doesn't ask questions, only tells the person what to do
- Impatient
- Rude



SECTION 3

THE ELEMENTS OF COUNSELING

8. **Critical with C** **Session 3.3 : Effective Listening**

Handout A:

Effective listening is a fundamental skill in counseling and in interpersonal communication in general. Refer to Handout A for definition and for more information.



- Effective listening is a primary tool for showing respect and establishing rapport with the client. When a counselor does not listen well, it is easy for a client to assume that his or her situation is not important to the counselor, or that he or she as an individual is not important to the counselor. Thus, it is hard to develop the trust necessary for good counseling if the counselor is not listening effectively.
- Effective listening is also a key communication skill for counseling. It is important for most efficiently determining what the client needs, what the client's real concerns are, what the client already knows about his or her situation, what the client believes about what he/she can do, and the expectations that the client has.

Effective Listening

Listening skills can be improved by :



- Maintaining eye contact with the speaker (within cultural norms)
- Demonstrating interest by nodding, leaning toward the client, and smiling
- Sitting comfortably and avoiding distracting movements
- Paying attention to the speaker (e.g., not doing other tasks at the same time, not talking to other people, not interrupting, and not allowing others to interrupt)
- Listening to your client carefully, instead of thinking about other things or about what you are going to say next
- Listening to *what* your clients say and *how* they say it, and noticing the client's tone of voice, choice of words, facial expressions, and gestures
- Imagining yourself in your client's situation as you listen
- Keeping silent sometimes, and thus giving your client time to think, ask questions, and talk

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.4 : Effective Counseling Skills

Information resource 'A' : Effective Counseling Skills for Good Client-Counselor Interaction

1. There are important factors that affect good client-counselor interaction, including in the counselling of ART clients (see Handout A). These factors play a critical role in enabling counsellors to establish a good rapport with clients at the beginning of a client visit, and especially if it is the first visit.
2. Respect : In essence these factors represent good communication skills for client-counselor interaction, especially in counseling. You may be already familiar with some of these factors, and this session will explore a few in more detail.

3. **Praise and Encouragement :**

- **Praise** means the expression of approval or admiration.
- **Encouragement** means giving courage, confidence, and hope.

- 4.

Empathy : Empathy is the ability to recognize and understand another person's state of mind, beliefs, desires and emotions. Empathy is not the same as sympathy where you just feel sorry for the other person.

Empathy is :

- Listening to all the feelings of another (Do not listen selectively.)
- Responding with understanding. (Do not try to minimize, change, or "solve" another person's feelings.)

When empathizing, we do not:

- judge (evaluate or "label" the person's feelings)
 - try to solve the problem for them
 - advise (tell what to do)
 - question (keep seeking more information)
- These actions may be appropriate at other times, but not when we want to show empathy.

5. Paraphrasing: Effective listening is a critical skill in showing empathy. In addition, paraphrasing provides a practical way to show empathy in counseling.

Paraphrasing means stating in your own words what someone has just said.

These factors and communication skills play an important role in establishing good rapport between the Counselor and the client. Refer to Handout 'A' on some practical suggestions on how to apply the above principles in practice.

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.4 : Effective Counseling Skills

Information resource 'B'

Group	Sample client's statements	Sample Counselor's responses
Paraphrasing	You have no idea how difficult my life is.	I hear that you have faced a lot of difficulties because of your HIV status. Despite all the problems you are facing you have come to see me, and I am here to help you as much as possible.
Praise	What do you know about living with AIDS? You are not positive!	I may not have your understanding of what it is to be living with this condition, but I really admire your strengths and courage and I want to help you to stay as healthy as possible.
Encouragement	I can't talk about this thing. It's too much for me.	I see many clients who feel like you do. It takes a lot to cope with this condition, but now we can do something to help you get better and I am here to help you as much as possible.
Empathy	How do you expect me to remember to take all these pills every day at the same time for the rest of my life?	I know that this is really difficult and I guess that if I were in your situation probably I would feel in a similar way. I really don't want you to feel bad because you forgot to take a dose. I want to help you to make sure that in future you don't forget because I care about your health.

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.4 : Effective Counseling Skills

Handout A : Building Rapport with Clients

Critical factors that impact rapport-building for counseling clients on ART

1. Welcome the client :



- Greet the client warmly and make introductions.
- Help the client feel comfortable and relaxed.
- Be aware of your body language. Maintain eye contact.

2. Elicit concerns :



- Identify the reason for the client's visit, i.e., his/her concerns and priorities.
- Use praise and encouragement as appropriate.
- Show respect.

3. Listen to feelings :



- Use empathy, not sympathy.
- Do not speak before listening.
- Understanding is as important as giving advice.

4. Assure privacy and confidentiality :



- Explain the reasons for asking very personal questions during the counseling session.
- Put asking personal questions in the context of needing to understand the client's personal and social circumstances in order to better address his/her concerns, and that this is standard practice with all clients.
- Explain the purpose of and the policy on confidentiality.
- Create an atmosphere of privacy by ensuring that no one can overhear your conversation, even if you are not able to use a separate room.

These factors create rapport built on trust, respect, and support. They help make the client feel "heard" and more in control of his/her situation. This in turn contributes to motivate the client to engage with the counselor. This is essential for the success of ART.

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.5 : Asking Open-Ended Questions

Handout A : Open-Ended and Closed Questions



Why Do We Ask Questions During Counseling?

- To assess the client's HIV needs and knowledge
 - To involve the client as an active partner and elicit his or her needs, concerns, and preferences
 - To establish a good relationship by showing concern and interest
 - To prioritize the key issues to target during the (normally) brief time available for counseling
 - To determine what educational or language level will be best understood by the client
 - To avoid repeating information that the client already knows
 - To identify areas of misinformation to correct
-

[Adapted from: Tabbutt, 1995.]



Types of Questions

Closed questions usually will be answered with a very short response, often just one word. A closed question calls for a brief, exact reply, such as "yes," "no," or a number or fact. These are good questions for gathering important medical and background information quickly. Examples include:

- How old are you?
 - How many children do you have?
 - When was your HIV test?
 - When did the [name of symptom] start?
-



Open-ended questions are useful for exploring the client's opinions and feelings and usually require longer responses. These questions are more effective in determining what the client needs (in terms of information or emotional support) and what he or she already knows. Examples include :

- How can we help you today? Why did you come here today?
 - Can you tell me about your symptoms?
 - How do you feel about starting ART?
 - What is your home situation?
 - What have you heard about adherence?
 - What questions or concerns does your husband/partner have about your condition?
-

Adapted from: EngenderHealth, 2003



SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.6 : Using Language Clients Can Understand

Information resource 'A'



1. The importance of simplifying medical and technical terminology when counseling Clients on ART is of utmost importance. **Why should we do this?** Because our clients may come from many different backgrounds. Even clients with high levels of literacy may still feel intimidated by complex clinical terminology.



By communicating in the language understood by the clients and using simple words we ensure that clients feel that we treat them as equals, and we also ensure that we effectively communicate critical content and messages.

2. Refer to the handouts listed in previous sessions and think through how this information should be communicate in a simple way that is understood by all people.
 - a. How HIV attacks our health; HIV and opportunistic infections; Explain the evolution of HIV to AIDS; Relation between HIV and TB. (Session 1.4-Handout B)
 - b. Most common opportunistic infections that; How to prevent? Importance of treating OI first before starting ART. (Session 1.4-Handout C)
 - c. Role of ART in treating HIV infection. Antiretroviral drugs: how they interfere with the HIV virus; the different ARV and the most commonly used; why do we use combinations of ARV; types of regimens; benefits and goals of ART. (Session 1.5-Handout A) and (Session 1.6-Handout A)
 - d. Adherence and resistance: what happens after we take the drugs? Adherence: what it means. Resistance: what it is; what happens to HIV when we take the drugs correctly and when we don't take them correctly. (Session 1.7-Handout A, B and C)
3. It is important to remember that

For simplifying information you have to be as creative as possible, e.g., by using body language, by making drawings. If available, the counselor should have photos showing signs and symptoms of OI. Simplifying complicated technical information is not an easy task. It is best to start practicing during the training sessions and later make repeated efforts to make messages simple for them to be understood by all.

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.8 : Counseling Practice : Assess

Information resource 'A'

1. Often counselors have very large client loads and very limited time for each client. A common challenge is to provide good services even in such circumstances. One strategy that counselors can use is to tailor the questions and the information-giving process to the specific needs and concerns of clients. In order to do this, we need to structure our counseling sessions in ways that enable us to create and maintain trust with the client while concurrently making the best use of the limited time available.
2. For this purpose, prioritize the critical aspects/messages of the ASSES step with each category of clients in order to identify issues that need to be addressed with all Clients on ART and issues that require particular attention with each specific group of clients.
3. For sake of explanation and understanding Clients on ART are categorized as :
 - A. **Clients who are preparing for ART.** These clients have not yet started treatment, but have been assessed to be eligible to go on ART.
 - B. **Clients who are initiating ART.** These clients are actually starting treatment.
 - C. **Clients who are on ART** and to whom we need to monitor and support for adherence.
4. ***Refer below for guidance on what aspects of "Assess" need to be stressed with each category of clients. Refer to questions in Handout A "Questions for Assessing" to help select questions to "Assess" a client.***

Issue	Category of ART Client
1. Welcome the client. <ul style="list-style-type: none"> • Greet the client warmly and make introductions. • Help the client feel comfortable and relaxed. 	All
2. Elicit concerns. <ul style="list-style-type: none"> • Identify the reason for the client's visit, i.e. the client's goal for today's visit. 	All
3. Assure privacy and confidentiality. <ul style="list-style-type: none"> • Explain the reasons for asking very personal questions during the counseling session. • Put it in the context of needing to understand the client's personal and social circumstances in order to better address his/her concerns, and that this is standard practice with all clients. • Explain the purpose of and the policy on confidentiality. • Create an atmosphere of privacy by ensuring that no one can overhear your conversation, even if you are not able to use a separate room. 	All (Some of these messages may become redundant over time, especially if the client and the Counselor develop trust and confidence. However, clients should always be reassured about confidentiality, and privacy should always be maintained.)
4. Understanding of ARV therapy.	All
5. Interest in receiving therapy.	A
6. Understanding about the information received in previous visits about the illness, the treatment, and possible side effects.	A B
7. Determining if there is an adherence problem and what it might be.	C

SECTION 3

THE ELEMENTS OF COUNSELING

Session 3.8 : Counseling Practice : Assess

Handout A : Questions for Assessing

These questions and statements are provided as samples and they do not intend to be prescriptive. They are not ranked by order or importance. Counselors need to select and adapt these questions to the specific clients they see, i.e. whether they see a client who is preparing for ART, a client who requires support for ARV initiation, or a client on ART who requires adherence support.

Assess

1. How can I help you today? What is the main reason you came to see me today?
2. What do you remember of the information about HIV and AIDS that you have received so far?
3. What do you remember about how HIV can affect the body?
4. What is ART? What are the main benefits of ART for a person who is living with HIV or AIDS?
5. How do you expect that the treatment would improve your health?
6. How have you been looking after your health so far?
7. What is your main motivation in considering starting ART?
8. What kinds of medicines have you taken in the past that required sticking to very precise doses and schedules?
9. What problems did you have with these medicines?
10. How did you resolve these problems?
11. What would you need to do to help the treatment work as well as possible for you?
12. How long would you have to be on ART?
13. Why is it important not to miss a dose when you are on ART?
14. What possible side effects may happen when we take this treatment?
15. Does ART cure people with HIV?
16. If you were on ART, why would it still be very important to practice safer sex?
17. How are you managing being HIV-positive with your family/spouse/partner?
18. Why would it be important to tell your family/spouse/partner about your HIV status?





19. If you told them about your HIV status, how would this make it easier for you to take care of your health and take your treatment properly?
 20. Why would it be important for your spouse/partner/children to get tested for HIV?
 21. Why is it important to come regularly to the health center for someone on ART?
 22. Why is it important not to mix ARV with other drugs or herbal treatment without checking with the doctor first?
 23. What could you do if you had problems with your ARV, for example if you had side effects?
 24. What problems would you face taking your treatment at work or if you had to travel?
 25. Many clients have trouble taking medicines. What difficulties are you having in taking your ARV?
 26. When and how do you take the pills?
 27. When is it most difficult for you to take your pills?
 28. How are you managing these difficulties?
 29. Sometimes it is difficult to take the pills every day at the same time. How many have you missed in the last (*insert agreed time period, e.g., 4 days*)?
 30. Did you miss the morning or evening dose? Why?
 31. Who do you trust that might become a person to support you with your treatment, for example to talk to when you feel worried or upset?
 32. What do you know about groups or individuals in your community that provide support to people living with HIV and AIDS?
 33. How do you feel about these groups? How useful could they be to you?
 34. How would you feel if I helped you to keep track of your treatment, for example by making sure that we count your pills every time you come to see me?
 35. What could you do if you forgot to take a dose at the prescribed time?
 36. What could you do if you needed help in between clinic visits? Where could you get access to a telephone to call us? How would you do this?
 37. How have you been since the last time we spoke?
 38. How have you organized yourself at home to help you take your pills according to your treatment plan?
 39. Did you run out of pills? When did it happen? What did you do?
-

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.1 : Introduction to Side Effects of ART

Information resource 'A'

1. ART regimens can cause side effects. Although the role as Counselors is not to provide the clinical treatment, but you need to have a good understanding of side effects in order to help refer clients to clinicians in a timely fashion, as well as to provide support to help clients implement practical strategies for self-management.
2. Most drugs have side effects. In most cases these side effects are mild, and not everybody using the same drug will experience them. A very important message to remember is that less than 5 percent of clients taking ART will have serious clinical side effects. However, many more will have less serious but annoying side effects, especially at the beginning of the therapy.
3. Refer Handout A: Common Side Effects and Responses.



4. **Why should we inform and educate clients about side effects?**

- It's the client's right to know in order to make an informed decision about ART.
- Clients can better prepare themselves.
- Clients can better understand that not all side effects present the same level of seriousness or long-term impact.
- Clients are partners in managing their therapy and they need information and education to be able to self-manage, when appropriate.
- Clients can better understand the importance of seeking help early.
- Knowing about side effects empowers clients to feel more in control of their condition.
- Clients are aware of drug interaction between commonly used ART medicines (like Nevirapine) and medicines used to treat TB infection (eg. Rifampicin)
- Most importantly, clients understand the risk of treatment failure if they stop taking the drugs without discussing options with the clinical team.



5. **What might be the consequences of side effects on clients?**

- Clients can become very worried that the therapy is making them feel worse than HIV, especially in the initial phases of ART.
- Clients may seek information from unreliable sources and they may get wrong information.



- Clients may get discouraged and depressed.
- Clients may stop taking their treatment correctly without seeking help or advice, and this will increase the risk of treatment failure.
- Clients may start “forgetting” to take their treatment, or stop it altogether.



6. **What is the first thing to do if clients complain about side effects?**



- We must take their complaints seriously. We must help them to find ways to manage their treatment.
-



7. **What might be the consequences of drug interactions on clients?**



- Rifampicin (TB medicine) decreases the level of Nevirapine in the body. When this happens the ART regimen is unable to control HIV virus multiplication and resistance to ART can occur.
 - Therefore a person who is being treated with a Rifampicin containing TB regimen should not be treated for HIV infection with Nevirapine based ART regimen
 - Therefore it is important for counselor to check and counsel about this drug interaction.
-

8. The main role of a counselor in dealing with side effects is to support clients continue their treatment effectively when facing these issues. For serious side effects, clients need clinical advice, and Counselors must be able to motivate clients to seek help early and refer them to clinicians. For other side effects, Counselors should be able to support clients to self-manage, when appropriate.

9. **Good management of side effects and prevention of drug interactions includes:**



- Discussing very common possible side effects *before* the person starts taking the medicine(s).
 - Giving advice on how to manage these side effects. (Treatment teams should use the client treatment card.)
 - Informing the client that there might be potentially serious side effects, and telling the client to seek help urgently and early if they occur.
 - Giving immediate attention to side effects: access to the clinic or by phone.
 - Initiating a discussion about side effects, even if the client does not mention them spontaneously.
 - Educating the client about drug interaction between Nevirapine and Rifampicin.
 - Referring the client to peer educators.
-

SECTION 4









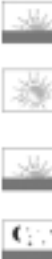
SUPPORTING CLIENTS ON ART

Session 4.1 : Introduction to Side Effects of ART

Handout A : Common Side Effects and Responses

Source : Family Health International (FHI); ART Basics/Side Effects, Flip Chart







Headache

Side Effect	What to do	Go to the Clinic if:
	<p>Rub the base of your head with your thumbs & temple gently. Rest in a quite dark room with your eyes closed.</p>  <p>Place cold cloth over your eyes and forehead</p>  <p>Avoid things with caffeine such as coffee, strong tea and sodas.</p>  <p>Take 2 tablets of paracetamol every 4 hours with food.</p> 	<p>Your vision becomes blurry or unfocussed.</p>  <p>Aspirin or paracetamol does not stop the pain.</p>  <p>You have frequent or very painful headaches.</p>  











Dry mouth

Side Effect	What to do	Go to the Clinic if:
	<p>Rinse your mouth with clean warm water and salt.</p>  <p>Avoid sweets</p>  <p>Avoid things with caffeine such as coffee, strong tea and sodas.</p> 	<p>You also have spots on your tongue or in your mouth.</p>  <p>You have trouble swallowing food.</p> 

Skin Rashes

Side Effect	What to do	Go to the clinic if:
	<p data-bbox="730 583 923 697">Wash often with unscented soap and water</p>  <p data-bbox="730 943 904 1012">Keep the skin clean and dry</p>  <p data-bbox="730 1258 1161 1292">Use calamine lotion to soothe itching</p>  <p data-bbox="730 1602 973 1671">Avoid the sun when you have a rash</p> 	<p data-bbox="1226 583 1534 697">If the side effects persist, visit your doctor for consultation.</p> 






Diarrhoea

Side Effect	What to do	Go to the clinic if:
	<p>Eat small meals more times a day</p>  <p>Eat easy foods- ex. bananas, rice</p>  <p>Drink lots of clean boiled water</p>  <p>Boil water for 20 minutes to make it safe.</p> <p>Take Oral rehydration salts (ORS)</p>  <p>Avoid spicy or fried food</p> 	<p>There is blood in the stools</p>  <p>You have diarrhoea more than 4-8 times a day</p>  <p>You also have fever</p>  <p>You are thirsty but cannot eat or drink properly</p> 

Anaemia

Side Effect	What to do	Go to the clinic if:
 <p data-bbox="365 1281 697 1395">Signs that you have anemia include pale (white) palms and fingernails.</p>	<p data-bbox="736 580 1016 656">Eat fish, meat, chicken, legumes</p>  <p data-bbox="736 1001 1180 1076">Eat spinach, dates, jaggery, dark leafy greens.</p>  <p data-bbox="736 1437 1122 1513">Take iron tablets prescribed by a doctor</p> 	<p data-bbox="1228 580 1547 734">You have been tired for 3-4 weeks, and you are feeling more and more tired.</p>   <p data-bbox="1228 1586 1514 1616">If your feet are swelling</p> 









Feeling Dizzy

Side Effect	What to do	Go to the clinic if:
 <p>These side effects may occur when taking efavirenz (EFV). They usually go away after a few weeks.</p>	<p>If you feel dizzy, sit down until the feeling goes away.</p>  <p>Try not to lift anything heavy or move quickly.</p>  <p>Take EFV right before you go to sleep.</p> 	<p>If the side effects persist, visit your doctor for consultation</p> 











Hair Loss

Side Effect	What to do	Go to the clinic if:
	<p data-bbox="738 583 1174 656">Protect hair from damage- don't use dye, straightening.</p>   <p data-bbox="738 1632 1159 1705">Don't buy products that promise to grow hair back.</p> 	<p data-bbox="1232 583 1541 693">If the side effects persist, visit your doctor for consultation</p> 








Tingling feet & hands

Side Effect	What to do	Go to the clinic if:
	<p>Wear loosefitting shoes and socks</p>  <p>Keep feet uncovered in bed,</p>  <p>Walk a little but not much.</p>  <p>Soak feet in warm water/massage with cloth soaked in warm water</p>   <p>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 days without visiting to the clinic.)</p>	<p>The tingling does not go away or gets worse.</p>  <p>The pain is preventing you from being able to walk.</p> 







Nausea and Vomiting

Side Effect	What to do	Go to the clinic if:
	<p>Ask your doctor if you can take ART drugs with food</p>  <p>Eat lots of small meals rather than big meals.</p>  <p>Take sips of clean, boiled water, weak tea, or Oral rehydration salts (ORS) until the vomiting stops.</p>  <p>Avoid spicy or fried foods.</p> 	<p>You also have fever.</p>  <p>You have sharp pains in stomach.</p>  <p>There is blood in the vomit.</p>  <p>Vomiting lasts more than a day.</p>  <p>You are very thirsty but cannot eat or drink properly</p> 






Unusual or bad dreams

Side Effect	What to do	Go to the clinic if:
 <p>These side effects may occur when taking efavirenz (EFV). They usually go away after a few weeks.</p>	<p>Try to do something that makes you happy and calm right before you go to sleep.</p>  <p>Avoid alcohol and street drugs as these will make things worse.</p>  <p>Avoid food with a lot of fat.</p> 	<p>If you can't sleep for several nights.</p>  <p>Day - 1</p>  <p>Day - 2</p>  <p>Day - 3</p>

Feeling Tired

Side Effect	What to do	Go to the clinic if:
	<p data-bbox="743 583 1149 654">Get up and go to bed at the same time everyday.</p>  <p data-bbox="743 1120 948 1150">Get little exercise</p>  <p data-bbox="743 1666 1110 1738">Keep easy to make food for when you are too tired to cook</p> 	<p data-bbox="1236 583 1441 654">You feel too tired to eat.</p>  <p data-bbox="1236 1223 1508 1333">You cannot swallow or eat enough to keep strong.</p> 

Feelings of sadness or worry

Side Effect	What to do	Go to the clinic if:
 <p>These side effects may occur when taking efavirenz (EFV). They usually go away after a few weeks.</p>	<p>Talk about your feelings with others.</p> 	<p>You have serious, sad or very worrying thoughts.</p>  <p>You are thinking about killing yourself.</p>  <p>You are very aggressive or very scared.</p> 

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.2 : Counseling for ART Side Effects

Information resource 'A'

1. It is important for counselors to practice how to give simple and short answers to the questions that will be asked by people on ART. Refer to Handout A.
2. As Counselors we often need to refer clients to clinicians. The role of a is not to learn details of clinical aspects of HIV treatment and “replace” clinicians in providing acute care. Counselors should focus on developing answers to help clients understand what's happening to them and motivate them to seek help and continue with their regimen while their problems and their treatment are being reviewed.
3. You should always ask yourself whether the information you gave to the client was :
 - Sufficiently clear?
 - Adequate to address client's immediate concern?
 - Useful to get an idea of what to do about the issue?

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.2 : Counseling for ART Side Effects

Handout A : General messages about side effects

Questions clients may have	Sample short and simple answers
Will the drugs cause side effects?	Not all Clients on ART experience side effects, but it is possible to have side effects at the beginning of the treatment. The majority of Clients on ART don't have serious side effects, but in some cases it can happen. In that case, the doctor would review your treatment.
Will I have serious side effects?	Many clients experience side effects, but usually they are not serious.
Should I stop taking the drugs if I get side effects?	Don't stop taking the drugs without telling us, because this can cause more problems later on when you start them again. If you get side effects, please come to the clinic or call us on the phone.
Do all ARV drugs give the same side effects?	No, some ARV has very specific side effects. For example, efavirenz may cause strange dreams, but they go away after a few weeks.
How long after starting treatment can side effects occur?	Usually at the beginning of treatment, but side effects diminish over the next few weeks.
What kind of side effects could I get?	It depends on the drugs in your regimen, but the most common ones are nausea, headache, dizziness, diarrhoea, feeling tired, and muscle pain.
How dangerous are side effects?	Most side effects are not dangerous, but it's important to see the doctor if they don't go away after a few weeks or if they start to become worse.

What can I do if I get side effects?	You can manage some side effects yourself following the doctor's advice. For others, you may need to come to the clinic. The most important thing is to seek help early. Don't stop taking the drugs without talking to us, because this can make the drugs stop working for you if you start taking them again later on.
Can I take other medicines (e.g: TB medicines) when I am taking ART?	Yes, you can. However, you have to inform your doctor promptly any time you start a new medicine for other medical problems. For example if you start treatment for TB infection one of the TB medicine called Rifampicin reduces Nevirapine level and thus the ART regimen will be ineffective.

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.2 : Counseling for ART Side Effects

Handout B : Questions about side effects

Questions clients may ask about potentially serious side effects and side effects occurring later during ART. Write your answers in the space beneath each question.

Why do I have yellow eyes?
People tell me that I'm very pale. Why is this happening to me?
I have a lot of pain in my tummy and I can't breathe well. What can I do?
I have headache and muscle pain. Can I stop at least one of the drugs?
My legs are tingling all the time. What should I do?
I'm taking my drugs properly, but I have fever. Why is this happening?
I have diarrhoea and I'm sure it's because of the drugs. What can I do to stop this problem?
I'm taking Efavirenz (EFV) and I'm sure it's giving me headache. I want to stop it.

I started ART recently and now I've got herpes. Why is this happening?

I started ART two weeks ago and I have a headache all the time. Can I stop the drugs?

I've been on ART for a few weeks and I have nausea all the time. What can I do to stop this problem?

My vomiting is not stopping. What can I do?

The doctor said the drugs could make me dizzy. Should I stop taking them?

I got this rash around my eye. Should I see the doctor?

I was taking ART regimen and it contained Nevirapine. I liked it as I did not have side effects. But when I was started on TB treatment last week the doctor switched me to ART regimen containing Efavirenz (instead of Nevirapine)

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.3 : Prevention of HIV Transmission to Partners

Information resource 'A'

1. There are several types of sexual behaviors (Example: Vaginal Sex, Oral sex, anal sex, hugging, kissing etc.) and the risk of HIV and STD transmission is different for each of these behaviors. It can be No Risk," "Low Risk," "Medium Risk," or "High Risk.
2. Even though they are already infected with HIV virus, **HIV-positive people need to know about HIV prevention.**



- A person's partner could still be HIV-negative, so the couple could still prevent a new infection.
- HIV-positive people need to disclose their HIV status to sexual partners and engage in safe sex in order to prevent passing their infection to others.
- A person can become reinfected with a different type of HIV from a partner. This can make a person's immune system weaker.
- A person can become reinfected with a drug-resistant HIV virus.
- Risk of unwanted Pregnancy

The above situations generally fall into the following real life situations
1) discordancy of HIV status in couples; 2) disclosure; and 3) HIV reinfection.

Key Messages :

- ***Prevention and care are more than complementary; they are indivisible. This is true for everybody, but especially for people living with HIV and AIDS because of their increased vulnerability to OI, to stigma and discrimination, and because of the challenges that sustaining a chronic condition presents, not only to sustaining adherence to a complex treatment regimen but also to safer sexual practices.***
- ***We can better appreciate the indivisible link between care and prevention when we consider that much of what happens in helping clients to explore their own needs is about helping them to accurately perceive their own risk—whether for unintended pregnancy, STI, complications, for not getting re-infected with a strain of HIV resistant***

to ARV, or for managing a relationship between HIV discordant partners—so they can make decisions that will reduce their level of risk as well as the level of risk of others.

- *The risk transmission of HIV or STI depends not only on sexual practices, but also on factors such as the difficulty of knowing a partner’s sexual history, current practices with other people, and infection status.*
- *Behaviors that may be low-risk in one relationship could be high-risk in another. For example, a “typically” high-risk behavior such as anal sex would carry no risk at all for HIV or STI transmission if neither partner were infected. This makes the concept of risk confusing to Counselors as well as to clients.*
- *As a result of this confusion, it is especially important in counseling to use simple explanations to help clients better understand the risk for infection with HIV or an STI. Here are some examples:*
- *Risk for STI: any behavior (not just sexual) that allows contact between the infected area of one person and another person.*
- *Risk for HIV: any behavior (such as sexual contact, blood contact, and mother-child contact) that exposes one person to the body fluids (blood, semen, vaginal fluid, or breast milk) of an infected person.*
- *It may not be possible to eliminate risk altogether, but risk reduction can have a significant positive impact on the client’s health. This is why we think of risk as a continuum, in which clients can be encouraged to consider behaviors that are in a lower-risk category, even if that behavior is not entirely risk-free.*

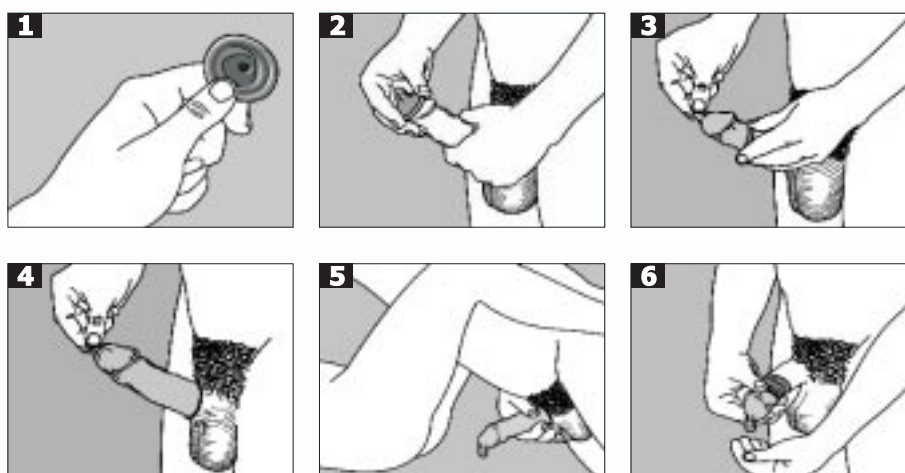
Using a Male Condom

1. Buying: Always check the **expiry date** on the package to make sure that the date has not already passed. If used after its expiry date, the quality of the condom cannot be assured. **Do not use the condom after the expiry date.**
2. Storing: Store the condom in a cool, dry place. Do not carry the condom in your wallet for a long period. Heat can destroy the quality of the condom.

3. How to use?
 - a. Use a new condom for each act of vaginal, anal, or oral intercourse.
 - b. Use the condom throughout sex- from start to finish.
 - c. The wrapper should be opened after the penis is erect and the condom should be removed carefully. The wrapper should not be opened using teeth or scissors as it may tear into the condom.
 - d. Pinch the air out of the tip of the condom by holding the tip of the condom between two fingers. If there is air inside the tip of the condom, it could burst.
 - e. Holding the condom tip between your index finger and thumb of one hand, place the condom on the tip of the erect penis.
 - f. Unroll the condom over the length of the penis with the other hand, leaving 1 to 2 centimeters of the condom at the tip of the penis. Do not apply Vaseline, lotions, oil or cold cream on the condom as this can weaken it.
 - g. After ejaculation, hold the condom at the base while the penis is still erect.
 - h. Remove the penis from the partner's body, take the condom off, tie it to prevent spills, and dispose it.

Condoms should not be re-used

Steps
in
Condom Use

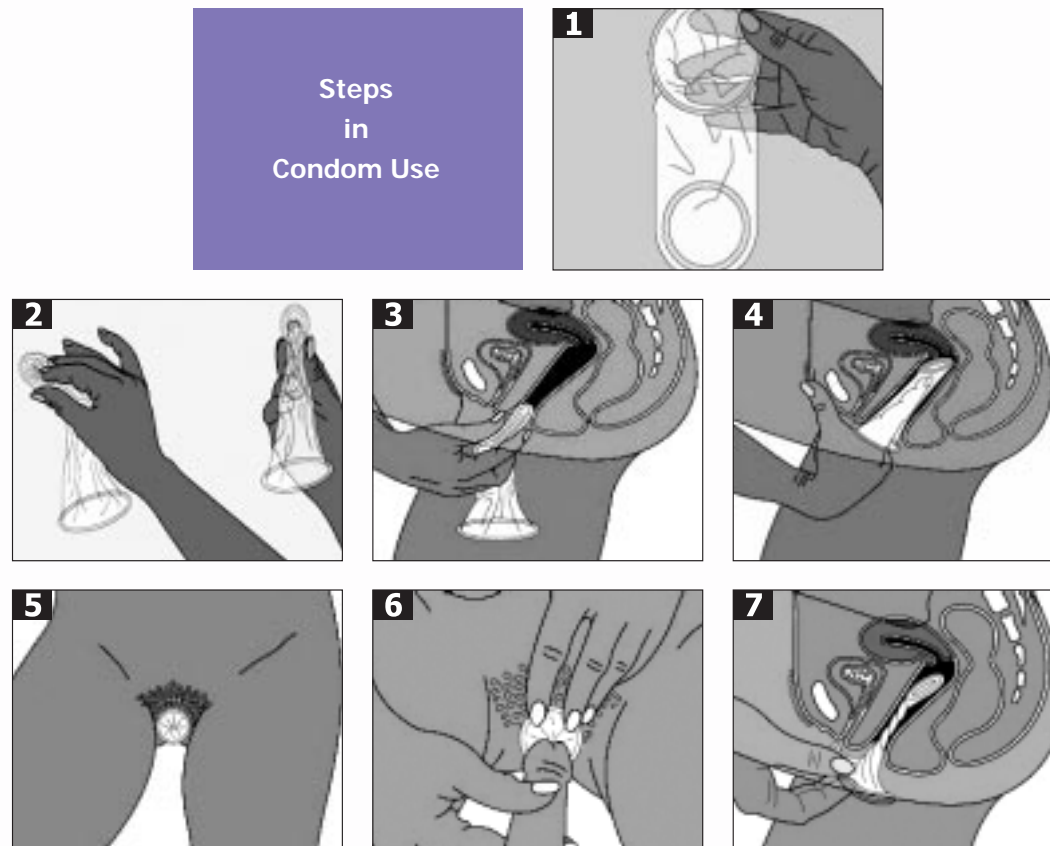


Source : EngenderHealth 2005, illustrated by David Rosenzweig

Using a female condom

- a. Female condoms are expensive and only a very minimal population of women have access to it. But the benefit is same as that of using male condoms.
- b. Buying: Always check the **expiry date** on the package to make sure that the date has not already passed. If used after its expiry date, the quality of the condom cannot be assured. **Do not use the condom after the expiry date.**

- c. Unroll the condom, and separate the two rings. Rub the condom gently to evenly spread the lubricant. The loose ring inside the pouch is called the inner ring and the ring connected to the opening of the pouch is called the outer ring.
- d. Hold the inner ring with your thumb and your middle finger and pinch the edges together.
- e. Place your index finger between the thumb and middle finger to prevent the condom from slipping. Use the middle finger to guide the condoms into the vagina. Push the ring until it covers the mouth of the uterus, once it is inserted the ring will fall into place.
- f. The outer ring will protect the outer lip of the vagina. Insert a finger to ensure that the condom is in place and is not twisted.
- g. After the ejaculation remove the condom by pulling it and removing it carefully so that you don't spill its contents.
- h. Dispose the condom.



Source : http://www.ripnroll.com / female_condoms.htm
Rip n Roll Inc 1996-2003 - female condom picture page

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.4 : Special Considerations for ART in Pregnant and Post-Partum Women

Handout A : Special Precautions for Pregnant and Post-Partum Women



A. When to Give ART to Pregnant Women?

Most HIV+ pregnant women are too early in their infection to be medically eligible for ARV therapy for their own health. The medical eligibility criteria for pregnant women are the same as for other adults. The main concerns relate to giving ART during the first-trimester when the theoretical risk to the fetus is highest.

For women who are medically eligible for ART and severely ill, the benefits of ART outweigh any theoretical risk to the fetus. For clients in clinical stage 3, it is important to obtain a CD4 count if this is possible to be sure that they require ART.



For women who are medically eligible with less advanced disease, delay until the second trimester can be considered. There are (small) risks and benefits to either choice.

Women who are not eligible for ART should be offered a standard ARV prophylaxis regimen to prevent HIV transmission to their infant, according to national policy. The simplest regimen consists of a single-dose of Nevirpaine at onset of labor, plus a single dose of Nevirpaine for the infant soon after birth.

Infants born to women receiving ART should receive one-week Zidovudine or single-dose Nevirpaine or both one-week Zidovudine and single-dose Nevirpaine.



B. What Is Prevention of Parent-To-Child Transmission (PPTCT)?



Transmission of HIV from mother to child can take place during pregnancy, during labor and delivery, or after birth through breast-feeding. Without intervention, about one-third of children born to an HIV-positive mother will acquire HIV. This is also known as vertical transmission. Prevention of this vertical transmission is called the **Prevention of Parent-To-Child Transmission (PPTCT)**.

Women who are on ART do not need additional ARV prophylaxis; however, some prophylactic treatment should usually be given to the newborn—follow the guidelines in your PPTCT program. Continue ART during labor.

All women on ART still need the other PPTCT interventions :

- counseling on reproductive choice and family planning to prevent unintended pregnancy
- safer labor and delivery
- safer infant feeding

Counseling on reproductive choice and infant feeding choice requires special training. If you have not been trained to provide these PPTCT interventions, refer the client to someone who has been trained. And try to get this training yourself!

C. Special Precautions in Pregnant Women

Some antiretroviral drugs may be harmful for the unborn baby if the mother takes them. That is why we need to determine the pregnancy status before deciding which drugs to give. Zidovudine-Lamivudine- Nevirpaine is a good combination for pregnant women. The fixed drug combination Stavudine-Lamivudine- Nevirpaine is a good alternative.

It is essential to avoid - efavirenz (EFV) during pregnancy. This is because it may be harmful for the foetus. - ART regimen containing combination of **“both”** Stavudine and didanosine should be avoided. These two drugs cause serious side effects to the mother and can even results in death.

D. Adherence in Pregnant and Post-Partum Women

Adherence to ART can be more difficult during pregnancy because of morning sickness and GI upset which can be made worse by nausea from ART. Women may also be hesitant about taking ARV drugs during pregnancy because of fears that they will harm the fetus.

Physical changes post-partum, the demands of caring for the newborn baby, and post-partum depression can all make adherence difficult in the post-partum period. All these point to the need for special attention to adherence and support to the woman. ART and breastfeeding: If the woman has decided to breastfeed after infant feeding counseling, she should continue her current ART regimen while breastfeeding. The results of studies to see if this will help prevent transmission through breast milk are not yet available.



SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.4 : Special Considerations for ART in Pregnant and Post-Partum Women

Information Resource 'A' : Prevention of Parent-to-Child Transmission

There are three different times when a mother can transmit HIV to a child. HIV can be transmitted: 1) when the baby is still growing in the uterus, 2) during delivery, or 3) while breastfeeding.



It is recommended that most HIV-positive pregnant women receive one dose of the drug nevirapine at the onset of labor. The newborn should also receive a dose of nevirapine 2 to 3 days after delivery. However, if a pregnant woman has a CD4 count of 200 or less, then a woman should start ART immediately during her pregnancy. Pregnant women already on ART should continue their ART regimen. If the woman is on efavirenz, then she will be asked to stop taking it or change the combination if she is considering pregnancy. Handout B explains how parent to child transmission can be prevented. Decision finally lies with the couple. Women might decide to breast feed or bottle feed.

If they decide to bottle feed. These are few issues to consider.

Reasons for not being able to bottle-feed include:

- Parents may not be able to afford baby formula.
- Parents may not have access to clean water.
- Parents may insist on breastfeeding for cultural reasons or for fear due to the stigma of bottle-feeding.

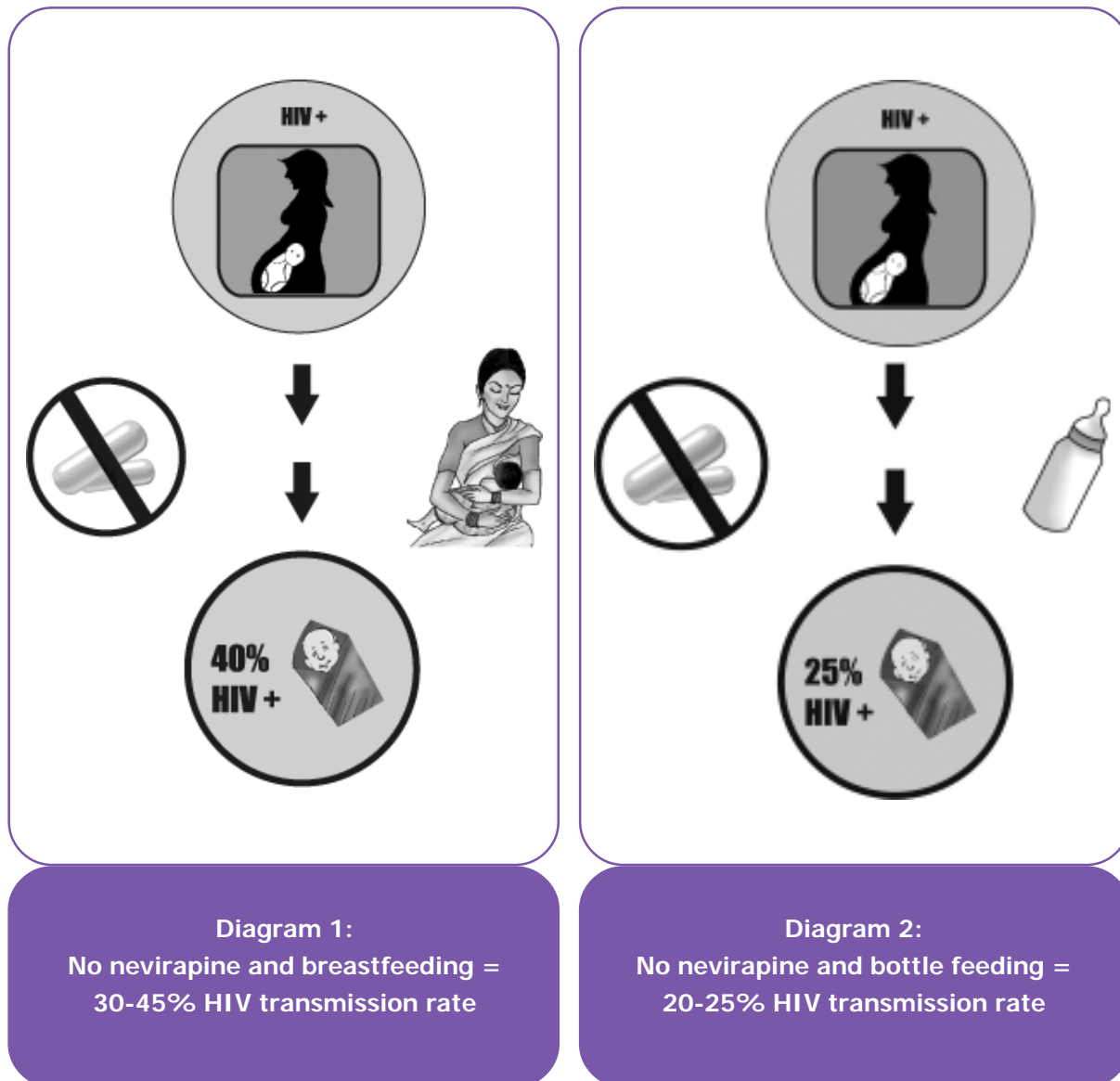
If parents decide to breastfeed it is essential that they do not bottle-feed. If the parents decide to bottle-feed, it is essential that they do not breastfeed.

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.4 : Special Considerations for ART in Pregnant and Post-Partum Women

Handout 'B' : Reducing Parent-to-Child Transmission



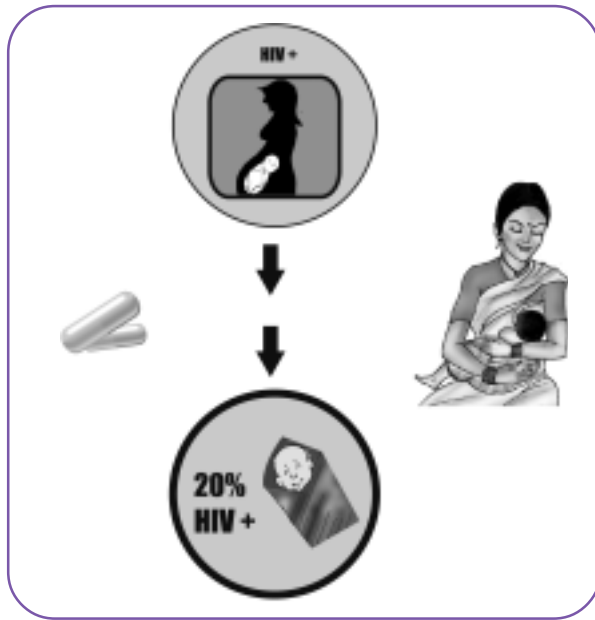


Diagram 3:
Nevirapine and breastfeeding
=
15-25% HIV transmission rate

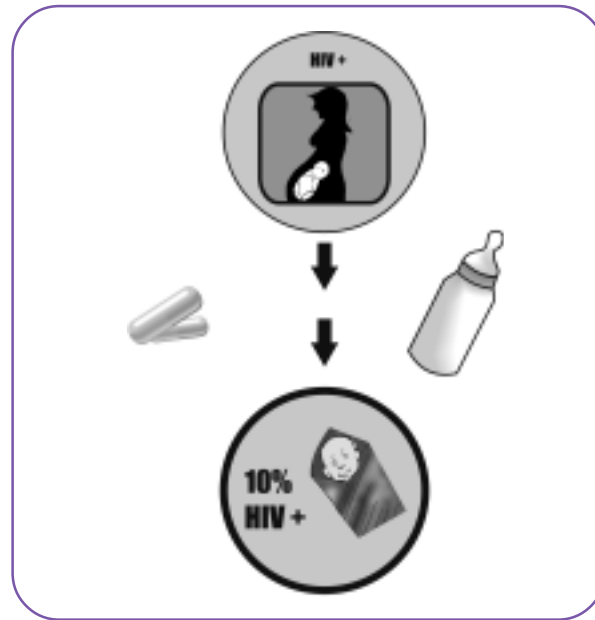


Diagram 4:
Nevirapine and bottle-feeding
=
5-15% HIV transmission rate

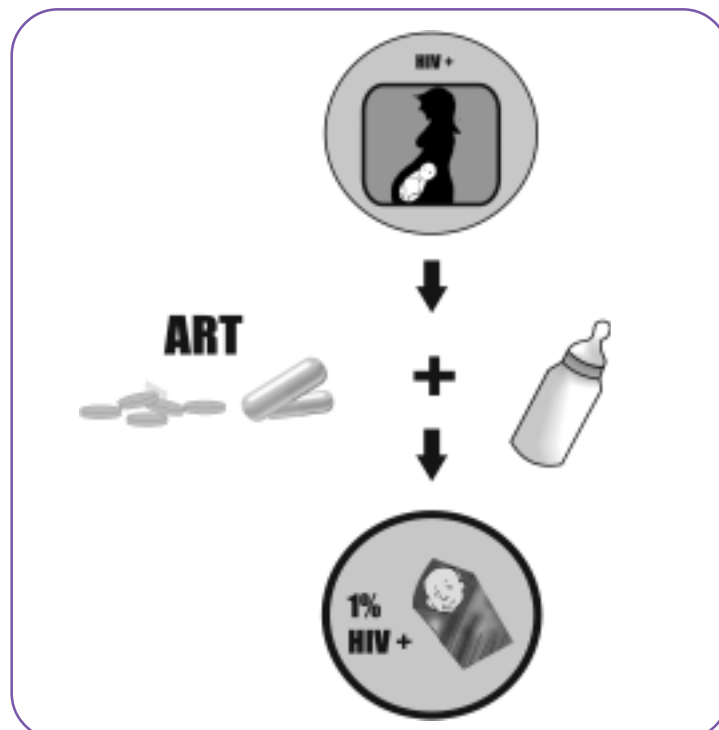


Diagram 5:
Three-drug ART and bottle-feeding
=
1% HIV transmission rate



Only

or



Only



Parents should either exclusively breastfeed or exclusively bottle-feed. Doing both increases the risk of HIV transmission to the baby.

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.5 : Nutrition

Information resource 'A'

1. There are several simple and cost efficient ways people living with HIV can eat nutritiously for optimal health. All kinds of food are generally categorised under four headings :
 1. Carbohydrates (rice, wheat),
 2. Proteins (pulses, egg, meat),
 3. Fats (oil, ghee), and
 4. Vitamins and Minerals (vegetables, fruits, dates).

Refer to Handout 'A': Healthy Foods, which provides examples of types of important food.

2. While counselling clients on nutrition and diet it is important to remember to identify dishes that are usually eaten in their areas that people can afford. The dishes they select should have at least one kind of food from each of the four food groups mentioned and also be cost effective.

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.5 : Nutrition

Handout A : Healthy Food



1. Energy-giving foods (carbohydrates)

- Rice, wheat, maize, ragi, potatoes, yam, tapioca, plantains, sugar, jaggery, animal fats, vegetable oils



2. Health-giving foods (fruits and vegetables)

- All vegetables and fruits,
- Especially dark-green leafy vegetables and orange-colored vegetables and fruits (different kinds of spinach, pumpkin, orange, papaya, etc.)



3. Bodybuilding foods (proteins and dairy)

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



SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.6 : Treatment and Adherence Issues for Special Populations

Handout A : HIV exposure on the job

Health care workers can be exposed to HIV infection at work. As counselors you may have to counsel a health worker who is accidentally exposed to HIV via a syringe or needle stick at work.

ART for health workers exposed to body fluids of people who have or are suspected of having HIV

The risk of HIV transmission following needle stick exposure to blood and other body fluids containing HIV virus is 0.3% (3 out of 100 persons).

Chances of HIV transmission are high :



- If the HIV viral load in the source person is high.
- If the needle is hollow (has a bore), such as syringe needles
- The wider the bore more the chances.

Chances are low :



- If the needle pierces through a glove.
- If the needle is solid, such as suturing needles.
- If the fluid has dried.

What to do after a needle stick which is contaminated with HIV infected blood :



- Clean the site with soap and rinse with a lot of water.
- Have a medical professional counsel the exposed health care worker.
- Immediately consult a doctor for ART.
- Provide clinical follow-up care.
- Test both the client and the person who had a needle stick for HIV, hepatitis B, C and syphilis.



Role of ART :

- ART is effective in preventing HIV if taken as soon as possible.
 - The sooner ART is started the more effective in preventing HIV transmission.
 - ART is not effective if started after three days after a needle stick.
 - Usually 2 or 3 ARV drugs are given.
 - ART should be taken for **one month**.
 - Counsel and follow up for serious adverse effects is a must.
-

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.6 : Treatment and Adherence Issues for Special Populations

Handout B : Concerns for special populations

While antiretroviral therapy improves the quality of life of people living with HIV, access to these drugs is very difficult if you are a person from a population with special needs such as children, intravenous drug users (IVDU), sex workers, and men who have sex with men (MSM), suffer from double stigma associated with their social and their HIV status and require tailored programs to address their needs in treatment and adherence. Criminal laws and enforcement practices can also influence these groups by affecting the ability of public health centers to effectively deliver prevention, care, and treatment services to these populations.

1. HIV in Children and ART :

1. Standard HIV tests will show a positive HIV test in children born to HIV-infected mothers, until they are 18 months old.
2. CD4 counts are used differently in children (% used instead of absolute CD4 count).
3. Similarity :
 - a. The same “window period” of three months applies to HIV antibody tests on babies as in adults.
 - b. A negative antibody test on a baby proves that the baby was not HIV infected within the past few months. An HIV antibody test that is negative three months after a baby has stopped breastfeeding reliably proves that the baby is not HIV infected.
 - c. ART in children reduces opportunistic diseases, hospitalizations, prolongs survival, and improves the quality of life.
 - d. Similar ART regimens are used.
 - e. First-line regimen in children is the same as the first-line regimen in an adult.
 - f. Some adult preparations can be used in children.
 - g. They have similar drug side effects and toxicity.
 - h. Drug adherence is the most critical factor in treatment success.
 - i. Poor adherence results in drug resistance and treatment failure.





4. Differences with adults and issues with ART in children :
 - a. Determining the dose of ART medicine is more complicated.
 - b. Taste issues affect adherence in children
 - c. Follow-up is dependent on care takers
 - d. Adherence depends primarily on the caretaker.
 - e. Nevirapine, as a single drug is given during delivery to prevent HIV transmission to children. However this does not prevent transmission in all children. Among children who become infected with HIV in spite of Nevirapine there is likelihood that the virus in their body will be resistant to Nevirapine. In such cases Nevirapine-based ART regimens will not work.
 - f. The family must be counseled and educated about ARV, including the need for adherence with follow-up medical visits and with medications. Giving medication twice daily to a small child without ever missing a dose is difficult and usually requires the participation of more than one caregiver. One caregiver may be at work or away when a dose is due, and then the other caregiver must give the child the medication. Usually several counseling sessions should be provided to the family before medications are prescribed, so that adherence is excellent from the first dose.
 - g. All infants **born to HIV positive mothers** should be on **cotrimoxazole starting at six weeks of age and until they are proven to NOT have HIV which usually is confirmed at 18 months of age**. Cotrimoxazole prevents PCP infection; an opportunistic infections of the lungs.

II. Issues specific to drug users

1. Everyone believes that drug users are incapable of following the prescribed regimen for antiretroviral therapy.
2. It is not possible to insist on stopping the use of drugs as a condition of medical treatment if this is beyond the capabilities of the drug user. It is also unjust to judge people as likely to be noncompliant with ART simply because they are drug users and to withhold ART on this basis.
3. Criteria for initiating ART in substance-using people do not differ from general recommendations; therefore, intravenous drug users who are eligible for ART should be ensured access to this life-saving therapy.
4. Adherence to treatment is profoundly affected by systems of care; if the system meets the needs of the socially marginalized, there is a vast improvement in adherence to treatment.
5. The key to effective treatment is careful assessment and education of the person, leading to development of an individualized treatment plan to maximize adherence
6. Special considerations for this population include



- a. Dealing with instability in lifestyle, which challenges drug adherence.
 - b. Accounting for the potential drug interactions of ARV with agents such as methadone, which decreases the level of efavirenz in the body.
 - c. Dealing with arrest and detention can affect adherence for drug users in prison.
 - d. ART medications can cause liver side effects, and for people using drugs there is a higher risk of having liver complications because people using IV drugs are likely to have Hepatitis B and C which damage the liver.
7. To help people adhere to ART in such settings, counselors can recommend the following :
- a. Directly observed therapy can be implemented.
 - b. Dispensing of medications in pre-filled pillboxes, initially on a weekly basis, then every two or four weeks.
 - c. Dispensing on a weekly or more frequent basis at needle exchange or other harm reduction sites.

III. Issues specific to sex workers :

1. Lack of information about ART; stigma, blame, and fear of discrimination prevent HIV positive sexworkers from seeking treatment.
2. Criteria for initiating ART are the same for everyone irrespective of their occupation therefore, sex workers who are eligible for ART should be ensured access to this life saving therapy.
3. The uncertainty in lifestyle created by the socioeconomic situation of a sex worker impacts access to ART and adherence.
4. Arrest and detaining of sex workers in prison can affect their adherence.
5. Counselors can play a role by acting as a bridge between the service providers and the sex workers who need treatment, informing, educating, and supporting them to access the treatment and motivating them to adhere to their drugs.
6. Educating police personnel about the importance of ART, timely medication dosing, and communicating with other facilities in advance can eliminate or limit missed doses.

IV. Issues specific to men who have sex with men

1. Lack of information about ART; stigma, blame, and fear of discrimination prevent HIV+ MSM from seeking treatment.
 2. Criteria for initiating ART are the same for everyone irrespective of their sexuality; therefore, men who have sex with men who are eligible for ART should be ensured access to this life-saving therapy.
 3. Counselors can play a role by acting as a bridge between the service providers and the HIV positive MSM who need treatment by informing, educating, and supporting them to access the treatment and motivating them to adhere to their drugs.
-



SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.7 : Monitoring Adherence with Clients Who Are Using ART

Information resource 'A'

1. Treatment teams dealing with clients who are using ART need to monitor adherence to treatment. Monitoring adherence is an important task but it can be very difficult. There is no one particular way of monitoring adherence. It is difficult to assess adherence levels based on a person's socioeconomic or literacy status. However, there are some tools, which can guide us in this process. These should include
 - Counting pills
 - Whether the person is following up with the clinic
 - Asking the client open-ended question about pill taking
 - Checking with family members or friends who come with the person

SECTION 4

SUPPORTING CLIENTS ON ART

Session 4.7 : Monitoring Adherence with Clients Who are Using ART

Handout 'A' : Assessing adherence

Critical elements for monitoring adherence for clients using ART

1. Usually providers ask how many doses the client forgot in the last three days, week and month, or the most recent recall of a missed dose. However, often clients say what they think the provider wants to hear instead of what really happened. Asking questions respectfully and using good client-provider interaction skills are therefore essential to create trust and confidence. For example :
 - “Many people on ART have trouble taking their medicines. What kind of problems are you facing?”
 - “I can help you better if you tell me when and how you take each pill. Would you explain it to me?”
 - “When is it most difficult for you to take the pills?”
 - “I understand that sometimes it is difficult to stick to your schedule with the drugs. How many have you missed in the last three days?”
2. If the client uses a self-monitoring diary, or visual literacy schedule, or a pill chart, ask him/her to show it to you.
3. Ask about important factors that may interfere with adherence :
 - a. Have there been any difficulties with the health worker? Try to find out why and check if there have been misunderstandings. Do not take things personally. Use praise, encouragement, empathy, paraphrasing.
 - b. Is there a literacy issue? Use color and pictures, other aids.
 - c. Does the client understand the illness and the treatment? Explain again the basics. Use visual aids.
 - d. Other beliefs that are creating difficulty or confusion? Do not judge. Show respect, but address misconceptions.
 - e. What family and social support is available to the client? Link the client to peer support, social institutions, NGOs, support groups.
 - f. Any problem of stigma and discrimination, e.g., taking the pills at work? Teach the client to pack the drugs needed for 1 day in a small bag, help the client think of places at work where he/she can have privacy (e.g., the toilet).



- g. Reinforcing interventions that match the client's needs and adherence problems. Suggest that the client takes extra drugs with him/her if traveling. Suggest the client keep a small supply of drugs where he/she may need them in an emergency—in the car, at work, at a friend's place.
 - h. Is the client focusing too much on the NOW, e.g., discomfort of side effects? Show acceptance for how the client feels. Explain that many people feel the same, and help the client see the advantages of focusing on the long-term benefits for the client and his/her loved ones. Many Clients on ART whose lives have improved with ART went through a time when they were very ill and could only think about surviving or arranging things for when they would die.
 - i. Any difficulty accessing the health facility? Help the client find out if it is possible to get subsidized transport.
 - j. Other immediate life needs that are felt as more pressing? Do not ignore these issues, and try to find solutions.
 - k. Barriers associated with the regimen, e.g., frequency of doses? Motivate the client to check with the clinician if the regimen can be adapted, and/or offer to talk to the clinician.
 - l. Side effects? Refer to the clinician, and/or call him/her to communicate the issue and motivate the client to stick to the regimen while it is being reviewed.
-


SECTION 4

SUPPORTING CLIENTS ON ART


Session 4.8 : Final Counseling Practice

Handout A : Critical elements to address with clients initiating ART and with clients who are using ART

ADVISE :

- 
1. Ensuring that the client understands the importance of adherence and the risk of resistance. **Reinforcing the information given before.**
 2. Explaining side effects: common side effects that are uncomfortable but not dangerous; potentially serious side effects that may occur; side effects that may occur later in ART. **Advising on any suggested changes in the regimen (only after consulting with the clinician). Usually side effects require only changing one drug, not stopping; consult with a doctor or medical officer if this is necessary.**
 3. Explaining that the client can still transmit HIV infection when on ART and the importance of continuing to practice safer sex. **Reinforcing this message.**
-

AGREE :

- 
1. Checking and ensuring that the client is still ready and willing to initiate ART (with clients initiating ART). **Discussing the agreements reached and for the commitments they require.**
 2. Making sure that the client understands that his/her life depends on taking the medicines every day:
 - a. Twice daily, without interruption
 - b. At the right time, every 12 hours or close to it
 - c. Do not discontinue ART. If the client stops, after some time he/she will become ill.
 - d. Do not share ART with family or friends; the drugs only work if taken in full dose

These messages need reinforcing with clients who are using ART: Stressing the risk of resistance; if this happens, the regimen may have to be changed; the second-line regimen is often more expensive and sometimes not so easy to take (more pills), and it can also cause more side effects. If a client has to change regimen several times, it may happen that in the end there are no more treatment options because HIV becomes resistant to many types of drugs.

3. Agreeing on a plan for support, e.g., identifying a support group or a treatment buddy.
 4. Ensuring that the client understands the importance of seeking help if there are any problems with the drugs and he/she will not stop the treatment without first talking to the treatment team. **Reinforcing these messages, especially if there is any change in regimen.**
-

ASSIST :

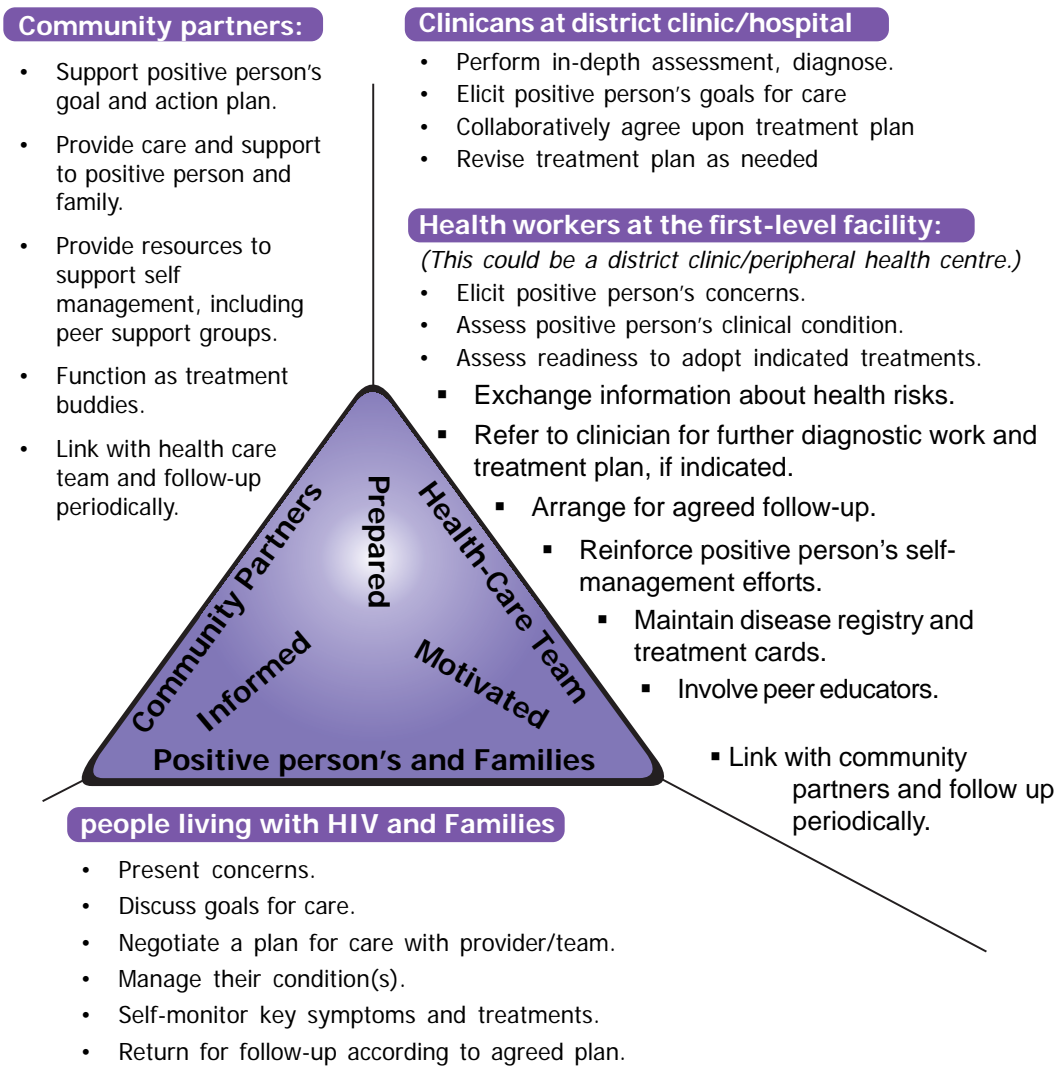
1. Coming up with a plan for how the client will remember to take the medicines; i.e., linking taking the drugs to daily events; how to make this a habit; how to remember when to take the drugs; e.g., making a written schedule or a visual one (e.g., draw a simple table using different colors for each drug, and next to each color draw as many dots as the doses to take, and a sun if to be taken during the day or a moon if to be taken at night); providing a pillbox, a pill chart or other aids. **Providing adherence support. Getting help if any adherence problem arises. Linking the client with home-based care and home visits.**
 2. Eliciting concerns and using empathy. **Important with all clients.**
 3. Encouraging the client to join a support group. **Helping the client and the treatment buddy/peer supporter find solutions.**
 4. Arranging a home visit, if feasible.
-

ARRANGE :

1. Next follow-up visit in clinic, home visit if feasible, next visit with district clinician. **Recording adherence data on client card. Arranging for refills.**
 2. How the client can access help between visits, e.g., through telephone. **Making sure that the client and the treatment buddy understand the follow-up schedule/plan and how to contact the clinical team if there is any problem.**
 3. Ensuring that the client understands where and when he/she will see the health worker (e.g., usually every week for two weeks initially, then every two weeks for two months, then monthly. Once stable and symptom-free for one month, the client may need to see the health worker only every three months).
-



ANNEXURE 1 - COORDINATED APPROACH TO CHRONIC CARE



Source : World Health Organization (WHO). 2004. *General Principles of Good Chronic Care. Integrated Management of Adolescent and Adult Illnesses: Interim Guidelines for Interim Health Care Facilities.* Geneva WHO/CDS/IMAI/2004.3 Rev 1.

Notes

Cover Concept: 'Treatment information and education empowers people living with HIV, enhances access to treatment and improves the quality of life'.

EngenderHealth Society

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