



**Community Counsellor Training Toolkit**

**Module 5**

# **Adherence Counselling**

## **Participant Manual**

**LifeLine/ChildLine Namibia**



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Developed by Lisa Fiol Powers, Family Health International (FHI), Namibia, in collaboration with staff from LifeLine/ChildLine, Namibia.

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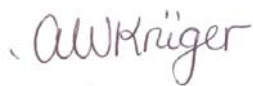


## **Foreword**

In 1988, I started working as a young community liaison officer for a Namibian non-profit organisation. This experience opened my eyes to the tremendous gaps between the values, norms and cultural influences of the country's different ethnic and racial groups and between those living in urban and rural settings. These differences in experience and perspective added to the tension amongst people, leading to a lack of trust and an inability to work together.

Fortunately, Namibians have experienced tremendous social growth since then, as these manuals for training community counsellors demonstrate. They include such sensitive subjects as stigma, coercion and cultural practices detrimental to health. These pioneering learning tools reflect the significant progress made as a result of the great partnerships developed throughout Namibia over the last 18 years. It is heart-warming to witness the openness and trust people from different cultures have achieved by offering counselling to a neighbour, a friend, a stranger.

I am proud to be associated with these manuals. I am proud of every trainer of LifeLine/ChildLine Namibia and every Namibian trainee who contributed. Thanks go to the many partners in faith-based organisations, non-governmental organisations, and the Ministry of Health and Social Services, especially NACOP—Special Programmes Division, which made such important contributions. Ms. Lisa Fiol Powers, a consultant seconded by Family Health International to upgrade and develop these manuals, deserves special thanks. In addition to these dedicated partners, we also want to thank the U.S. President's Emergency Plan for AIDS Relief, which provided funding. We will forever be grateful to you all.



Amanda W. Krüger  
NATIONAL DIRECTOR

*LifeLine/ChildLine Namibia*

[director@lifeline.org.na](mailto:director@lifeline.org.na)



## Acknowledgements

Over the last eight months I have lived, breathed and dreamt about community counselling, training and curricula. Developing the Community Counselling Training Toolkit has been an incredible experience for me. It enabled me to share my passion and concern to provide psychosocial support and counselling to meet the needs of so many around the world, particularly those affected by and infected with HIV. For me, it has been an honour to live and work in Namibia and to share in the lives of so many who are tirelessly working to fight HIV and its effects.

As is true with all curricula development, the entire team creates the finished product. The team I have worked with at Family Health International (FHI) and LifeLine/ChildLine has been especially generous, delightful and supportive.

Let me start by thanking the training team at LifeLine/ChildLine. The training team includes staff trainers Nortin, Frieda, Maggy, Angela and Cornelia, and volunteer trainers Dube, Christine, Hilarie, Emmy, Emelle and Jonas who have been absolutely fabulous to work with. When I rushed to complete drafts of Facilitator Manuals just days before a training workshop, the trainers never lost patience, even though it meant they had limited time to prepare for their sessions. Their enthusiasm and willingness to try new material has never ceased to amaze me. They have welcomed new ideas and significant changes to both the training materials and the methodology. The encouragement and feedback I have received from the trainers has been invaluable! You have been a delightful group of people to work with on this project.

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None of this would have been possible without the incredible support from the entire staff at Family Health International/Namibia. You are all a truly talented, dedicated and fun group of people. I would specifically like to thank Rose de Buyscher for making this whole project possible, not only through the allocation of funds, but also for her support in turning what began as a “harmonisation” into a more extensive project involving significant changes to existing curricula and the design and development of new material. The technical contributions and support for person-centred counselling offered by Dr. Fred van der Veen enabled me to challenge some of the rigid tenets of HIV counselling, and encourage counsellors to focus on their client’s emotional needs rather than adhering to fixed protocols.

Finally, I would like to express my deepest gratitude to Patsy Church for her inspiration and generosity in providing so many resources, for engaging in so many stimulating conversations, for being a cheerleader at times, and for always believing that these materials could make a difference. Patsy tirelessly read through drafts and offered valuable feedback and encouragement. Patsy has not only become a role model, she has become a dear friend.

My hope is that, with this Training Toolkit, community counsellors in Namibia will be better equipped to support their clients emotionally, offering them hope as they wrestle with so many difficult issues such as stigma, loss, coping with their HIV status, death and treatment, as well as financial and emotional uncertainty.

Lisa Fiol Powers, MA (Clinical Psychology)  
Family Health International, Namibia



**ADHERENCE COUNSELLING: PARTICIPANT MANUAL**  
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## List of Basic Counselling Skills

Below is a list of the basic counselling skills. You will need to continuously remind yourself of these skills as you are practising structured types of counselling.

### **Empathy\***

### **Listening Skills\***

Reflecting Skills:

#### **Reflecting Feelings\***

Restating/Reframing

#### **Affirmation\***

#### **Summarising\***

Probing/Action Skills:

#### **Asking Questions (Clarifying)\***

Interpretation or Making Statements

Confrontation or Challenging

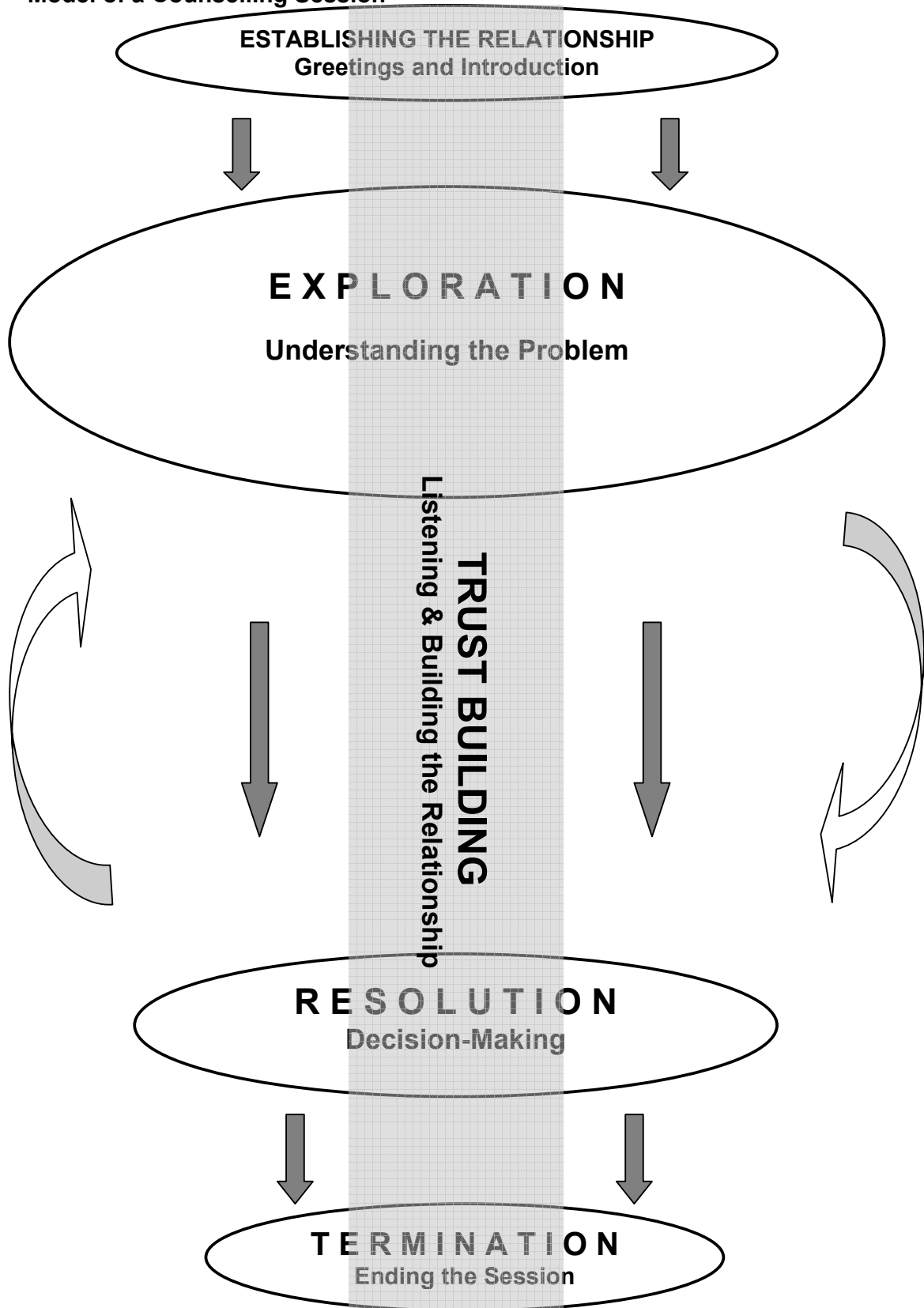
Information Sharing and Education

Problem-Solving/Problem Management

\* These are the **essential counselling skills**.



**Model of a Counselling Session**





## ART Pre-Knowledge Assessment

### I. True or False

1. ART is a cure for AIDS.
2. As the viral load increases (gets larger), the CD4 count usually decreases (gets smaller).
3. The purpose of ART Maintenance Counselling is to teach the client about HIV/AIDS and ART.
4. The window period is the period after starting ART until the drugs start working.
5. HIV uses the CD4 cells to grow and replicate or multiply.
6. There are no problems with starting and stopping anti-retroviral treatment.
7. ARVs must be taken at the same time every day.
8. A person's experience of side effects has no effect on adherence.
9. A personalised treatment plan is the plan that doctors and nurses make clients follow for treatment.
10. The counsellor's responsibility is to tell the client exactly how to adhere to his/her ART.
11. ART is treatment for life.
12. In Namibia, a person can start ART without a treatment supporter.
13. There is a higher risk of HIV transmission from a man to a woman than from a woman to a man through sexual intercourse.

### II. Matching: Match the word in column A with its definition in column B.

Column A	Column B
14. Adherence	a. Currently the best monitor for HIV disease progression.
15. CD4 Count	b. A specific plan intended to improve health.
16. Disclosure	c. The participation of a client in the plan of care or treatment.
17. Resistance	d. Not taking the recommended dose, not taking it at the recommended time, or not taking it in the recommended way.
18. Non-adherence	e. The primary step in breaking down stigma.
19. Regimen	f. When medication is no longer effective at suppressing the virus.

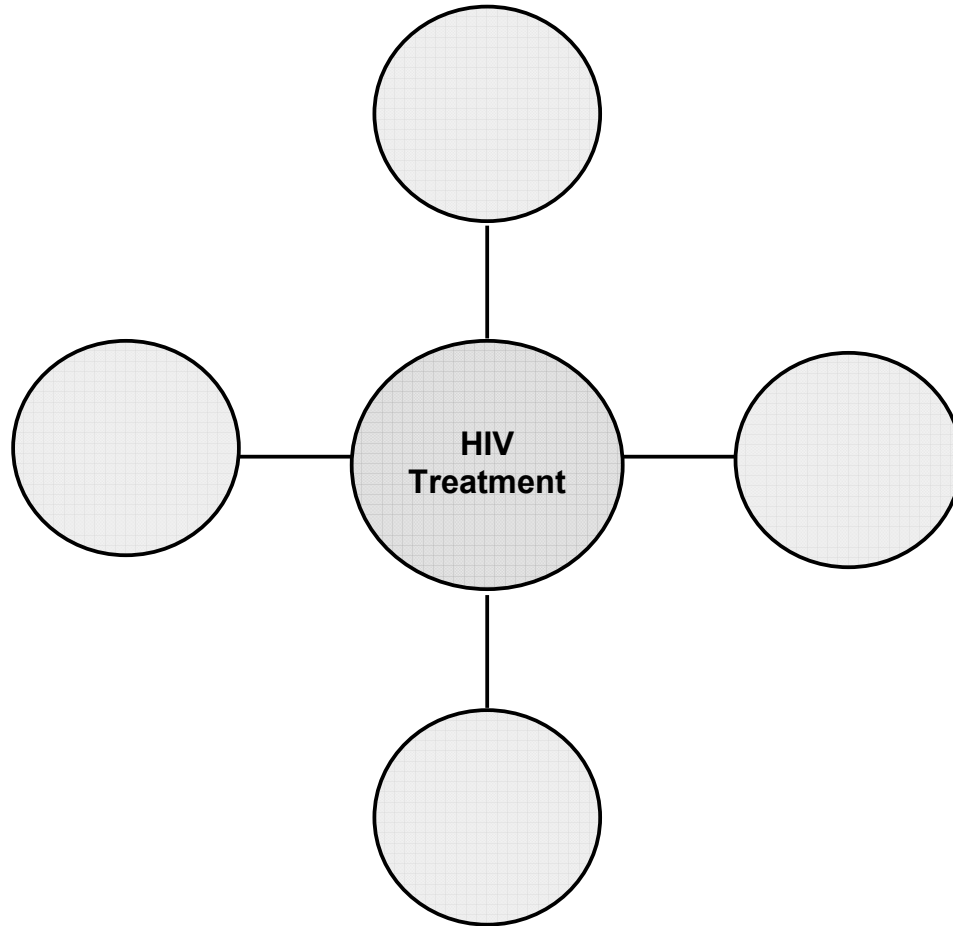
List 5 things that influence a client's adherence to treatment:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_



**Adherence Counselling Introduction:  
Expectations and Concerns**

Example: Mind Map/Spider Diagram



## Mind Map/Spider Diagram: What Do You Know about HIV Treatment?



## Personal Experiences with Medication

### Small Group Discussion

- Think about and discuss times in your life when you have been on medication. This could have been medication for a chronic illness like diabetes, for short-term treatments like antibiotics, or medicine for more severe illnesses.
- For how long did you take medication?
- Did you experience any side effects?
- Was it important to take the medication following specific instructions?
- How were you about taking your medication? Did you remember every dose?

## Natural Course/Progression of HIV Review

How HIV is Measured or Monitored:

### 1. CD4 Count

- Currently the best monitor for HIV disease progression
- Number of CD4 cells per cubic millimetre of blood
- Normal range: 600 – 1,200 CD4 cells per cubic millilitre of blood (mL<sup>3</sup>), and is generally higher than 500 in uninfected people
- Normal range of CD4 count varies from person to person, day-to-day, and hour to hour.
- As the HIV virus progresses, the number of CD4 cells decline and the CD4 count goes down.
- The CD4 count is one of the measures used to determine when a client should start antiretroviral treatment.
- When the CD4 count falls below 200 cells per cubic millilitre of blood, the body can develop life-threatening illnesses from other infections, which are called opportunistic infections.

#### Key Terms

- Window period
- CD4 Count
- Viral Load
- Opportunistic Infections (OI)

#### Percentage of CD4:

- Measures CD4 cells to total immune system cell (white blood cell) population.
- Normal range: approximately 40%
- If below 15%, the person is at serious risk of being sick or getting an opportunistic infection such as TB or malaria.

### 2. Viral Load

- Another measure of disease progression is viral load, or the amount of the virus in the body.
- A viral load counts the number of HIV particles in a sample of blood.
- It is expressed as the number of “copies” of HIV RNA per millilitre of blood. Below 10,000 copies or less is considered low and above 50,000 copies is high.
- Viral load does not measure the virus present in the brain and genital fluids, where the effects of ARVs may vary.
- Currently, viral load tests are not done in the public sector in Namibia.



### Relationship between CD4 Count and Viral Load:

- The higher the viral load, the faster the CD4 count reduces.
- The lower the viral load, the slower the CD4 count reduces.
- However, this relationship is not always clear.

### Progression of HIV Infection

HIV Infection	Initial infection with HIV virus
<b>Window Period (Acute Phase)</b> <i>Usually 2 - 6 weeks, but can last up to three months</i>	No signs or symptoms of disease and no detectable antibodies to HIV. An HIV antibody test would be negative even though the virus is present.
<b>Sero-conversion</b> (production of antibodies) <i>Brief period after 2 – 6 weeks, may last up to three months</i>	Development of antibodies: may include flu-like symptoms. About 25% of people experience no illness during this stage and most do not visit health care facilities.
<b>Asymptomatic HIV</b> <i>Lasts from less than one year to 10-15 years or more</i>	Antibody tests show up positive but there are no signs or symptoms of illness. (incubation period)
<b>HIV/AIDS – Related Illnesses (Symptomatic Phase)</b> <i>Lasts months or years</i>	Signs and symptoms of disease increase because HIV is weakening the immune system. Illnesses are usually not life-threatening at first, but become more serious and longer lasting.
<b>AIDS (Advanced HIV disease)</b> <i>Usually less than one to two years without treatment.</i>	Terminal Stage: life-threatening infections and cancers occur because the immune system is severely damaged. The client dies when an untreatable illness develops. Life expectancy depends on many factors, including antiretroviral treatment, medication for opportunistic infections and holistic health care, especially nutrition.

Adapted from Helen Jackson. 2002. AIDSAfrica: Continent in Crisis, SAfAIDS, Zimbabwe.

- Clients can live for many years after being infected with HIV.
- Progression of the disease to the advanced stage of AIDS varies in time and from person to person.



- A small proportion of clients may develop AIDS (advanced HIV disease) in less than 5 years.
- Another small proportion of clients can live over 15 years without any signs and symptoms of the disease.
- Most people take an average of 10 years to progress from infection to AIDS (advanced HIV) without any treatment.

**Window Period:**

- The period between the time of infection and when an HIV test result will be positive. It can range from 2 weeks to 3 months.
- This is because the HIV test does not actually test for the HIV virus in the body; instead, it tests for the antibodies. Remember it takes a while for the B cells to produce the antibody. This time can vary from person to person.
- The amount of HIV virus in the body is very high right after infection because the B cells have not produced the antibodies that defend against the HIV virus.
- A person can infect another person from the moment he/she is infected with HIV.

**Additional Factors that contribute to HIV infection developing into AIDS (HIV-related disease):**

- Infection with different types of HIV virus (multiple strains)
- Natural genetic or biological differences in individuals' immune systems
- Stress on the immune system from general lack of fitness and exposure to other infections, such as parasites
- Repeated STIs (sexually transmitted infections) that keep the immune system busy and appear to speed up HIV replication or growth.
- State of mind, such as anxiety and depression
- Other health stressors such as overtiredness, poor diet or nutrition and heavy drinking.

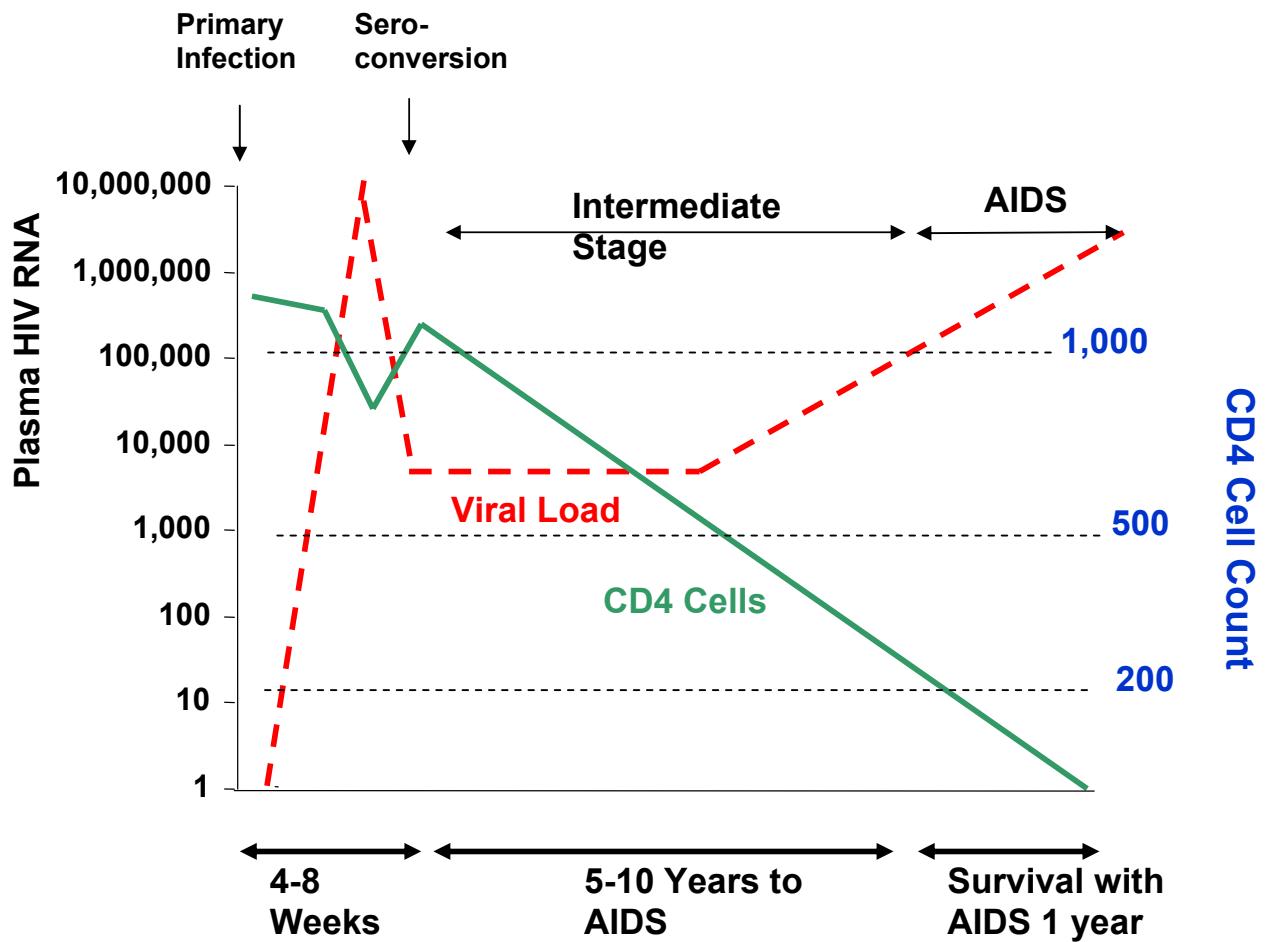
**Opportunistic Infections:**

- Infections that attack the body when it is weak, i.e. when the immune system is damaged
- People are at a greater risk of contracting other illnesses as a result of their compromised immune systems due to the HIV infection.
- Opportunistic infections develop during the HIV/AIDS-related illness phase.
- Opportunistic infections cause very serious problems when a person's immune system is weakened by HIV.
- These infections can include the following:



- Tuberculosis (TB)
- Malaria
- STIs (sexually transmitted infections)
- Pneumonia
- Oral herpes (sores in the mouth)

### CD4 Count, Viral Load and Clinical Course of Untreated HIV Infection in Adults





## REVISED WHO CLINICAL STAGING OF HIV/AIDS FOR ADULTS AND ADOLESCENTS

(Interim African Region version for persons aged 15 years or more with positive HIV antibody test or other laboratory evidence of HIV infection)

**Table 1. Revised WHO Clinical Staging of HIV/AIDS for adults and adolescents**

### Primary HIV Infection

Asymptomatic  
Acute retroviral syndrome

### Clinical Stage 1

Asymptomatic  
Persistent generalized lymphadenopathy (PGL)

### Clinical Stage 2

Moderate unexplained weight loss (<10% of presumed or measured body weight)  
Recurrent respiratory tract infections (RTIs, sinusitis, bronchitis, otitis media, pharyngitis)  
Herpes zoster  
Angular cheilitis  
Recurrent oral ulcerations  
Papular pruritic eruptions  
Seborrhoeic dermatitis  
Fungal nail infections of fingers

### Clinical Stage 3

*Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:*

Severe weight loss (>10% of presumed or measured body weight)  
Unexplained chronic diarrhoea for longer than one month  
Unexplained persistent fever (intermittent or constant for longer than one month)  
Oral candidiasis  
Oral hairy leukoplakia  
Pulmonary tuberculosis (TB) diagnosed in last two years  
Severe presumed bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)  
Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis

*Conditions where confirmatory diagnostic testing is necessary:*

Unexplained anemia (<8 g/dl), and/or neutropenia (<500/mm<sup>3</sup>) and/or thrombocytopenia (<50,000/mm<sup>3</sup>) for more than one month



#### **Clinical Stage 4**

*Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations:*

- HIV wasting syndrome
- Pneumocystis pneumonia
- Recurrent severe or radiological bacterial pneumonia
- Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration)
- Oesophageal candidiasis
- Extrapulmonary TB
- Kaposi's sarcoma
- Central nervous system (CNS) toxoplasmosis
- HIV encephalopathy

*Conditions where confirmatory diagnostic testing is necessary:*

- Extrapulmonary cryptococcosis including meningitis
- Disseminated non-tuberculous mycobacteria infection
- Progressive multifocal leukoencephalopathy (PML)
- Candida of trachea, bronchi or lungs
- Cryptosporidiosis
- Isosporiasis
- Visceral herpes simplex infection
- Cytomegalovirus (CMV) infection (retinitis or of an organ other than liver, spleen or lymph nodes)
- Any disseminated mycosis (e.g. histoplasmosis, coccidiomycosis, penicilliosis)
- Recurrent non-typhoidal salmonella septicaemia
- Lymphoma (cerebral or B cell non-Hodgkin)
- Invasive cervical carcinoma
- Visceral leishmaniasis

## Opportunistic Infections

### Definition of Opportunistic Infections (OIs)

- OIs are infections or illnesses that take advantage of HIV-related damage to the immune system. They make someone sick when his/her body is already weakened by the HIV virus.
- They are called “opportunistic infections” because they take the opportunity of a weakened immune system in order to make the person sick. While the immune system is working properly, the body can fight these germs that cause disease, but when the immune system is damaged the germs can grow and make the person sick.
- For an HIV-infected person, the risk of getting opportunistic infections is higher when his/her CD4 count falls below 200.
- Opportunistic infections are serious; they are the main cause of death for people with HIV or AIDS.

### Examples of Opportunistic Infections

- Candida or thrush (oral or genital)
- Kaposi’s Sarcoma (skin cancer)
- Pneumonia (PCP)
- TB
- Herpes Zoster
- Cryptococcal Meningitis

### Signs and Symptoms of Opportunistic Infections

It is important to be able to recognise the signs and symptoms of opportunistic infections. These are basically symptoms of illness:

- Diarrhoea
- Severe stomach or abdominal pain
- Vomiting
- Significant weight loss
- Loss of appetite
- Sores in mouth or on tongue, i.e. oral thrush, cold sores
- Vaginal thrush, burning or itching
- Fever or night sweats, shaking or chills



- Problems seeing or changes in vision
- Continuous headaches
- Swollen glands for at least three months
- Skin problems, i.e. eczema, psoriasis, dry, itching skin, boils and sores
- Respiratory problems, i.e. colds, flu, bronchitis, pneumonia and tuberculosis
- Cough lasting over 3 weeks
- Swelling, itching, soreness or discharge from the vagina or penis
- Changes in menstrual cycle (period)
- Pain during sex

### **Tuberculosis (TB)**

- TB is an illness caused by a bacterium that usually infects the lungs but can also infect other parts of the body.
- The TB germ can live in your body for many years without causing any signs of infection. You can stay healthy even with the TB germ in your body. You could have the TB germ without knowing it.
- 80% of TB affects the lungs, but TB can affect any organ in the body.
- TB of the lungs (pulmonary TB) is highly contagious; it spreads from one infected person to another by coughing, sneezing or spitting. It actually spreads through the air.
- When the immune system is weakened, i.e. during times of poor nutrition, not enough sleep, too much alcohol or prolonged illnesses like HIV, TB symptoms start.

Why are we learning about TB?

- TB is highly contagious.
- TB is deadly.
- TB can be cured.
- TB is a major killer of people with HIV.

TB can be “latent” or “active:”

- **Latent TB** is when the TB bacterium is in the body but the immune system can control it, so it does not cause illness. A person with latent TB cannot spread it to others. Latent TB can be diagnosed by a skin test performed at the hospital or clinic.
- **Active TB** is when the bacterium is in the body and the person is ill.



- If a person with latent TB becomes infected with HIV, he/she is more likely to develop active TB because his/her immune system can no longer control the latent TB.

Where you are most likely to become infected with TB:

- Hospital and clinics
- Overcrowded places, i.e. houses, bars, shebeens
- Prisons

Note: These are all places that are indoors, with poor ventilation and no sunlight.

### **TB and HIV in Namibia**

- Namibia has one of the highest rates of TB infection in the world.
- TB is the leading cause of illness and death of people living with HIV or AIDS. They are more susceptible to TB because of their weakened immune systems.
- One-third of HIV-positive people are infected with TB.
- TB leads to rapid progression of HIV; it allows the HIV virus to multiply more quickly.
- People with HIV are more likely to die of TB than those without HIV.

Note: Though HIV and TB are linked, one **cannot** assume that a person with TB has HIV. Not everyone with HIV gets TB, and not everyone with TB has HIV.

### **Symptoms of TB**

- A cough that lasts more than 3 weeks
- Blood in the sputum (spit)
- Chest pain
- Unexplained weight loss
- Loss of appetite
- Extreme tiredness (fatigue)
- Night sweats
- Difficulty breathing (breathlessness)

## **TB Treatment**

- TB can be cured, even if a person is HIV-positive.
- TB treatment is six to eight months long; adherence is very important with TB treatment, just as it is with HIV treatment.
- TB treatment is called DOTS: **D**irectly **O**bserved **T**reatment **S**upport. If the client does not adhere to treatment, or does not finish his/her treatment, the TB germ mutates (like HIV) into a stronger germ that is resistant to drugs so the medication no longer cures the TB germ.
- A person who does not complete treatment can become sick again, continue to spread the bacteria, or can develop drug-resistant TB.

## **TB Treatment with HIV Treatment**

- A person who has TB and HIV will usually be treated for TB first and then begin HIV treatment when indicated by a doctor.
- If the client's CD4 count is above 350, then he/she will complete TB treatment before considering HIV treatment.
- If his/her CD4 count is less than 200, the client will begin TB treatment immediately and then start HIV treatment at 8 weeks.
- A person with HIV can take both HIV treatment and TB medication; however, certain HIV treatment medication should be adjusted during the TB treatment.

## **Other Opportunistic Infections**

- Sexually transmitted infections (STIs): these are infections that are transmitted sexually. HIV is also an STI. Symptoms include: unusual discharge from penis or vagina; open sores or ulcers in the genital, groin or rectal areas; warts; and genital pain or itchiness. Most STIs can be cured with antibiotics.
- Thrush (Candida): yeast infection. White stuff on the top of the tongue, cheeks, and in the throat.
- Pneumonia: an infection that weakens the lungs. PCP, pneumocystic carinii pneumonia, is a common OI.

## Healthy Living: What to Do to Avoid Opportunistic Infections

(For reference)

1. Good personal hygiene
  - Take a bath at least once a day to keep your body clean.
  - Wear slippers or shoes to avoid small cuts that can cause infection.
  - Brush your teeth after eating.
  - Wash your hands with soap before eating and after using the toilet.
2. Clean water
  - Draw water from sources such as taps, deep wells or boreholes.
  - Store water in clean, covered containers such as buckets, pots or plastic containers.
  - Fetch stored water with clean cups.
  - Avoid making water dirty by dipping your hands in it.
  - Boil water from rivers and ponds before drinking. Boiling water is an important way to kill germs that may cause opportunistic infections.
  - Drink plenty of clean water every day.
3. Clean food preparation
  - Wash your hands with soap and clean water before preparing food.
  - Wash fruits and vegetables with clean water before you eat or cook them.
  - Use a clean table or chopping board to prepare food.
  - Serve food and water in clean utensils, i.e. plates, bowls, spoons and cups.
  - Avoid half-cooked meat. Meat that is not cooked properly can be a source of infection.
  - Wash utensils with clean water.
  - Cover food or put it in a clean cupboard away from flies for storage.
4. Maintain cleanliness around domestic and farm animals.
  - Keep animals and pets outdoors.
  - Ask someone else to clean up after animals, especially cats, kittens and chickens, if possible.
  - Always wash your hands with soap after touching pets and other animals.
  - Avoid contact with young animals, especially animals with diarrhoea.
5. Protect yourself from HIV re-infection.
  - If you have unprotected sex, you can be re-infected with a different strain of HIV, even if you are already HIV-positive.
  - If you get re-infected with a different strain off HIV, your immune system will get weaker.
  - HIV treatment does not protect you against HIV re-infection.
  - Protect yourself and your partner: always use a condom or avoid having sex.

6. Take good care of yourself.
  - Eat a balanced diet.
  - Exercise regularly.
  - Get enough sleep.
  - Avoid smoking.
  - Avoid taking alcoholic drinks.
  - Take only the medicines your doctor gives you.
  - Visit your doctor regularly.



## Common Opportunistic Infections (for reference)

Opportunistic Infection	Symptoms	Treatment	What the counsellor can do:
<b>Respiratory Infections:</b> affect the lungs			
Pneumocystis Carinii Pneumonia (PCP)	<ul style="list-style-type: none"> <li>▪ Cough</li> <li>▪ Shortness of breath</li> <li>▪ Fever</li> </ul>	Hospitalisation followed by daily dose of co-trimoxazole (antibiotic)	Support clients to take their daily co-trimoxazole
Tuberculosis (TB)	<ul style="list-style-type: none"> <li>▪ Cough for more than 3 weeks</li> <li>▪ Weight loss</li> <li>▪ Extreme tiredness</li> <li>▪ Night sweats</li> <li>▪ Difficulty breathing</li> </ul>	Anti-TB medication (usually for 6 months) using DOTS (Directly Observed Therapy)	Support clients to take their medication (adherence)
<b>Gastrointestinal Infections:</b> involve stomach and digestive system			
Candida	<ul style="list-style-type: none"> <li>▪ Pain in mouth and throat</li> <li>▪ Pain in swallowing</li> <li>▪ Fever</li> </ul>	Anti-fungal drug (fluconazole)	Support clients in taking food and medicine
Diarrhoea	<ul style="list-style-type: none"> <li>▪ Diarrhoea</li> </ul>	<ul style="list-style-type: none"> <li>▪ Rehydration: drinking sufficient water or oral rehydration fluid</li> <li>▪ Medication to treat the cause or symptoms of diarrhoea</li> </ul>	Help with offering drinks and food to cope with diarrhoea
<b>Neurological Infections:</b> (affect the central nervous system)			
Cryptococcal meningitis	<ul style="list-style-type: none"> <li>▪ Headache</li> <li>▪ Fever</li> <li>▪ Neck stiffness</li> </ul>	Hospitalisation, followed by daily fluconazole	Support clients in taking daily medicine
Cytomegalovirus infection (CMV)	<ul style="list-style-type: none"> <li>▪ Fever</li> <li>▪ Diarrhoea</li> <li>▪ Blindness</li> </ul>		
Herpes simplex virus (HSV)	Sores around the mouth and/or genitals	<ul style="list-style-type: none"> <li>▪ Acyclovir tablets (for 1-2 weeks)</li> <li>▪ Paracetamol for pain</li> </ul>	Support clients to keep sores clean and ease pain
Herpes zoster infections	Lesions on the back and other areas of the skin; can affect eyes	<ul style="list-style-type: none"> <li>▪ Acyclovir tablets (for 1-2 weeks)</li> <li>▪ Paracetamol for pain</li> </ul>	Support clients to keep sores clean and ease pain
<b>Cancer</b>			
Kaposi's Sarcoma	Lesions: purple or blue spots on the skin or in the mouth	Anti-cancer treatment	Support clients to ease pain
Non-Hodgkin's Lymphoma			
Cervical Cancer		Regular pap smear for women for screening	Encourage regular screening examinations

## Understanding HIV Treatment

### What is HIV Treatment (also called ARV Treatment or ART)?

- **Anti-Retroviral Treatment:** treatment for HIV.
- It is also called **ARV: Anti-RetroViral** and **HAART: Highly Active Anti-Retroviral Treatment**.
- HIV Treatment/ART consists of a combination of at least three different medicines that are taken together as treatment for HIV infection.
- HIV Treatment/ART helps reduce the amount of HIV virus in the body and strengthens the immune system.
- With less of the virus in the body, the immune system can become stronger and fight infections more effectively so the client will get sick less often.
- HIV Treatment/ART is not a cure it is a treatment. It does not get rid of the virus in the body; it suppresses or reduces it.

### Effects of ART (HIV Treatment): How HIV Treatment Works

1. Slows the growth of the HIV virus by reducing the viral load.
2. Allows the body to replace missing or destroyed CD4 cells, so CD4 count rises.
3. Prevent illnesses occurring due to the weakened immune system
4. Lengthens survival

### Who needs to take HIV treatment?

- Not all people with HIV need to take HIV treatment.
- HIV treatment should start when the virus has damaged the immune system to a certain level.
  - This is determined by finding out if the client has developed certain infections and by measuring the level of CD4 cells.
  - A doctor will do blood tests and decide if the client will benefit from HIV treatment.
  - The final decision about starting HIV treatment is made by the Health Care Team, which includes the client.

### **How does the HIV virus replicate, or grow?**

- Remember that HIV needs to attach to a host CD4 cell in order to replicate, or grow.
- Once the HIV virus attaches to a CD4 cell, it uses three enzymes (chemicals) to replicate:
  1. Reverse transcriptase enzyme
  2. Integrase enzyme
  3. Protease enzyme
- Without these three enzymes, the HIV virus cannot grow, even if it is attached to a CD4 cell.

### **HIV replication:**

- Replication happens rapidly; the virus produces billions of new viruses every day.
- It takes about 2.6 days for HIV to replicate from the time it enters the CD4 cell until new viruses leave the cell.
- During this process of replication, the virus makes a lot of mistakes; the virus mutates as it replicates.
- Sometimes these mutations create drug resistance. The virus changes and then the ARVs are no longer effective in suppressing the virus.

### **How does HAART suppress viral replication?**

- HAART is a combination of three drugs. These drugs act on the enzymes that the HIV virus uses to replicate.
- The current drugs act on the RTE (reverse transcriptase enzyme) and PE (protease enzyme).
- There are currently no drugs that act on the IE (integrase enzyme).
- By suppressing these enzymes that the virus needs to grow, the drugs keep the virus from growing.
- It is important to note that if HIV treatment is stopped, the virus will start to replicate again and HIV will progress.

### Categories of HIV treatment Drugs

Category of Drug	Abbreviation	Enzyme Inhibited
Nucleoside Reverse Transcriptase Inhibitors	NRTIs, also called Nukes	Reverse Transcriptase
Non-nucleoside Reverse Transcriptase Inhibitors	NNRTIs, also called Non-Nukes	Reverse Transcriptase
Protease Inhibitors	PIs	Protease

### Anti-Retroviral Medications

<b>NUKES</b> Nucleoside Reverse Transcriptase Inhibitors (NRTIs)*	<b>NON-NUKES</b> Non-Nucleoside Transcriptase Inhibitors (NNRTIs)*	<b>Protease Inhibitors (PIs)*</b>
Stavudine ( <b>d4T</b> )	Nevirapine ( <b>NVP</b> )	Lopinavir/Ritonavir ( <b>LPV/r</b> ); also known as Kaletra
Lamivudine ( <b>3TC</b> )	Efavirenz ( <b>EFV</b> )	Indinavir/Ritonavir ( <b>IDV/r</b> )
Zidovudine ( <b>AZT</b> )		Saquinavir/Ritonavir ( <b>SQV/r</b> )
Didanosine ( <b>ddl</b> )		Ritonavir ( <b>RTV</b> )
Tenofovir ( <b>TDF</b> )		Nelfinavir ( <b>NFV</b> )
Abacavir ( <b>ABC</b> )		

*\*Arranged in the order most commonly prescribed in Namibia.*

The current recommended HAART regimens in Namibia (as of the April 2003 Guidelines) include a combination of 2 NRTIs (two drugs from the first column) and a third drug to complement it, either a NNRTI or PI.

**Different Names for Drugs:** Most of the drugs or medications we are talking about have three different names. This is very confusing when you are first learning about the drugs.

1. Brand names: names companies use to identify their own particular drug.
2. Generic names: name used by all companies for the same drug.
3. Abbreviations: a shortened name for the generic name of the drug. These abbreviations are the names used by most medical professionals.

For instance, you can use the example of chocolate. Chocolate is a generic name for a type of food. Nestle or Cadbury are brand names.

We will be referring to either the generic names or the abbreviations for the drugs in this course. The bolded names listed in the ARV medication chart is the most commonly used name of the drug.



## What is a regimen?

- A specific plan intended to improve health.
- A drug regimen is a combination of medications that are prescribed by a doctor to improve a client's health.
- There are different drug regimens for different illnesses, i.e. the treatment of TB has its own regimen of medications that need to be taken to improve health.

In HIV treatment, there are also different regimens. These different regimens are numbered, i.e. first-line regimen (therapy or treatment) and second-line treatment.

### First-line Regimen:

- This is the name of a combination of ARV drugs used to “first” treat HIV.
- The first-line regimens or combinations of drugs are chosen because of their effectiveness in fighting HIV. They are also easier to take and usually have fewer side effects than the second-line regimens.

**Key Point:** Remember the ART regimens always include three drugs.

**Note:** Depending on availability, clients often will be given different versions of the same drugs when they go to collect their tablets. For instance, some of the drugs can be combined in one pill, so instead of taking three different tablets, the client may only take two. Or a client may be given the same drug but from a different company, so it may have a different brand name.

### Case Scenario: Explain HIV

**Case Scenario:** Your cousin tells you that she just tested positive for HIV. She has heard of ART and thinks that she should start taking ART immediately.

- In your pairs, role play the following:
  - Explain what HIV treatment is.
  - Describe how HIV treatment works.
  - Tell her when the body is ready for HIV treatment.
  - Offer suggestions for what she might do.

### ART First-Line Regimens

First-Line Regimen	Special Instructions	Side Effects
d4T, 3TC, & Nevirapine (NVP)	<ul style="list-style-type: none"> <li>▪ Nevirapine (NVP) will be given once per day for the first 14 days. If client has no sensitivity, it will be increased to twice per day.</li> <li>▪ May reduce effectiveness of oral contraceptives; barrier contraception should also be used.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Moderate or severe rash, usually during the initial 8 weeks of treatment. Refer to doctor. (NVP)</li> <li>▪ Nausea with vomiting and abdominal pain. Could indicate other serious side effects; refer to doctor.</li> <li>▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful, refer to doctor. (d4T)</li> <li>▪ Loss of weight in arms, legs, buttocks and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T)</li> <li>▪ Headache and nausea (3TC)</li> </ul>
AZT, 3TC & Nevirapine (NVP)	<ul style="list-style-type: none"> <li>▪ Nevirapine (NVP) will be given once per day for the first 14 days. If client has no sensitivity, it will be increased to twice per day.</li> <li>▪ May reduce effectiveness of oral contraceptives; barrier contraception should also be used.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Moderate or severe rash, usually during the initial 8 weeks of treatment; refer to doctor. (NVP)</li> <li>▪ Nausea with vomiting and abdominal pain could indicate other serious side effects; refer to doctor.</li> <li>▪ Headache and nausea (3TC, AZT)</li> <li>▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor.</li> <li>▪ Discoloured nails (AZT)</li> </ul>
AZT, 3TC & Efavirenz (EFV)	<ul style="list-style-type: none"> <li>▪ Efavirenz (EFV) should be taken before going to bed. If side effects are experienced, these should disappear after a few weeks and then EFV can be taken with other drugs in the evening.</li> <li>▪ Decrease EFV side effects by reducing fat in the evening meal, as high fat levels increase EFV in the blood.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Rash; if it becomes serious or causes concern, refer to doctor. (EFV)</li> <li>▪ Headache and nausea (3TC, AZT)</li> <li>▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor. (AZT)</li> <li>▪ Central nervous system (CNS) side effects: dizziness, vivid dreams, euphoria and feeling drunk or confused. If experienced, they usually disappear after the first few weeks.</li> <li>▪ Discoloured nails (AZT)</li> </ul>



First-Line Regimen	Special Instructions	Side Effects
d4T, 3TC & Efavirenz (EFV)	<ul style="list-style-type: none"> <li>▪ Efavirenz (EFV) should be taken before going to bed. If side effects are experienced, these should disappear after a few weeks and then EFV can be taken with other drugs in the evening.</li> <li>▪ Decrease EFV side effects by reducing fat in the evening meal, as high fat levels increase EFV in the blood.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Rash; if becomes serious or causes concern, refer to doctor. (EFV)</li> <li>▪ Headache and nausea. (3TC)</li> <li>▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful refer to doctor(d4T)</li> <li>▪ Loss of weight in arms, legs, buttocks and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T)</li> </ul>
d4T, 3TC & Lopinavir (LPV/r)	<ul style="list-style-type: none"> <li>▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood.</li> <li>▪ Reducing fat in the diet can help reduce side effects from Lopinavir.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Tingling in arms, fingers, legs and toes. May disappear with time. If it gets worse or becomes painful, refer to doctor. (d4T)</li> <li>▪ Loss of weight in arms, legs and face. Clients may think it is associated with disease progression. Support and reassure the client. (d4T)</li> <li>▪ Headache and nausea. (3TC)</li> <li>▪ Initially: stomach problems such as loose stools. (Lopinavir)</li> <li>▪ Long term: intermittent (on and off) diarrhoea and loose stools. (Lopinavir)</li> <li>▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir)</li> </ul>
AZT, 3TC & Lopinavir (LPV/r)	<ul style="list-style-type: none"> <li>▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood.</li> <li>▪ Reducing fat in the diet can help reduce side effects from Lopinavir.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness; refer to doctor. (AZT)</li> <li>▪ Headache and nausea. (AZT, 3TC)</li> <li>▪ Discoloured nails. (AZT)</li> <li>▪ Initially: stomach problems such as loose stools. (Lopinavir)</li> <li>▪ Long term: intermittent (on and off) diarrhoea and loose stools. (Lopinavir)</li> <li>▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir)</li> </ul>

**General Instructions:**

- Nevirapine (NVP) should never be taken with TB treatment.
- Efavirenz (EFV) is not recommended for women who wish to become pregnant or do not use contraceptives.
- Efavirenz (EFV) may affect the unborn child; do not take when pregnant.
- If clients are given other medications from a different doctor, it is important to tell the ART doctor.



## Second-Line Regimens

Second-Line Regimen	Special Instructions	Side Effects
AZT, Didanosine (ddl) & Lopinavir (LVP/r)	<ul style="list-style-type: none"> <li>▪ Lopinavir (LPV/r) should always be taken with a meal or a large snack to increase absorption into the blood.</li> <li>▪ Reducing fat in the diet can help reduce side effects from Lopinavir.</li> <li>▪ Didanosine should be taken on an empty stomach (no food or drink like juice, tea or coffee), for two hours before taking medicine and at least ½ hour after taking medicine.</li> <li>▪ Lopinavir and didanosine should not be taken together; wait at least an hour between taking one drug before taking the other.</li> <li>▪ May reduce effectiveness of oral contraceptives (barrier contraception should also be used).</li> </ul>	<ul style="list-style-type: none"> <li>▪ Tingling in arms, fingers, legs and toes. It may disappear, but if it gets worse refer to the doctor. (Didanosine)</li> <li>▪ Severe stomach upset, which may include abdominal pain, bloating and diarrhoea. (Didanosine)</li> <li>▪ Discoloured nails. (AZT)</li> <li>▪ Headaches and nausea. (AZT)</li> <li>▪ Initially stomach problems such as loose stools. (Lopinavir)</li> <li>▪ Long term, intermittent (on and off) diarrhoea and loose stools. (Lopinavir)</li> <li>▪ High cholesterol and re-distribution of fat in stomach, neck and shoulders. (Lopinavir)</li> <li>▪ Extreme malaise (tiredness and lethargy), muscle pain and weakness – refer to doctor. (AZT)</li> <li>▪ Nausea with vomiting and abdominal pain could indicate other serious side effects – refer to doctor.</li> </ul>
AZT, Didanosine (ddl), Indinavir (IDV) & Ritonavir (RTV)	<ul style="list-style-type: none"> <li>▪ Indinavir and Ritonavir may be taken with food to increase absorption.</li> <li>▪ Drink a minimum of 2 litres of water in addition to normal fluid intake to avoid kidney stones.</li> <li>▪ Drink a full glass of water with Indinavir.</li> <li>▪ Indinavir with Ritonavir and ddl should not be taken together; at least 1 hour should separate the dosing.</li> <li>▪ Didanosine should be taken on an empty stomach (no food or drink like juice, tea or coffee), for two hours before taking medicine and at least ½ hour after taking medicine.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Tingling in arms, fingers, legs and toes. It may disappear, but if it gets worse refer to the doctor. (Didanosine)</li> <li>▪ Severe stomach upset, which may include abdominal pain, bloating and diarrhoea. (Didanosine)</li> <li>▪ Initially stomach problems such as loose stools. (Indinavir and Ritonavir)</li> <li>▪ Long term, intermittent (on and off) diarrhoea and loose stools. (Indinavir and Ritonavir)</li> <li>▪ Kidney stones – pain in the lower back, at times extreme.</li> <li>▪ High cholesterol and re-distribution of fat in abdomen, neck and shoulders. (Indinavir and Ritonavir)</li> <li>▪ Discoloured nails. (AZT)</li> <li>▪ Headaches and nausea. (AZT)</li> </ul>





## **Adherence and Resistance**

### Compliance:

- The extent to which the client's behaviour, i.e. for taking medications, following diets, or other lifestyle changes, coincides with medical or health advice.

### Adherence:

- The degree to which a client follows a treatment regimen, which has been designed by a consultative partnership between the client and the health care worker/counsellor. It encourages discussion about the various factors in the client's life that will influence the ability to exactly follow the treatment.
- The engaged and accurate participation of a client in a plan of care

## **Similarities and Differences between Compliance and Adherence**

### Similarities:

- Both refer to a behaviour that follows advice or treatment.
- Both involve a health care worker.

### Differences:

- Compliance implies a value judgement; it assumes the health care worker's guidelines are always right, and the client's behaviour is measured against this standard. This makes it easier to blame the client for any failures in the treatment.
- In compliance, the health care worker is seen as the expert and the client as ignorant.
- Adherence implies a partnership between the client and the health care worker or counsellor.
- Adherence allows for a discussion between the client and the health care worker and a collaborative process to develop a plan or strategy.
- Adherence implies the client's understanding, consent and partnership.

### Why do we talk about adherence with HIV treatment? Why is this important?

- It is important to involve the client in his/her treatment. Let the client be his/her own expert.
- The adherence plan should be personalised to the individual client. What works for one person may not work for another.
- Adherence fits better with our basic counselling approach. Remember that the client is the expert on her/himself.
- Clients are crucial as members of the Health Care Team.



**HIV treatment adherence** means that the medication is taken according to the prescribed instructions:

- The recommended dose
- At the recommended time
- In the recommended way

Studies have shown that adherence with HIV treatment means taking at least 19 out of 20 doses. An adherence rate of more than 95% must be sustained in order for the replication of HIV to be controlled. For HIV treatment adherence, this means that a client cannot miss more than one dose a week.

Most people get better with treatment. For many, the treatment works for many years. For some, the treatment does not work or only works for a short time.

**Non-adherence** means that any one of the above three criteria is not met. If the client for any reason is NOT:

- Taking the recommended dose  
**OR**
- Taking it at the recommended time  
**OR**
- Taking it in the recommended way

Some examples of **non-adherence**:

- Missed doses, i.e. due to holidays, travel or forgetfulness
- Delayed doses, i.e. not taking the dose on time
- Failing to follow guidelines, i.e. because of social pressures, misinformation
- Drug holidays, i.e. structured treatment interruptions, temporary dislike of taking tablets

The result of being non-adherent is the possible development of drug resistance.

### **Why does the treatment not work for some people?**

1. The tablets do not work if you do not take them.
2. Some of the medicines do not stay in the body for a long time. You have to take these every 12 hours to maintain a consistent level of the drug in the body.
3. If you do not take the tablets every 12 hours each day, the virus changes (or mutates) and the medicines do not work anymore.

### **What is resistance?**

- A reduction in HIV's sensitivity to a particular drug.
- This means that a particular drug or combination of drugs, is unable to block replication of HIV, so the virus can continue to grow even in the presence of the drug.
- Some strains of HIV naturally develop resistance to anti-retroviral drugs because of the random mutations that happen regularly as the virus replicates.
- Resistance can make some drugs less effective or even completely ineffective.

### **How does resistance develop?**

- Through lack of adherence or low adherence. For instance, if someone taking ARVs misses many doses, the virus is likely to develop a resistance to some or all of those drugs.
- The more often the client misses doses or takes doses late, the more likely the virus will develop resistance.
- Resistant viruses can also be transmitted through unprotected sex. This is one reason people living with HIV need to avoid re-infection.

### **Why are we talking about resistance?**

- Resistance is a major reason why HIV treatment fails.
- If a client develops resistance to first-line regimens, then there are fewer treatment options. He/she will have to take the second-line regimens.
- Understanding resistance allows us to understand how important adherence is.

### **Second-line Regimens:**

- The second-line regimens are much harder to adhere to because they have more requirements and restrictions about how the medications should be taken.
- Second-line treatments have more severe side effects.
- If a client develops resistance to second-line regimens, there are currently no other treatment options in Namibia.



## Disclosure

Why would someone who is HIV-positive disclose his/her status?

1. Disclosure for support: HIV-positive status may be a crisis in a person's life. He/she will need support, but in order to get real support, he/she will need to disclose his/her status.
2. Disclosure for ethical reasons: An individual's HIV status involves other people, especially sexual partner(s). Not disclosing puts the partner(s) at risk.

**Key Point:** Disclosure is a process; it does not happen all at once.

In the beginning sessions of adherence counselling, a client should be encouraged to disclose his/her status. Developing a network of supportive people increases levels of adherence.

Research shows that those who take HIV treatment (ART) in secret have lower levels of adherence.

## Discussing Disclosure in Adherence Counselling

- How would you bring up the issue of disclosure with a client?
- What would your response be if you found out that your client has not disclosed his/her status to anyone?  
Possible questions include:
  - What keeps you from sharing your status with the people close to you?
  - Many people do not share their status with others because of fears they have. What fears might keep you from disclosing?
  - When you think about sharing your status with someone [you could actually name a person in your client's life, their mother, girlfriend, etc.], how do you feel?
  - What is it like for you to keep this secret all to yourself?
- How would you discuss to whom the client might be able to disclose?  
Some possible approaches:
  - Telling others your status is an important step before starting HIV treatment. If you think about disclosing your status to someone, what would you want that person to be like? What personality characteristics would you want that person to have? Can you think of anyone in your life who has some of those characteristics?

- Is there anyone in your life who you wished knew about your status?
- Who do you trust and confide in, in your life? What would it be like to tell that person about your status?
- Discuss the advantages and disadvantages of disclosure to specific people. Just as we have talked about the positive and negative consequences of disclosure, the client must explore the advantages and disadvantages of disclosure for him/herself. Naturally, in order for disclosure to be advantageous, the client must identify more advantages than disadvantages.
- Identify a person or several people to whom the client can disclose his/her status.
- Discuss details of how your client will disclose. Be specific and include the following:
  - Time
  - Place
  - Privacy
  - Ways of raising the issue
  - What will be said
- You can role play the disclosure with your client. You may start by playing the client's role and the client can play the role of the person he/she is telling. Then switch roles so the client is playing his/her own role.
- End by telling the client his/her strengths and how these strengths will assist him/her during this difficult process.

**Tips for Counselling and Disclosure:**

- Do not impose your views, beliefs or experiences concerning disclosure.
- Disclosure or not is the client's decision. Respect his/her decision.
- Who the client discloses to is also his/her choice. As the counsellor, you can encourage the client to disclose to people he/she lives with, but you cannot decide to whom the client should disclose.
- Try to be available to the client after he/she has disclosed. Talk about how it went.

## Adherence Factors

### Client Factors:

1. Client commitment: people who are committed to and actively involved in their treatment are more likely to achieve high levels of adherence.
  - Adherence rates vary not just between individuals but within the same individual over time.
  - An individual may achieve high levels of adherence sometimes and at others times will exhibit low adherence.
2. Cultural and socio-economic issues:
  - Religious beliefs about illness and medication may influence motivation and adherence.
  - Medication use may disclose HIV status.
  - Stigma may inhibit disclosure and result in low levels of support or adherence.
  - Poverty may prevent people from being able to eat nutritious food.
  - Drug and alcohol use may impair judgement and the ability to take medication on time.
  - Family responsibilities may require adults to place the health care needs of others before their own.
3. Psychological factors: Mental health problems, such as depression, can result in low adherence. Also, an individual's perception of his/her ability or inability to follow a medication regimen and whether one believes he/she can succeed or not can impact treatment adherence.
4. Health beliefs: Beliefs about health and illness, especially the necessity of medication to treat illness, can significantly impact treatment adherence.
  - Expectations of symptom relief can have an effect on adherence. If these expectations are unrealistic, there may be poor adherence.
  - Side effects can make adherence very difficult. A client's concern about potential harm from HIV treatment can be increased by his/her experience of side effects. Missed doses may be a client's attempt to reduce the side effects.
  - People on HIV treatment frequently say low adherence is due to their experiences of side effects.

### Provider Factors:

1. Offer support to all: You cannot predict future adherence based on client characteristics. Adherence is not linked to social class, education, gender, race or age.
2. Client education: Clients who understand how HIV treatment works and the importance of adherence seem to have better adherence rates.



- Very often, clients misunderstand health care providers' instructions.
  - Instructions should be given verbally and in writing. Check that the information that has been given is understood.
3. Medication alerts: People often forget to take their medication. Reminders to take medication are helpful, such as telephone, SMS, pill diaries, charts, medication containers and reminders from family and friends.
  4. Multi-disciplinary approach: Clients spend very little time with the doctor. Therefore, other health care professionals, such as nurses, pharmacists, and counsellors, should be involved in supporting client adherence.
  5. Provision of on-going support: Adherence is a process, not a single event. Support should be included in follow-up, as studies show that adherence decreases over time.
  6. Partnership of Health Care Team with client: Actively involve the client in adherence and his/her whole treatment, and provide support and respect from the Health Care Team.
  7. Attitude of health care providers: A friendly, supportive and non-judgemental attitude can help to develop a trusting relationship with the client. This relationship can influence adherence positively.

**Regimen Factors:**

1. Dosing requirements: The difficulty of the requirements for taking the medication, i.e. how many times a day, and food or water requirements.
2. Number of tablets: Combining drugs into one pill has been shown to increase adherence.
3. Side effects: This is the reason why clients report poor adherence.

**Key Point:** Adherence is dynamic. It changes in each client over time.

*Adapted from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.*



## Adherence Case Scenario

**Case Scenario:** Jacob is a 35-year-old unmarried man with HIV. He is a truck driver, and frequently is away from home for at least three days at a time, going to different cities. He shared the route with another driver, his cousin, who takes turns driving with him. He is occasionally sexually active with women when he is on the road. When he is in his hometown, he stays with his sister. When he is on the road, he sleeps in the truck. He believes that taking ART will help him feel better, but is not sure he will be able to remember to take the medicines on time.

- In your groups, discuss the following:
  - List some of the challenges that Jacob may face in achieving 100% adherence.
  - What are some ways that he may be able to overcome these challenges?
  - What are some of the positive factors that may contribute to adherence for Jacob?



## Tools and Systems for Adherence Sustainability

Examples of Tools to Sustain Adherence:

- Pill/tablet boxes: do not assume the clients know how to use pill boxes. Show them how to fill their pill boxes, count their tablets and monitor their adherence.
- Timers/alarm clocks
- Pagers
- Cell phone alarms
- Pictures
- Calendar
- Stickers



## HIV Treatment Regimen Chart: 28 Day Chart (example for reference)











Name \_\_\_\_\_ Month \_\_\_\_\_











Day	d4T	3TC	Nevirapine (NVP)
	AM PM ☀️      🌙	AM PM ☀️      🌙	AM PM ☀️      🌙
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			























## Example of weekly diary cards for an illiterate patient 4 weeks' supply (Regimen 1)

Copies can be handed out with instructions  
to fill pill boxes (egg carton) with a week's supply  
on an identifiable day, e.g. Sunday.

	D4T	3TC	EFV
	<input type="checkbox"/>	<input type="checkbox"/>	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	
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**This is not a line of treatment to follow.  
It is only an example of how illustrations can be used to assist patients.  
Actual pictures of the tablet could further assist the patient.**

## Nutrition

Definition of good nutrition: Eating foods each day that give you the vitamins and minerals you need to keep your body strong. There is no single food that has everything our bodies need. Good nutrition means eating a variety of foods.

### Basic Food Groups:

Does anyone know what the basic food groups are?

1. Fruits & vegetables: full of vitamins and minerals that are good for the body
2. Protein: good for muscle development and the immune system
3. Carbohydrates: provide the body with quick energy
4. Fat: how the body stores energy
5. Dairy: this is sometimes included as a food group, and contains some protein and fat

### HIV and Nutrition:

When your body fights infection, it needs more energy and you need to eat more than normal. This is sometimes difficult for people living with HIV, because when we are sick, we usually eat less than normal. In addition, many of the opportunistic infections related to HIV as well as the side effects of HIV and/or treatment may reduce a person's appetite or make it difficult to eat.

People living with HIV need to eat:

- Lots of protein, especially low-fat protein such as chicken breasts, fish, lean cuts of pork and beef and low-fat dairy products.
- 5 – 6 servings of fruits and vegetables per day. In order to get all the different vitamins and minerals, eat a variety of different-coloured fruits and vegetables.
- Carbohydrates provide energy. Half of one's diet should consist of carbohydrates such as grains, i.e. maize meal, bread, cereal, porridge, rice, pasta, vegetables and fruits. Try to eat whole grains.
- Eat very little sugar, sweets and cool drinks. They have very few nutrients and the sugar can cause side effects like thrush (Candida) to become worse.
- Have a serving or more of nuts, seeds or beans every day. These include peas and peanuts.

#### **Key Points:**

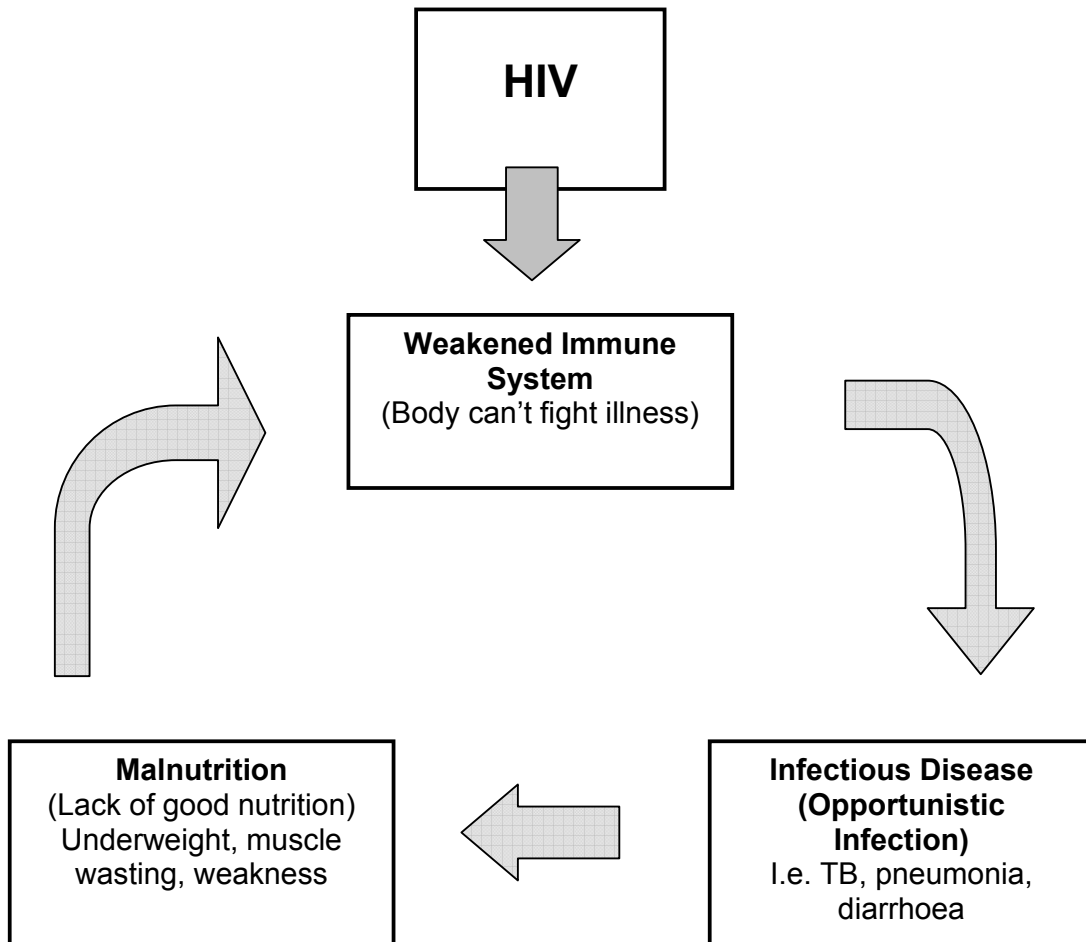
- Eat a variety of foods.
- Eat small but frequent meals.
- Eat starchy food, i.e. bread, porridge, potatoes, rice, pasta, with every meal.
- Eat fruit and vegetables every day.
- Eat meat and dairy foods (milk, yogurt, cheese) every day.
- Drink lots of water every day.



- Eat when hungry; it is good to snack, but make sure they are healthy snacks. Ideally, include protein and some carbohydrates in snacks.
- Drink 1 –2 litres of water every day.
- Yoghurt is good for digestion.
- Avoid: sweetened drinks (cool drinks like Fanta, Coke or sweetened fruit juices), sweets (cookies, candies) and junk food (chips, crisps, fried food).

### Vicious Cycle of HIV and Malnutrition

Malnutrition is not having enough food to eat or not eating nutritious food or food that is good for you.



# GETTING THE RIGHT NUTRITION

**Fats, Oils & Sweets**  
**USE SPARINGLY**

**KEY**

- Fat (Naturally occurring and added)
- ▼ Sugars (Added)

These symbols show fats and added sugars in foods.

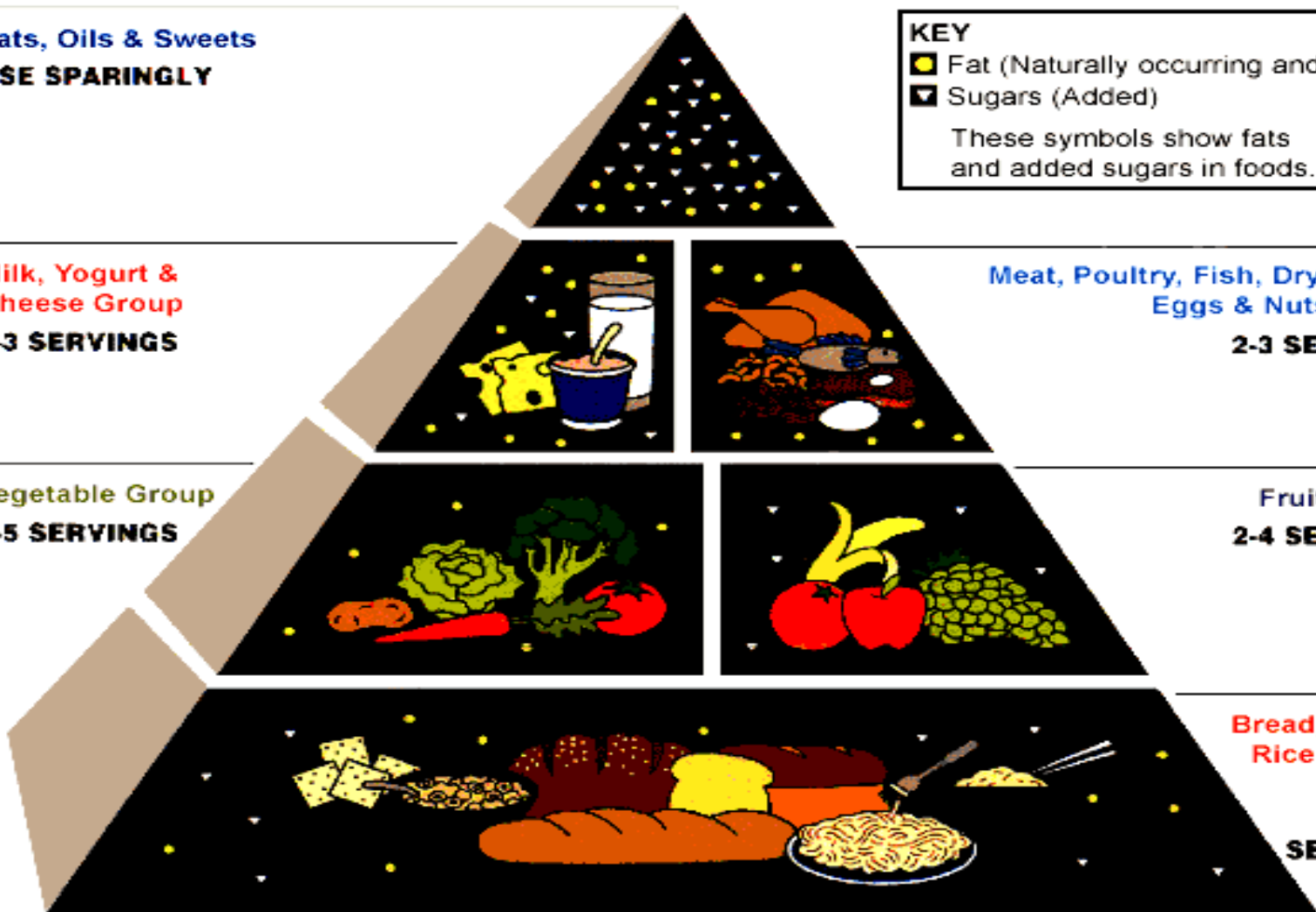
**Milk, Yogurt & Cheese Group**  
**2-3 SERVINGS**

**Meat, Poultry, Fish, Dry Beans, Eggs & Nuts Group**  
**2-3 SERVINGS**

**Vegetable Group**  
**3-5 SERVINGS**

**Fruit Group**  
**2-4 SERVINGS**

**Bread, Cereal, Rice & Pasta Group**  
**6-11 SERVINGS**



## Benefits & Limitations of HIV Treatment (ARV or ART)

Benefits/Advantages	Limitations/Disadvantages
HIV-positive people on HIV treatment live healthier, longer lives than HIV-positive people not on HIV treatment.	No cure
	Life-long treatment
	ARVs suppress the virus but do not eliminate it
	Strict adherence required, i.e. timing, frequency and dosing
	Close monitoring required.
Delayed onset of opportunistic infections	Risk of resistance
Quality of life improves, and clients can work	Side effects may reduce life quality.
Reduces transmission from mother to child	Long-term effects of HIV treatment unknown.
	Transmission may still occur.
Parents stay alive longer, so there are fewer orphans	
People are encouraged to go for VCT and to disclose their status.	More drugs and different services needed.
	HIV can still be transmitted sexually while on HIV treatment.

## Inter-Disciplinary Team & the Role of the Community Counsellor

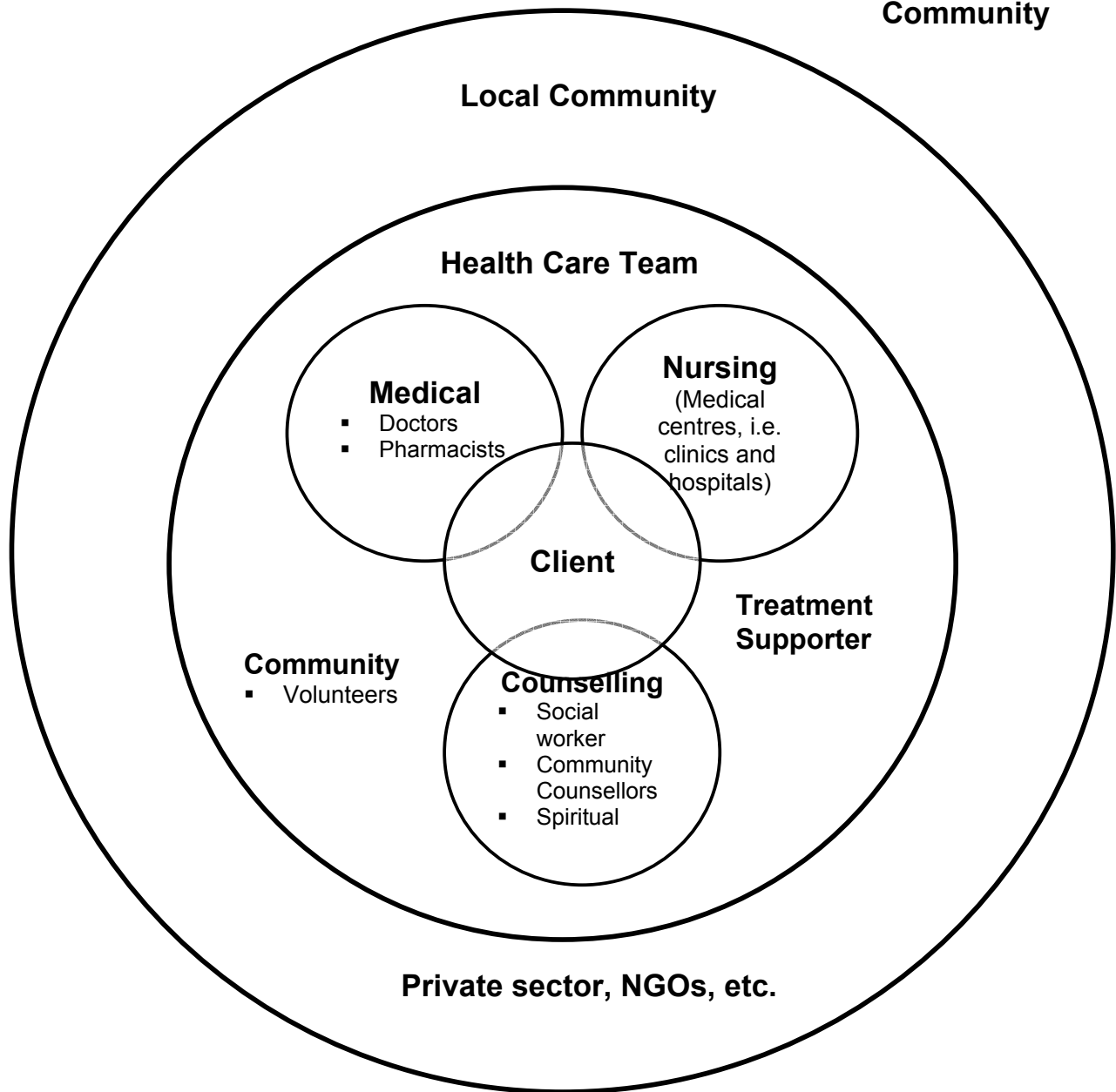
### Key Points:

- Doctors, pharmacists and nurses are the ones who provide medical information, such as information on medication, side effects, treatment regimens, etc.
- The Community Counsellors' primary role is to **support the client emotionally**. There is no one else in the health care team whose role is to support the client. The counsellor can do this by: listening to the client's experiences and supporting the client in healthy living and adherence, assessing the client's understanding, and exploring issues and potential solutions for adherence. Community counsellors are NOT information givers or trained health workers.



## Inter-Disciplinary HIV Treatment Adherence Team

Larger  
Community



## HIV Treatment Guidelines & Treatment Supporter

### Namibian Guidelines for HIV Treatment:

#### **Basic Medical Criteria for ART in Namibia**

##### **Adults:**

CD4 Count < 200, WHO Stage III or IV

##### **Pregnant Women:**

CD4 Count < 250, WHO Stage III or IV

##### **Children:**

Based on CD4 percentage

- HIV treatment and adherence is a team effort. The Health Care Team should work together to determine the client's preparedness for HIV treatment.
- The doctor and nurses will determine the client's eligibility according to the medical criteria. There are many things they have to consider and tests they need to do in order to determine medical eligibility for HIV treatment.
- The social criteria and client preparedness is determined by the entire Health Care Team.
- As a counsellor, you will be involved with the whole Health Care Team in determining whether a client meets the social criteria for beginning HIV treatment.

#### **Social Criteria** used to determine if a client is eligible for HAART in Namibia:

- Has lived at a fixed address for the past 3 months
- Has ready access to a designated treatment centre for follow-up
- Client is committed to long-term HAART, adherence to treatment, practising safer sex, and allowing home visits if indicated
- Client has identified someone at home, in the community, or at the workplace to serve as a therapy supporter

*Taken from MoHSS. April 2003. Guidelines for HAART in Namibia.*



## HIV Treatment Adherence Counselling Overview

**Key Point:** Many think that by giving instructions to a client on how to take ARVs, the client will adhere. However, there is a lot more to adherence than giving instructions. This is what adherence counselling is about.

It is helpful to think about HIV treatment adherence counselling as having a number of stages. These stages are helpful for the whole Health Care Team, but are most important for the client to go through. These stages are key to understanding adherence as an ongoing process.

The four stages of ARV adherence counselling are:

1. Pre-HIV Treatment Initiation
  2. HIV Treatment Initiation
  3. HIV Treatment Maintenance
  4. Re-Motivation or Treatment Change
- HIV Treatment Adherence Counselling begins after a client already knows his/her HIV-positive status.
  - Remember that HIV treatment is treatment for life, at least until a cure is found. Therefore, this adherence model is for the duration of treatment, for the rest of the client's life.
  - While this model clearly outlines separate counselling sessions in each stage, remember that this may not always work. Sometimes a number of sessions may be combined in order to best meet the needs of the client.
  - A high level of adherence can best be met if this four-stage model of adherence counselling is followed. It allows the client to take an active role in the treatment process and gives him/her the time to fully understand and develop a successful adherence plan.

### Stage 1: Pre-HIV Treatment Initiation

- In stage 1, the client already knows his/her HIV-positive status. He/she has been tested for HIV.
- In this stage, the client begins to think and talk about the possibility of beginning anti-retroviral treatment.
- This discussion happens between the client and the counsellor, as well as involving other members of the Health Care Team, such as doctors and nurses. The client also should be encouraged to discuss starting treatment with his/her friends and family.



- The counsellor must explore the client's thoughts and feelings about HIV treatment and what this would involve.
- The **purpose** of the first stage:
  - Educate client on HIV/AIDS and introduction to HIV treatment
  - Determine client's HIV treatment readiness: does he/she meet the MoHSS criteria?
  - Establish full commitment to treatment
  - Prepare client for what treatment involves
  - Select and involve treatment supporter
  - Develop a personalised treatment and adherence plan

### **Stage 2: HIV Treatment Initiation**

- Once the client meets the MoHSS criteria and is informed and committed to treatment, he/she can begin HIV treatment.
- At this stage, the client may experience a wide range of feelings and thoughts. The client is required to make lifestyle adjustments and faces issues that might make adherence difficult. He/she should be able to explore and address all of these issues with his/her Health Care Team.
- The **purpose** of the second stage is to:
  - Tailor the HIV treatment regimen to the client
  - Discuss side effects
  - Develop a personalised adherence plan
  - Problem solve about factors that may lower adherence.

### **Stage 3: HIV Treatment Maintenance**

- Once the client has started on HIV treatment, other issues may come up. These could include how to deal with side effects and factors that influence adherence.
- Counselling at this stage should focus on listening to the issues the client is dealing with and helping him/her to identify problems and develop strategies for solving them.
- The **purpose** of the maintenance stage is to:
  - Simplify the HIV treatment regimen
  - Avoid drug interactions and minimise side effects
  - Discuss client's coping mechanisms and reinforce strengths

### **Stage 4: Re-Motivation or Treatment Change**

- Clients may continue with the same regimen but require ongoing re-motivation and support from the Health Care Team to maintain high adherence.



- After a period of time, clients may need to change their treatment regimen. This could be for a number of different reasons, such as treatment failure, toxicity (very severe side effects), or non-adherence. If treatment is changed, the client will need to be counselled about his/her new treatment regimen.
- The **purpose** of the fourth stage is to:
  - Re-motivate the client on the same regimen, provide support, and make adjustments to the adherence plan
  - HIV treatment adjustment or change: develop new adherence plan, problem-solve factors that influence adherence

*Adapted from Kerry Saloner. February 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. Supported by The Centre for the Study of AIDS, University of Pretoria and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.*



## HIV Treatment Adherence Counselling Model

### Stage 1: Pre-HIV treatment: Meets MoHSS Criteria for ART?

**Medical Criteria by the Doctor:**  
 CD4<200, WHO Stage III or IV  
 Pregnant Women: CD4<250, WHO  
 Stage III or IV

**Social Criteria:** Committed to treatment, access to treatment centre, fixed address for 3 months, identified a suitable treatment supporter

Pre-HIV  
 treatment  
 Assessment  
**Counselling**

Additional  
 Pre-HIV  
 treatment  
**Counselling**

**Counselling**  
 with Treatment  
 Supporter

### Stage 2: Start HIV treatment: Has Met MoHSS Criteria for HIV treatment

Meet with doctor, pharmacist, nurse and counsellor on the day treatment is started.

**Doctor:**  
 HIV  
 treatment  
 prescription

**Pharmacist:**  
 Provide  
 medication  
 &  
 instructions

**Nurse:**  
 HIV  
 treatment  
 information

**Counselling**  
 with  
 Treatment  
 Supporter

### Stage 3: HIV treatment Maintenance

**Doctor:**  
 Evaluate  
 progress and  
 side effects.

**Nurse:**  
 Side effects and  
 answer questions

Supportive Adherence  
**Counselling**  
 2 weeks after starting HIV  
 treatment or as needed

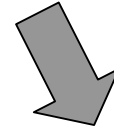
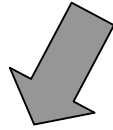
Every month for the first three months on HIV treatment, then every 3 months

**Doctor:**  
 Physical  
 exam  
 evaluate  
 side effects

**Pharmacist**  
 Consultation  
 and receive  
 medication

**Nurse:**  
 Blood tests  
 & side  
 effects

**Adherence  
 Counselling**  
 with treatment  
 supporter



### Stage 4: Re-Motivation or Treatment Change

#### Re-Motivation

- Re-motivate the client/client on the same HIV treatment regimen.
- Re-assess adherence and commitment

**Re-Motivation  
Counselling:**  
Re-assess  
adherence, adjust  
adherence plan

**Nurse:**  
Monitor side  
effects, check  
adherence

#### Treatment Change

- HIV treatment adjustment or change due to toxicity (very severe side effects), non-adherence (resistance) or treatment failure.

**Doctor:**  
New treatment  
regimen  
prescription

**Pharmacist:**  
Provide new  
drug regimen  
and  
instructions

**Nurse:**  
Blood tests and  
new instructions

**Adherence  
Counselling:**  
Develop adherence plan  
with new drug regimen,  
with treatment supporter

## Stage 1: Pre-HIV Treatment Initiation

	Task	Whose responsibility?
I.	<b>Client Education</b> about HIV infection and HIV/AIDS disease stages. (Usually done by the nurses)	Health Care Team
II.	<b>Introduction to HIV treatment</b> and adherence programme. Discuss risks and benefits of HIV treatment.	Health Care Team
III.	<b>HIV Treatment Readiness Assessment:</b> The Health Care Team needs to assess the client on the following:	Health Care Team
	<b>1. Medical Component:</b> meets the Namibian guidelines for the <u>medical criteria</u>	Doctor and Nurses
	<b>2. Counselling Component:</b> meets the Namibian guidelines for the <u>social criteria</u> Assessment is made through several (usually 3-5) counselling sessions.	Community Counsellor & Health Care Team
IV.	<b>Establish Client's full commitment</b> to HIV treatment before moving to Stage 2, HIV Treatment Initiation.	Health Care Team

### Recipe for Successful HIV Treatment: Key Ingredients

- Provide information, education and support prior to HIV treatment initiation.
- Ensure HIV/AIDS and HIV treatment education.
- Encourage the client's belief in the need for treatment and adherence.
- Provide information on difficulties of following treatment regimen and on side effects.
- Establish a foundation for long-term adherence through support and counselling.

### Pre-HIV Treatment Initiation Counselling:

- Should begin at least two to four weeks before starting treatment, but can begin much earlier than this. Pre-HIV treatment initiation counselling can begin as soon as a client tests positive for HIV.
- A person with HIV can be monitored for years before needing to start HIV treatment.
- Pre-HIV Treatment Initiation Counselling will require at least two counselling sessions before beginning treatment. It can take 3 – 6 sessions, depending on the commitment and preparedness of the client.

Pre-HIV Treatment Counselling has three main goals:





- To assess the client's understanding of HIV treatment and adherence.
- To assess the client's commitment and readiness to take HIV treatment medication.

To develop a personalised treatment plan, taking into account factors influencing adherence and the client's lifestyle.

**Key Point:** Starting ART is NOT an emergency. The client must be assessed, properly prepared for, and committed to treatment.

**Key Points:**

- Counselling is NOT just giving information or education.
- The counsellor must explore and listen to the client.
- Do not forget your basic counselling skills, especially reflecting skills.
- Telling the client of the importance of adherence will not necessarily make him/her adhere!

**Key Points about the Pre-HIV Treatment Initiation  
Counselling Checklist:**

- You do not have to follow this precise format. This is not VCT.
- All issues/topics should be discussed with the client, but not necessarily in this particular order.
- Ideally, this checklist should be covered over several counselling sessions. There is too much to explore and discuss in one session.
- Your role is to explore and assess the client's understanding and concerns, NOT simply to give information.
- Do not forget your basic counselling skills.



## Pre-HIV Treatment Initiation Counselling Checklist

- Focus on how to ask questions. Keep in mind that the counsellor is exploring, supporting, and assessing, NOT simply giving information.
- Encourage the client to talk and tell their history, specifically their HIV history.
- Remember the person-centred counselling approach we discussed in Basic Counselling. Remember that the client is the expert on him/herself.
- *Refer to the Model of Stage 1: Pre-HIV Treatment Initiation Counselling.*

### 1. History

- Find out how the client feels about his/her HIV status, how they found out and when.
- Do NOT ask the client how he/she was infected with HIV. You do not need to know how he/she got the virus.
- Use your basic counselling skills, specifically reflecting skills, i.e. reflect feelings and restate/rephrase.

### 2. Knowledge Assessment

- The doctor, nurses and pharmacist are the people who will be primarily giving information to the client about HIV progression and HIV treatment. These medical professionals have the background and more complete knowledge of these issues, so it is best if they provide this information to the client.
- Our role as community counsellors is to make sure the client understands what he/she has already been told.
- Your role is also to support the client emotionally through this process.
- Be careful not to only give information. Instead, find out what the client already understands. Ask questions like: “Can you tell me what you understand about HIV treatment?” or “What is your understanding of the importance of adherence?”
- If the client does not understand or has a misconception, you can correct him/her at that point. Do this gently; build on the part of the client’s understanding that is correct.
- If you do not know the correct information, tell the client this. It is OK to say that you do not know: you are not a medical professional. You can then refer the client back to a nurse or the doctor. You may even go with the client to have his/her questions answered.



### 3. Disclosure/Treatment Supporter

- In order to adhere to HIV treatment, the client needs a lot of support. Therefore, it is important to assess who they have disclosed to and how it was received.
- In this stage, you will also be talking with the client about a treatment supporter. The Namibian treatment guidelines require the involvement of a treatment supporter. For some clients, this will be easy; they may have a number of people they could choose from. For others, this may be much more difficult, and you may have to help them determine who might make a good treatment supporter.
- How would you talk about a treatment supporter with a client?
- For some clients, selecting a treatment supporter will involve disclosing his/her status to the supporter.
- The issue of a treatment supporter should be discussed during the first counselling session. Ideally, the treatment supporter will come to later counselling sessions with the client.

### 4. Assess Healthy Living/Lifestyle

- Intimate Relationships/Patterns of Sexual Behaviour: Establish the client's sexual patterns, i.e. if he/she is in a committed relationship or has multiple partners, if he/she practises safe sex, etc.
  - Remember that one of the social criteria for starting HIV treatment in Namibia is practising safer sex. What exactly does practising safer sex mean?
  - Be careful to probe non-judgementally and without asking leading questions; otherwise, the client will only tell you what you want to hear.
  - Brainstorm some questions you could ask. Stress how to ask these questions, using supportive and open body language.
  - Important points to stress with your clients: HIV can still be transmitted while on HIV treatment. Although the risk of transmission is reduced due to reduced viral load, the risk of re-infection is still present.
- Substance Use: Assess the client's use of any substances, including alcohol, drugs (legal and illegal) and caffeine.
  - Currently, there is nothing in the Namibian HIV Treatment Guidelines prohibiting the use of alcohol. However, alcohol use can influence adherence.
  - Excessive alcohol consumption often leads to non-adherence due to forgetting, depression, vomiting or reduced food intake.
  - Brainstorm some questions you could ask. Stress how to ask them, using supportive and open body language.



- **Diet/Nutrition/Exercise:** A healthy diet full of nutritious food is important, both for overall health and the effectiveness of HIV treatment.
  - Assess what the client eats and when.
  - You can also give the client some suggestions for nutritious foods that are readily available.
- **Rest:** Rest is also an important part of healthy living
  - You may offer suggestions for better rest if a client is having trouble.
- **Stress/Management:** Identify stresses in the client's life and assess how he/she handles them.
- **Long-term Plans:** Often, clients who have been living with HIV and have experienced some sickness may not have thought about long-term plans. The purpose here is to explore what the client wants to do in years to come. HIV treatment often gives people many more years of healthy living, so they are able to live longer and do more than they had expected.

**5. HIV Treatment Readiness:** The whole Health Care Team is assessing the client's readiness for beginning HIV treatment, but as the counsellor, you should focus on the client's personal motivation, commitment and emotional response.

- **Motivation:** Explore the client's motivation; everyone has different reasons for wanting to start HIV treatment. Listen; do not assume you know.
- **Advantages/Disadvantages:** Explore the client's personal advantages and disadvantages for treatment. It is important that the client does not begin HIV treatment expecting everything to be solved. There are definitely some disadvantages, and the client needs to be realistic about this.
- **Commitment:** HIV treatment is life-long treatment that is difficult to adhere to; therefore, clients must be very committed.
  - Pay attention to the following things related to commitment: disclosure to family and friends, involvement of family and friends in healthy living and treatment, commitment in relationships, i.e. committed and stable relationships with friends and family.
- **Emotional Responses:**
  - A client's emotions will be varied, and they may change from hour to hour. Explore this with the client and normalise all of his/her feelings.

**6. Factors Influencing Adherence:** When exploring adherence factors with clients, it is important to personalise them. You want to understand what factors the client thinks will influence his/her adherence, both positively and negatively.

- When exploring adherence factors with clients, you may want to begin with a general question, such as, "What sorts of things do you think will influence



your adherence to HIV treatment? Think of things that will influence your adherence, both positively and negatively.”

- If the client cannot think of things or only thinks of things in one or two categories, you can explore each of the categories on the Pre-HIV Treatment Initiation Checklist with him/her.
- The purpose of exploring adherence factors with a client in counselling is to help him/her be realistic about the difficulties and challenges of taking ARVs. It also helps to determine what to focus on in the client’s personalised treatment plan.

**7. Personalise a Treatment Plan:** The tendency is to try to make every client’s treatment, or adherence, plan the same. However, each plan for treatment needs to be unique to that individual. Remember, the client is the expert on him/herself.

- Empower the client to be actively involved in his/her treatment; encourage the client to educate him/herself and to ask a lot of questions.
- Brainstorm how to adhere to HIV treatment: This is where you identify solutions or techniques for dealing with the client’s adherence concerns.
  - Based on what were identified as the client’s factors that influence adherence, discuss ways that the client can overcome the factors that might negatively affect adherence.
- Lifestyle Adjustments: Make sure the client understands how much HIV treatment will influence his/her lifestyle. Be realistic about this and help the client anticipate these changes.
- Assessment Tools: Clients need to take responsibility for monitoring their treatment plan.
  - Explore how the client plans to monitor and assess his/her HIV treatment.



## Stage 1: Pre-HIV Treatment Initiation Counselling Checklist

Encourage the client to tell his/her story and to share his/her experiences; this is trust building.

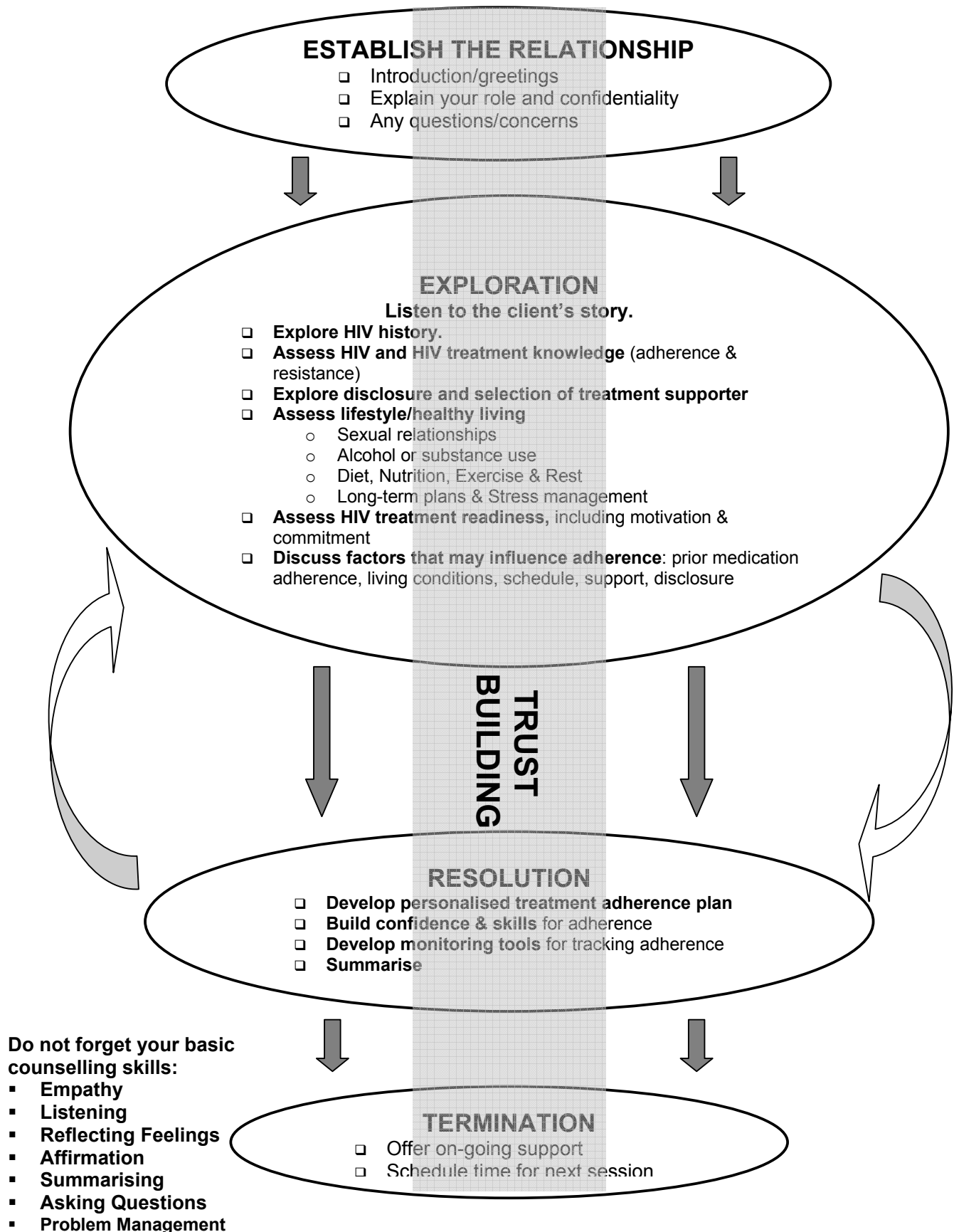
<b>1.</b>	<p><b>History</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>HIV history:</b> year of diagnosis, why tested             <ul style="list-style-type: none"> <li>○ How long have you known your HIV status?</li> <li>○ Can you tell me the story of how you learned your status? <i>OR</i> How did you find out your HIV status?</li> </ul> </li> <li><input type="checkbox"/> <b>Attitude towards HIV status:</b> <ul style="list-style-type: none"> <li>○ How do you feel about your HIV status?</li> </ul> </li> </ul>
<b>2.</b>	<p><b>Knowledge Assessment:</b> Check the client's understanding.</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>HIV treatment:</b> Client needs to understand HIV treatment as life-long treatment, not a cure.             <ul style="list-style-type: none"> <li>○ Can you tell me what you understand about HIV treatment?</li> </ul> </li> <li><input type="checkbox"/> <b>Importance of adherence</b> <ul style="list-style-type: none"> <li>○ What do you understand by HIV treatment adherence?</li> <li>○ Why do you think adherence is so important with HIV treatment?</li> </ul> </li> <li><input type="checkbox"/> <b>Consequences of non-adherence:</b> resistance             <ul style="list-style-type: none"> <li>○ What might happen if you do not take your medicines as prescribed?</li> <li>○ One of the main purposes of our counselling is to find ways to help you adhere to HIV treatment and to support you in that process.</li> </ul> </li> </ul>
<b>3.</b>	<p><b>Disclosure/Treatment Supporter</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Disclosure:</b> <ul style="list-style-type: none"> <li>○ Have you told anyone about your status? If so, who? When?</li> </ul> </li> <li><input type="checkbox"/> <b>Reactions from others:</b> <ul style="list-style-type: none"> <li>○ How did the person/people you told respond?</li> </ul> </li> <li><input type="checkbox"/> <b>Household disclosure:</b> <ul style="list-style-type: none"> <li>○ Does anyone you live with know your status? If so, who?</li> </ul> </li> <li><input type="checkbox"/> <b>Discuss treatment supporter:</b> Define who this should be, qualities of a good treatment supporter, and how to select this person.</li> <li><input type="checkbox"/> <b>Identify treatment supporter:</b> You may need to discuss how to ask the person or how to disclose to him/her.</li> </ul>
<b>4.</b>	<p><b>Assess Healthy Living/Lifestyle</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> <b>Intimate Relationships/Patterns of Sexual Behaviour:</b> <ul style="list-style-type: none"> <li>○ Can you describe your relationships? Can you describe your sexual behaviour?</li> <li>○ Do you have more than one sexual partner?</li> <li>○ In your sexual relationships, do you do anything to prevent the transmission of HIV? What about preventing pregnancy?</li> </ul> </li> <li><input type="checkbox"/> <b>Substance Use:</b> drugs or alcohol             <ul style="list-style-type: none"> <li>○ Do you use any drugs? If so, what? How often?</li> <li>○ Do you ever drink alcohol (beer/wine)? If so, how often? How much do you usually drink?</li> <li>○ How many drinks did you have last week?</li> </ul> </li> <li><input type="checkbox"/> <b>Diet/Nutrition/Exercise:</b> <ul style="list-style-type: none"> <li>○ What do you normally eat for breakfast/lunch/dinner?</li> <li>○ Do you eat at other times of the day?</li> <li>○ Do you exercise? If so, what do you do? How often?</li> </ul> </li> <li><input type="checkbox"/> <b>Rest:</b> <ul style="list-style-type: none"> <li>○ How much sleep do you normally get at night?</li> <li>○ Do you ever have trouble sleeping?</li> </ul> </li> </ul>



	<ul style="list-style-type: none"> <li>❑ <b>Stress Management:</b> <ul style="list-style-type: none"> <li>○ Can you identify anything as a problem in your life?</li> <li>○ How do you deal with problems?</li> </ul> </li> <li>❑ <b>Long-term Plans:</b> <ul style="list-style-type: none"> <li>○ What do you want to do in 2 years?</li> <li>○ What do you want your life to be like in 5 years?</li> </ul> </li> </ul>
5.	<p><b>HIV Treatment Readiness</b></p> <ul style="list-style-type: none"> <li>❑ <b>Motivation:</b> <ul style="list-style-type: none"> <li>○ Why do you want to start HIV treatment?</li> </ul> </li> <li>❑ <b>Advantages/Disadvantages of being on HIV treatment:</b> <ul style="list-style-type: none"> <li>○ What do you see as the good things about starting HIV treatment?</li> <li>○ What about any negative or bad things about being on HIV treatment?</li> </ul> </li> <li>❑ <b>Commitment:</b> <ul style="list-style-type: none"> <li>○ We have talked a lot about adherence. How are you feeling about committing to life-long HIV treatment?</li> </ul> </li> <li>❑ <b>Emotional responses:</b> <ul style="list-style-type: none"> <li>○ When you think about starting on treatment, how do you feel?</li> </ul> </li> </ul>
6.	<p><b>Factors Influencing Adherence</b></p> <ul style="list-style-type: none"> <li>❑ <b>Prior medication adherence:</b> <ul style="list-style-type: none"> <li>○ Have you ever taken medication before? If so, for how long? How often?</li> <li>○ Did you have trouble remembering to take your tablets?</li> </ul> </li> <li>❑ <b>Views about being on medicine:</b> <ul style="list-style-type: none"> <li>○ How do you feel about being on medicine?</li> <li>○ Do you have any concerns about that?</li> </ul> </li> <li>❑ <b>Living Conditions:</b> <ul style="list-style-type: none"> <li>○ Where are you staying now? How long have you been living there?</li> </ul> </li> <li>❑ <b>Schedule:</b> <ul style="list-style-type: none"> <li>○ Can you tell me about your normal daily schedule?</li> <li>○ What time do you normally get up/go to sleep?</li> <li>○ Do you take care of anyone, such as children or an elderly relative?</li> </ul> </li> <li>❑ <b>Support:</b> <ul style="list-style-type: none"> <li>○ Who do you get support from? Do they know your status?</li> </ul> </li> <li>❑ <b>Difficulties of adherence:</b> <ul style="list-style-type: none"> <li>○ What do you think will be hard for you about being on HIV treatment?</li> </ul> </li> </ul>
7.	<p><b>Personalise a Treatment Plan:</b> Remember, the client is the expert on her/himself.</p> <ul style="list-style-type: none"> <li>❑ <b>Empower</b> the client to be an <b>active participant</b> in his/her treatment plan.</li> <li>❑ <b>Brainstorm how to adhere to HIV treatment.</b> <ul style="list-style-type: none"> <li>○ Many clients develop ways of remembering to take their medicines. Let's talk about how you might be able to remember to take your medicines.</li> </ul> </li> <li>❑ <b>Lifestyle Adjustments:</b> <ul style="list-style-type: none"> <li>○ How will HIV treatment fit into your daily schedule?</li> <li>○ Will you have to change anything in your life in order to adhere to HIV treatment? If so, what?</li> </ul> </li> <li>❑ <b>Assessment Tools:</b> Develop tools for assessing the treatment plan, i.e. medication diaries, calendar, pill chart, etc. <ul style="list-style-type: none"> <li>○ It is important to tell your doctor if you are late or forget to take your medicines. How are you going to keep track of this?</li> </ul> </li> </ul>



# STAGE 1: PRE-HIV TREATMENT INITIATION





## Managing Side Effects

**Symptom:** a physical condition which shows that you have a disease; the condition is a result of the disease.

**Side effect:** an effect that a drug has on your body in addition to treating an illness.

Some facts about side effects:

- 40% of HIV treatment clients will not experience any side effects.
- Many side effects will resolve themselves within a few weeks or even days.
- However, 80% of clients who experience side effects will need help in dealing with them.

The tolerability of HIV treatment regimens is one of the important factors of treatment success. Being aware of these side effects beforehand has been shown to help clients understand, accept and continue on their medication through the challenges of the side effects. Therefore, it is important to talk with clients about the potential side effects and give the client tips for how to deal with them.

### Adjustment Period:

- When starting a new HIV treatment regimen, there is a period of time when the body is adjusting and adapting to the new drug. This period is called the adjustment period.
- Symptoms of the adjustment period:
  - Headache
  - Nausea
  - Fatigue (tiredness)
  - Muscle pain in the arms
  - Occasional dizziness
- These symptoms may start about one week after beginning HIV treatment and last up to 4 – 6 weeks.
- Most of these side effects will disappear once the body has adjusted to the new medication.
- Warning clients about these adjustment side effects can prepare them and ease their concerns if they experience some of these side effects.

**Bottom Line:** All clients must consult their doctor if they think they are experiencing drug side effects. Some of the side effects may be very serious, and even potentially fatal.



## Side Effects: What to Look For and What to Do

**1. Fatigue:** This is tiredness even after you have rested. Tiredness, both physical and psychological, i.e. having trouble concentrating, that does not go away.

- What to look for: Take note of how long you have been feeling this way, when, i.e. is it only in the morning?, how often and how it affects you and your functioning.
- Fatigue can be caused by the HIV itself or other factors besides the medication. Other factors could include: stress, alcohol, poor diet, lack of sleep, overwork or other medical conditions.

### Tips/What to do about Fatigue:

- Go to sleep and wake up at the same time every day. Changes in your sleep schedule can actually make you more tired.
- Avoid alcohol, as it worsens the fatigue.
- Try to get some exercise. Exercise eases stress and often makes you feel stronger and more energetic.
- Keep easy to prepare, nutritious foods on hand for times when you are too tired to cook. It is important to eat well.

**2. Peripheral Neuropathy:** Numbness, tingling or burning in the hands, arms, feet or legs. This is caused by damage to the nerves. It may be caused by the HIV itself or be a side effect of the medication; it is primarily a side effect of D4T and ddI.

- What to look for: Burning, stinging, stiffness, tickling or numbness in the feet, toes or hands.

NOTE: Peripheral neuropathy can be very serious. Tell your doctor about any symptoms, as nerve damage is permanent.

### Tips/What to do about Peripheral Neuropathy:

- Tell your doctor.
- Wear loose-fitting shoes and cotton socks. Wear padded slippers around the house. Good circulation around the feet can help reduce the effects.
- Massage your feet. This reduces pain temporarily.
- Soak your feet in cool water.
- Do not walk too much at a time.
- Keep feet uncovered in bed.



**3. Anaemia:** This is a depletion, or a shortage, of red blood cells that supply oxygen to different parts of the body. The result of insufficient oxygen in your blood is fatigue. Anaemia is a common symptom of HIV and a side effect of AZT.

- What to look for: Tiredness or fatigue (also see Fatigue)

Tips/What to do about Anaemia:

- Tell your doctor.
- Anaemia can be monitored by regular blood tests.

**4. Nausea and Vomiting:** This is very common during the adjustment period. However, persistent vomiting can lead to serious medical problems, such as dehydration, chemical imbalance, weight loss, etc.

- What is the difference between nausea and vomiting? Nausea means the person feels like vomiting but very often does not.
- What to look for: If a client is experiencing severe abdominal pain, trouble breathing and disorientation, refer him/her to the doctor. If vomiting more than three times a day, also refer client to the doctor. Vomiting may interfere with your ability to take your medicine and keeping the correct balance of medicine in your body, i.e. vomiting up the medicine.

Tips/What to do about nausea and vomiting:

- BRAT diet (bananas, rice, applesauce and toast) helps with nausea and vomiting.
- Keep dry crackers next to your bed. You can eat a few in the morning before you get out of bed. This can help reduce nausea.
- Avoid rich, spicy, strong smelling and greasy food.
- Try drinking peppermint, chamomile or ginger tea to calm the stomach.
- Cold carbonated drinks, such as ginger ale or lemonade, can help reduce nausea.
- It is important to replace fluids if you are vomiting, especially when it is hot outside. You could drink broth (clear soup), juice or iced pops.
- Take note of how often you are vomiting. If it continues, go to the doctor.

**5. Headaches:** ARVs can cause headaches, but headaches can also be a result of stress. Managing stress is critical to reducing headaches.

- What to look for: If headache is accompanied by fever, disorientation, altered consciousness, blurred vision or convulsions, refer to the doctor.



Tips/What to do about headaches:

- Take over-the-counter medication like paracetamol, aspirin or ibuprofen.
- Lay down in a quiet, dark room with your eyes closed. Place cold washcloths over your eyes. Massage the base of your skull with your thumbs, and/or both temples gently.
- Hot baths may help relieve tension headaches.
- An occasional headache is normal, but if the headache does not go away or you regularly wake up in the morning with headaches, talk to your doctor.

**6. Diarrhoea:** This can be a serious side effect that must be responded to quickly. Diarrhoea can also be due to other things besides the medication, such as bacterial infections.

- What to look for: Take note of how often and for how long diarrhoea persists. This is important information for the doctor. Diarrhoea can easily lead to dehydration. If a client has diarrhoea more than 5 times a day for 5 or more days and weight loss of more than 2 kgs, refer to the doctor.

Tips/What to do about diarrhoea:

- BRAT diet (see nausea & vomiting). Also eat oatmeal, cream of wheat and soft bread that is not whole grain.
- Anti-diarrhoeal medication like Lomotil and Immodium can help.
- Avoid skins of fruit and vegetables, as they are high in insoluble fibre and can make diarrhoea worse.
- Avoid milk products and greasy or very sweet foods; they can make diarrhoea worse.
- Drink lots of fluids, i.e. water, ginger ale, chicken or beef broth, and herbal tea.
- Drink between meals instead of with meals.
- Avoid caffeine, i.e. tea, coffee, Coke.
- Tell your doctor.

**7. Weight Loss:** Weight loss can be a serious problem with HIV, and should always be discussed with your doctor.

- What to look for: Any loss in weight, but especially weight loss without any changes in diet or exercise.



Tips/What to do about weight loss:

- Monitor your weight loss. Discuss with health care workers to determine the cause of the weight loss. Is it stress related, accompanied by nausea or vomiting, associated with new medication, the result of diarrhoea, or something else?
- Eat foods that are high in protein.
- High protein shakes that are low in sugar can help in gaining weight.

**8. Dry Mouth:** It is uncomfortable and can make chewing, swallowing and taking medicine difficult. Dry mouth also can affect one's sense of taste and cause further mouth problems, such as tooth decay and thrush (oral yeast infection).

Tips/What to do about dry mouth:

- Drink plenty of liquids during and between meals.
- Avoid sugary or sticky foods and caffeinated drinks, as these also dry out your mouth.
- Rinse your mouth throughout the day with warm salted water.
- "Slippery elm" or "liquorice" tea lubricates the mouth and is pleasant tasting.
- Doctors can prescribe mouth rinses or a synthetic saliva or anti-dry mouth medication if necessary.

**9. Rash:** This is a very common side effect of treatment, specifically for Nevirapine, Efavirenz and Nelfinavir. Rash is often more severe in women.

- What to look for: Monitor the skin for discolouration and changes in its surface: is the skin a different colour and does it feel different than normal, i.e. is it bumpy? If the skin peels, blisters or forms sores, refer to the doctor immediately.

Tips/What to do about rash:

- Use medicine like calamine lotion or antihistamines to soothe and comfort the skin.
- Use unscented, non-soap cleansers or oatmeal soaps.
- Do not take very hot showers or baths, as the heat will irritate the skin.
- Keep skin clean and dry.
- Drink plenty of water to keep skin hydrated.
- Avoid synthetic fabric; instead wear natural fabrics like cotton or silk.
- Stay out of the sun. Rash-affected areas should be protected from the sun, i.e. wear long-sleeves or a hat, etc.
- Tell your doctor, especially if the rash gets worse, if it involves the eyes or mouth, or if you feel ill at the same time.

**10. Menstrual Problems:** These problems include irregular, heavier, lighter and/or painful periods, or even the stopping of menstrual bleeding altogether. Ritonavir has been known to cause heavy (excessive) menstrual bleeding.

- What to look for: Women should track their menstrual bleeding and note any significant changes.

Tips/What to do about menstrual problems:

- Period problems can be related to many different issues, such as weight loss or stress levels. Consider what else is happening in your life.
- Hot water bottles or heating pads can help menstrual cramps. Place them over your lower stomach or back. You could also take a hot bath.
- Mild exercise, like walking or stretching, increases the blood flow and may reduce period pain.
- Oral contraceptives: Check to see that these will not interact with your HIV treatment. Talk to your doctor.

**11. Kidney Stones:** These are often a side effect of Indinavir, as crystals of Indinavir collect in the kidneys and can cause severe pain.

- What to look for: Severe pain from kidney stones happens suddenly. Clients often have no warning.
- Kidney stones take time to develop.
- Unlike other ARVs, Indinavir is processed through the kidneys; other ARVs are processed through the liver.

Tips/What to do about kidney stones:

- Drink lots of water. Take Indinavir with a full glass of water and drink at least 1 ½ litres of water daily in addition to normal fluid intake.
- Increase water intake during hot weather and if drinking any alcoholic beverages.

**4. Central Nervous System (CNS):** Nightmares, sleeplessness, sadness or worry; often side effects of Efavirenz.

- What to look for: Difficulty concentrating, confusion and abnormal thinking. Also, mood swings such as agitation, aggression, depression and euphoria (extreme happiness). Insomnia (inability to sleep) and vivid dreams.
- These side effects are the reason clients are instructed to take Efavirenz before going to bed.

Tips/What to do about CNS problems:

- Eat a low-fat meal before taking Efavirenz. High fat increases the absorption of Efavirenz and increases the side effects.
- Adjust meal times so you eat a while before taking Efavirenz.
- Keep records of symptoms to report to the doctor.



**Side Effects Chart**  
(For reference)

Side effect	What client can do	Seek help/go to clinic
Tiredness	<ul style="list-style-type: none"> <li>➤ Get up and go to bed at same time every day</li> <li>➤ Get some exercise</li> <li>➤ Keep easy to prepare foods in house</li> </ul>	<ul style="list-style-type: none"> <li>➤ You are too tired to eat or move</li> <li>➤ You cannot swallow or eat enough to feel strong</li> </ul>
Headache	<ul style="list-style-type: none"> <li>➤ Rest in a quiet, dark place</li> <li>➤ Place cold cloths on your eyes</li> <li>➤ Rub the base of your head or your temples with your thumbs</li> <li>➤ Take a warm bath</li> <li>➤ Avoid coffee, Coke, tea and other foods with caffeine</li> <li>➤ Take paracetamol</li> </ul>	<ul style="list-style-type: none"> <li>➤ Your vision becomes blurry or unfocussed</li> <li>➤ Paracetamol does not relieve the pain</li> <li>➤ Headaches are frequent or very painful</li> <li>➤ Your neck is stiff</li> </ul>
Tingling or pain in feet and hands	<ul style="list-style-type: none"> <li>➤ Wear loose fitting shoes and socks</li> <li>➤ Keep feet uncovered in bed</li> <li>➤ Walk a little, but not too much</li> <li>➤ Soak feet in cool water</li> <li>➤ Rub feet and hands</li> </ul>	<ul style="list-style-type: none"> <li>➤ The tingling does not go away or gets worse</li> <li>➤ The pain prevents you from walking</li> </ul>
Dry Mouth	<ul style="list-style-type: none"> <li>➤ Rinse your mouth with clean salted water</li> <li>➤ Suck on crushed ice or sip clean water</li> <li>➤ Avoid sweets and drinks such as coffee and Coke</li> </ul>	<ul style="list-style-type: none"> <li>➤ You also have spots (white or red) on your tongue or in your mouth</li> </ul>
Diarrhoea	<ul style="list-style-type: none"> <li>➤ Eat frequent small meals</li> <li>➤ Eat easy foods: bananas, rice, toast, applesauce</li> <li>➤ Avoid milk products</li> <li>➤ Do not eat spicy or greasy foods</li> <li>➤ Peel fruits and vegetables before eating</li> <li>➤ Drink lots of clean water and tea</li> <li>➤ Take ORS (oral rehydration salts)</li> </ul>	<ul style="list-style-type: none"> <li>➤ There is blood in the stool</li> <li>➤ You also have a fever</li> <li>➤ You have more than 4 watery or soft bowel movements per day</li> <li>➤ You are thirsty but cannot eat or drink properly</li> </ul>
Nausea, vomiting and low appetite	<ul style="list-style-type: none"> <li>➤ Take HIV treatment drugs with food</li> <li>➤ Eat frequent small meals</li> <li>➤ Eat bland foods (rice, porridge)</li> <li>➤ Take sips of tea or ORS until vomiting stops</li> <li>➤ Do not eat greasy or spicy foods</li> <li>➤</li> <li>➤</li> </ul>	<ul style="list-style-type: none"> <li>➤ You have sharp pains in your stomach</li> <li>➤ You also have a fever</li> <li>➤ You are vomiting blood</li> <li>➤ Vomiting lasts more than 1 day</li> <li>➤ You are thirsty but cannot drink or eat</li> </ul>

Side effect	What client can do	Seek help/go to clinic
Hair loss	<ul style="list-style-type: none"> <li>➤ Protect hair from damage: do not dye, straighten or plait</li> <li>➤ Do not buy products that promise to grow hair back</li> </ul>	
Anaemia	<ul style="list-style-type: none"> <li>➤ Increase foods with iron, such as fish, meat, chicken, spinach, asparagus, dark leafy greens and lima beans.</li> <li>➤</li> </ul>	<ul style="list-style-type: none"> <li>➤ You have been feeling tired for 3-4 weeks and it is increasing.</li> <li>➤ Both of your feet are swelling.</li> </ul>
Dizziness	<ul style="list-style-type: none"> <li>➤ If you feel dizzy, sit down until it goes away.</li> <li>➤ Try not to lift anything heavy or move quickly.</li> <li>➤ Take Efavirenz right before going to sleep.</li> <li>➤ Avoid driving a car, motorcycle or bicycle when dizzy.</li> </ul>	<ul style="list-style-type: none"> <li>➤ If the dizziness lasts more than 2 weeks</li> </ul>
Unusual or bad dreams	<ul style="list-style-type: none"> <li>➤ Try to do something that makes you happy and calm right before going to sleep.</li> <li>➤ Avoid alcohol and street drugs</li> <li>➤ Avoid food with a lot of fat</li> </ul>	<ul style="list-style-type: none"> <li>➤ If you cannot sleep for 3 or more nights</li> </ul>
Feelings of sadness or worry	<ul style="list-style-type: none"> <li>➤ Talk about your feelings with others (family, friends, other PLWHA)</li> <li>➤</li> </ul>	<ul style="list-style-type: none"> <li>➤ If you have serious, sad or very worrying thoughts</li> <li>➤ If you are thinking of harming yourself</li> <li>➤ If you are very aggressive or very scared</li> </ul>
Difficulty concentrating	<ul style="list-style-type: none"> <li>➤ Use reminders for important tasks, i.e. notes to yourself or help from family members</li> <li>➤ Allow extra time for activities</li> </ul>	
Skin rash	<ul style="list-style-type: none"> <li>➤ Keep the skin clean and dry</li> <li>➤ Wash with unscented soap and water</li> <li>➤ Use calamine lotion for itching</li> <li>➤ Avoid hot baths or showers</li> <li>➤ Avoid the sun if you have a rash</li> </ul>	<ul style="list-style-type: none"> <li>➤ Rash is accompanied by general ill feeling, fever, muscle or joint aches, blisters or mouth sores, inflammation of the inside of the eyelids, swelling of the face or tiredness</li> </ul>

*Family Health International, Adherence Support Worker Training: Facilitator's Guide. Zambia.*





## Symptom Management Guide

Symptom	What to do?
Loss of weight, wasting syndrome	<ul style="list-style-type: none"> <li>• Increase energy intake by eating more fats and oils</li> <li>• Increase protein intake: meat, fish, dairy products, eggs, beans, nuts, seeds</li> <li>• Exercise to maintain or increase muscle mass</li> </ul>
Loss of appetite or anorexia	<ul style="list-style-type: none"> <li>• Eat with family and friends</li> <li>• Eat snacks; eat small amounts often</li> <li>• Avoid alcohol and cigarettes</li> <li>• Drink liquids that provide energy: milk, juice, or tea with milk <u>after</u> or <u>between</u> meals</li> <li>• Add herbs or spices to increase flavour</li> <li>• Exercise before a meal</li> </ul>
Nausea or Vomiting	<ul style="list-style-type: none"> <li>• Eat frequent small meals: less spice, not fried or high in fat, and cold or room temperature.</li> <li>• Eat dry, salty biscuits, dry toast</li> <li>• Drink herbal and spice teas or juices</li> <li>• Avoid lying down until 20-30 minutes after eating</li> <li>• Rest between meals</li> </ul>
Mouth or Throat Sores	<ul style="list-style-type: none"> <li>• Rinse mouth or gargle often with mouthwash or warm salt water.</li> <li>• Eat soft, mashed foods such as soft porridge, noodles, oatmeal, yoghurt, mince meat, eggs, pumpkin, sour milk and paw-paw.</li> <li>• Avoid foods that irritate, like spicy foods, i.e. chillies, curries, and acidic foods, i.e. oranges, tomatoes, lemons, vinegar.</li> <li>• Avoid sugary foods (cakes, sweets, etc.) with ulcers.</li> </ul>
Changes in Taste	<ul style="list-style-type: none"> <li>• If meat is not appealing, eat other protein foods: beans, nuts, milk, poultry, fish or eggs</li> <li>• Use spices and herbs to improve flavour</li> <li>• If no mouth sores, add lemon juice to food</li> <li>• Maintain good oral hygiene: clean teeth and use an antiseptic mouth wash</li> <li>• Avoid drinking liquids from a tin</li> </ul>
Diarrhoea	<ul style="list-style-type: none"> <li>• Boil drinking water, and cook and store food safely and properly</li> <li>• Replace electrolytes with ORS (Oral Rehydration Salts), bananas, paw-paw, potatoes, and cooked spinach.</li> <li>• Dilute fruit juices with water and add a pinch of salt</li> <li>• Avoid foods high in processed sugar, i.e. sweets, cool drinks</li> <li>• Eat easy to digest foods: rice, toast, omahangu/pap, fruit, cooked beans, oatmeal, and yoghurt</li> <li>• With fat mal-absorption, avoid high fat foods: butter, oils, and fried foods</li> <li>• Eat small quantities of food often</li> </ul>
Metabolic Changes	<ul style="list-style-type: none"> <li>• Reduce intake of high fat and foods with added sugar</li> <li>• Increase physical activity, such as walking, jogging, swimming, or gardening.</li> <li>• Adhere to HIV treatment dosage and schedules</li> </ul>
Anaemia (iron deficiency)	<ul style="list-style-type: none"> <li>• Eat foods high in iron, such as meat, poultry, eggs, beans, and fortified cereals</li> <li>• Eat high-iron foods with foods high in vitamin C, such as citrus fruits and juices, paw-paw, mangoes, tomatoes, and avocados</li> <li>• Avoid tea with iron-rich meals because tannins in tea inhibit iron absorption.</li> </ul>
Vitamin A deficiency	<ul style="list-style-type: none"> <li>• Increase fruit and vegetable intake, especially sweet potatoes, carrots, pumpkin, squash, melons/paw-paw, and vitamin-fortified cereals</li> </ul>

**Source: Government of the Republic of Namibia, Ministry of Health and Social Services. Draft 2005. Nutrition Management of HIV/AIDS: A Resource Guide for Clinical and Community-Based Health Workers. Windhoek, Namibia.**



## Stage 2: HIV Treatment Initiation

### HIV Treatment Initiation Chart

	Task	Whose responsibility?
I.	<b>Client education and understanding</b> of antiretroviral treatment.	Health Care Team
II.	<b>Instructions on HIV treatment regimen:</b> which medications, when to take, correct dosing, side effects, etc.	Doctor, Nurses and Pharmacist
III.	<b>HIV Treatment Preparedness:</b> The Health Care Team needs to prepare the client on the following: 1. <b>Medical component</b> 2. <b>Counselling component</b>	Health Care Team  Doctor and Nurses Community Counsellor
IV	<b>Establish client's full understanding</b> and reinforce <b>commitment</b> to HIV treatment.	Health Care Team

\* Notice the purpose is more specific and is focussed on the specific regimen.

HIV Treatment Initiation Counselling takes place on the day the client receives his/her medication and begins HIV treatment.

- Counselling should always be done with the treatment supporter present.
- HIV Treatment Initiation Counselling takes place after the client has met with the counsellor a few times, usually 2-4 sessions.

The aims of HIV treatment Initiation Counselling are:

- Assess and reinforce client's understanding of his/her HIV treatment regimen instructions.
- Review the client's personalised adherence plan.
- Boost client's confidence in his/her ability to adhere to HIV treatment.

### HIV Treatment Initiation Checklist

#### 1. HIV Treatment Readiness

- You have already assessed the client's readiness in Pre-HIV Treatment Initiation Counselling. Here you are exploring how the client is feeling, as well as his/her expectations, hopes, and concerns about treatment.
- Pay attention to conflicted feelings and validate everything the client is feeling.  
Validate: accept all feelings the client expresses. It is OK to have conflicted feelings, i.e. excited and scared at the same time.

#### 2. Regimen Instructions Assessment

- In order to assess whether the client understands how to take his/her medicine, you have to listen to the client.



- DO NOT tell the client how to take the drugs. LISTEN to the client tell you how he/she is planning to take his/her medicine.
- Make sure the client understands that the medications are only for him/her. The client should not share medicine with others. He/she must take all the doses and continue with the medication, even if he/she feels better.
- Also ask about late or missed doses. Below are the general instructions for missed doses. Remember that you are listening to the client's understanding of the instructions he/she already has received. Keep in mind that there are many variations to the instructions for missed doses, depending on the specific medication. You will need to check with the doctor about the specific instructions for missed doses with each particular regimen.
  - Do not take two doses at the same time.
  - Do not take the missed dose close to the time of the next dose.
  - Take the missed dose if within 3 hours of the scheduled time.
  - If you are more than 3 hours late for a dose, drop the missed dose and take the next dose on time as scheduled. Make note of the missed dose, along with the reason for missing the medication.
- Only provide information on how to take the regimen if your client gives you incorrect information.
- If the client tells you the correct instructions, encourage him/her. Use this as an opportunity to build the client's confidence in his/her ability to adhere.

### 3. Treatment Supporter

- There are many ways that clients can use the treatment supporter. There is no right way to involve the treatment supporter; this depends on the relationship of the treatment supporter with the client. Let the client personalise this as well.
- Below are some suggestions for the role of the treatment supporter:
  - Reminding client of regular drug doses at the right time.
  - Identifying serious side effects and seeking medical help.
  - Provide help with common side effects.
  - Collecting medication in case of an emergency.

### 4. Factors Influencing Client's Adherence

- Remember to personalise the adherence factors for your specific client. However, there are some common adherence issues.
- Side Effects:
  - In countries where HIV treatment has been available for a long time, about one in six people stop taking treatment because of the side effects or inability to maintain the strict drug regimen.



- Make sure the client understands the potential side effects of his/her ARV regimen. Once again, listen to him/her tell you what the side effects are.
- The client should also know what to do if he/she experiences these side effects.

**Key Point:** The key to coping with side effects is to know what to watch for and to have a plan in place to respond if or when problems occur.

- Personal Adherence Concerns: Explore all adherence concerns, as well as potential solutions.
  - You may discuss this here or when discussing the personalised adherence plan.
- Identify Personal Positive Adherence Factors: Encourage client to identify personal factors or characteristics that will help him/her adhere to HIV treatment.
  - It is important to boost the client's confidence.

#### **5. Personalised Adherence Plan**

- Review the client's personal plan for adherence; this includes what time of day he/she will take the tablets and how the client will remember to take them.
- Make sure clients are specific about their plans.
- Include the treatment supporter in the adherence plan.
- Has the client anticipated problems and how to resolve them?
- Make sure the client is realistic. For instance, it is unreasonable for someone to expect to always remember to take his/her tablets. How is he/she going to remember?

#### **6. Monitoring Adherence and Treatment**

- Assess the client's understanding of how he/she should monitor his/her adherence. The client should also understand how the clinic/hospital will monitor his/her progress.
- Once again, ask the client to explain this to you so that you can listen to him/her instead of telling the client how to do it.
- Schedule a date and time for the next appointment.

**Role Play Scenario:**

A 35-year-old woman has already been counselled twice. She has met the medical and social criteria for treatment and is now ready to start ART. She has studied through primary school and lives with her husband, who is also infected but not on treatment. She is a part-time domestic worker.

She has a CD4 count of 96 and has agreed to start treatment. Her treatment regimen is d4T, 3TC and Nevirapine (NVP). She has already met with the doctor and pharmacist to receive her drugs.

She has come with her husband; he is her treatment supporter.

**Tips for Helping Others Learn How to Take HIV Treatment:**

- Do not assume that the client can read or understand what is written on his/her prescription. You should explain it to the client verbally and offer to write it or have it translated into his/her local language.
- Do not assume that the client already had the medication explained to him/her by the doctor or pharmacist, or that he/she understands it. Ask the client to tell you what he/she understands.
- Do not assume that the client will remember what you say. If he/she can write, you can encourage the client to write the instructions down by him/herself.
- Involve the treatment supporter; ask him/her to remember as well or to write the instructions down. This way, he/she can act as a “back-up” if the client is confused, does not understand, or does not remember the instructions for taking his/her medicine.
- Pictures can be helpful for reminding the client when and how much medication to take.

## Stage 2: HIV Treatment Initiation Counselling Checklist\*

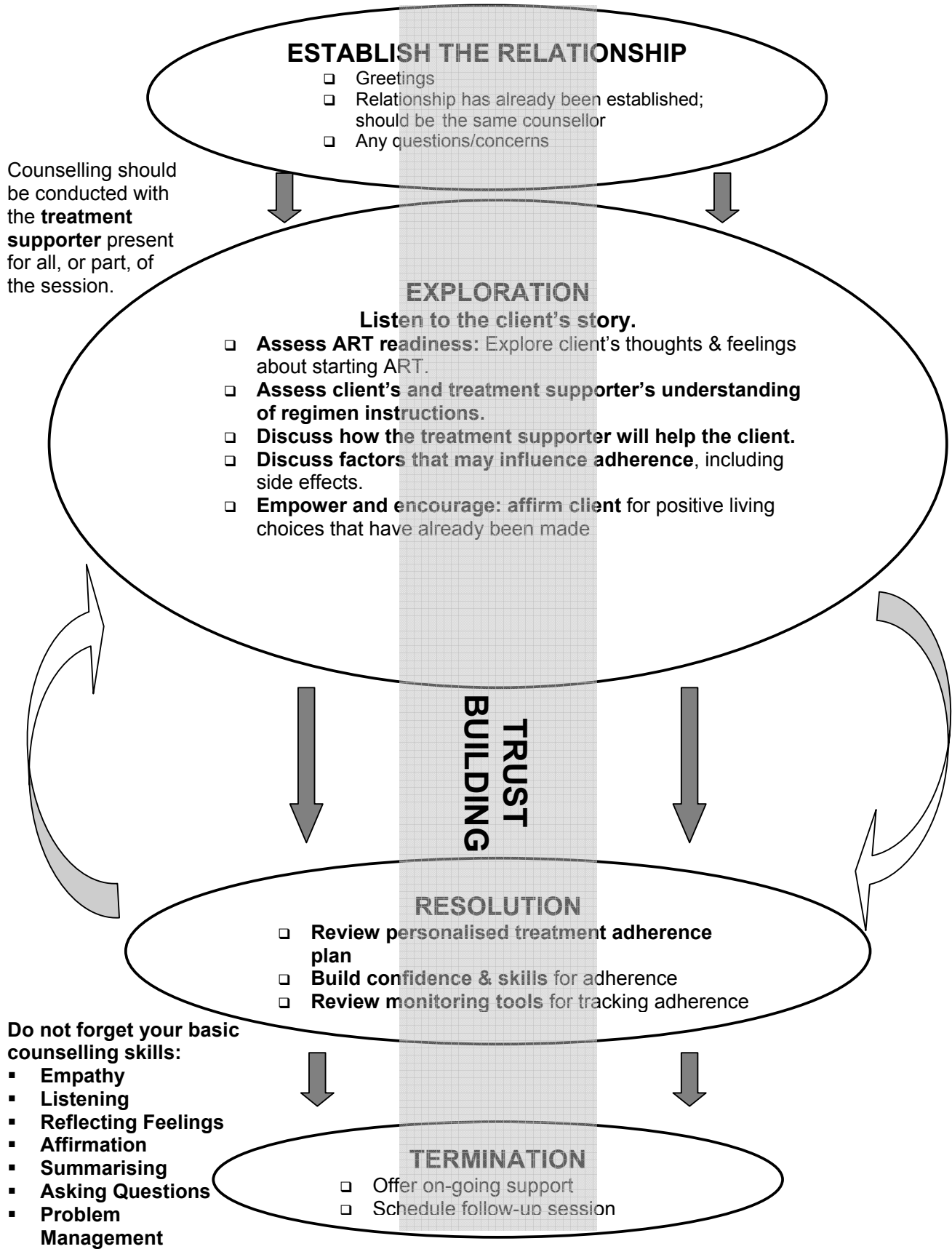
<b>1.</b>	<p><b>HIV Treatment Readiness</b></p> <ul style="list-style-type: none"> <li>❑ <b>Emotional responses:</b> Explore how the client feels. <ul style="list-style-type: none"> <li>○ How are you feeling about starting your ARV regimen today?</li> </ul> </li> <li>❑ <b>Expectations:</b> Make sure expectations are realistic. <ul style="list-style-type: none"> <li>○ What are your expectations for treatment?</li> </ul> </li> <li>❑ <b>Concerns:</b> Listen to concerns. <ul style="list-style-type: none"> <li>○ Do you have any concerns about treatment and adherence?</li> </ul> </li> </ul>
<b>2.</b>	<p><b>Regimen Instructions Assessment:</b> Make sure the client understands how to take his/her medication. <u>Listen</u> to the client's understanding.</p> <ul style="list-style-type: none"> <li>❑ <b>ARV Regimen:</b> Assess client's understanding. <ul style="list-style-type: none"> <li>○ Can you explain to me what you understand about your treatment regimen?</li> <li>○ When are you supposed to take each of your tablets?</li> <li>○ Are there any special requirements for taking these drugs, i.e. food or drink requirements?</li> </ul> </li> <li>❑ <b>Late and Missed Doses:</b> Reinforce the importance of taking tablets on time. <ul style="list-style-type: none"> <li>○ What will you do if you are late with a dose?</li> <li>○ Do you know what to do if you miss a dose?</li> </ul> </li> </ul>
<b>3.</b>	<p><b>Treatment Supporter</b></p> <ul style="list-style-type: none"> <li>❑ <b>Role of Treatment Supporter</b> <ul style="list-style-type: none"> <li>○ We have discussed your treatment plan. How can your treatment supporter help?</li> <li>○ How can you and your treatment supporter work as a team?</li> </ul> </li> <li>❑ <b>Verify Understanding:</b> Make sure the treatment supporter also understands the ARV regimen and requirements.</li> </ul>
<b>4.</b>	<p><b>Factors Influencing Client's Adherence:</b> Personalise it.</p> <ul style="list-style-type: none"> <li>❑ <b>Side Effects</b> <ul style="list-style-type: none"> <li>○ Many people on HIV treatment say that the side effects of the drugs affect their adherence. Let's talk a little bit about that.</li> <li>○ Has anyone explained to you some of the side effects you can expect with your HIV treatment regimen? If so, can you explain them to me?</li> </ul> </li> <li>❑ <b>Personal Adherence Concerns:</b> Explore any and all adherence concerns, and help client think of solutions. <ul style="list-style-type: none"> <li>○ What sorts of things do you think will affect your adherence?</li> <li>○ If the client cannot think of any potential problems, offer some: "What about a change in your routine, such as when you travel or family comes to visit you?" OR "How will you feel about taking your medication in front of people?"</li> </ul> </li> <li>❑ <b>Identify Personal Positive Adherence Factors:</b> help the client identify characteristics about him/herself, lifestyle or past experiences that will help the client adhere to HIV treatment. <ul style="list-style-type: none"> <li>○ Can you think of any things about yourself or your life that predict adherence to HIV treatment?</li> </ul> <p>If the client cannot think of anything, offer some suggestions, i.e. "You have told me about your skills in organisation; this skill will be very useful with HIV treatment adherence."</p> </li> </ul>

5.	<p><b>Personalised Adherence Plan</b></p> <ul style="list-style-type: none"> <li>□ <b>Empower</b> the client: boost his/her confidence, but be realistic about the treatment plan.</li> <li>□ <b>Lifestyle Adjustments</b> <ul style="list-style-type: none"> <li>○ How are you planning to fit HIV treatment into your daily routine?</li> <li>○ Do you anticipate any challenges with this? How will you overcome them?</li> </ul> </li> <li>□ <b>Memory Aids:</b> Explore use of cell phone, pictures, and reminders. <ul style="list-style-type: none"> <li>○ How are you going to remember to take your drugs?</li> <li>○ Do you have a plan to help you remember to take your medication?</li> </ul> </li> <li>□ <b>Support:</b> Encourage support from others in addition to the treatment supporter; include family, friends, community, church, etc. <ul style="list-style-type: none"> <li>○ Where are you going to get the support you need for HIV treatment adherence?</li> </ul> </li> </ul>
6.	<p><b>Monitoring Adherence and Treatment:</b> Personal role and health facility's role in monitoring HIV treatment.</p> <ul style="list-style-type: none"> <li>□ <b>Personal Monitoring Tools:</b> suggest pill diaries, charts, etc. <ul style="list-style-type: none"> <li>○ Why is it important to monitor your own adherence?</li> <li>○ How are you going to keep track of your adherence?</li> </ul> </li> <li>□ <b>Hospital/Clinic Monitoring:</b> Make sure client understands the health care facility's monitoring plan. <ul style="list-style-type: none"> <li>○ Can you explain how the clinic will be monitoring your progress on HIV treatment?</li> <li>○ When are you supposed to return to the clinic?</li> <li>○ Schedule next appointment.</li> </ul> </li> </ul>

\* Counselling should be conducted with the treatment supporter.



## STAGE 2: HIV TREATMENT INITIATION



### Stage 3: HIV Treatment Maintenance

Goals of HIV Treatment Maintenance:

- **Medically:** The doctors and nurses monitor the client's drug interactions and experience of side effects. They also monitor the CD4 count and other measures through blood tests.
- **Counselling:** Offer continued support and reinforce commitment to HIV treatment.

\*Remember: adherence changes over time. Someone may be adherent when he/she starts treatment, but this can change.

What might influence adherence to treatment over time?

- Moving
- Change in marital status
- Having children
- Job change
- Break-up of a relationship

#### HIV Treatment Maintenance Checklist

- 1. Overall Functioning:** In this section, you are exploring how the client is doing on HIV treatment and how he/she feels about being on HIV treatment.
  - The counsellor should offer support and encouragement.
  - Keep in mind that when a client first starts on treatment, he/she has a number of expectations.
  - Affirm the client for what he/she has done to adhere to treatment.
- 2. Regimen Adherence:** Explore how the client is taking his/her HIV treatment. Is he/she following the treatment instructions?
  - It is crucial that questions are NOT asked in a judgemental or leading way. You want the client to answer honestly instead of telling you what he/she thinks you want to hear. You can do this by carefully wording your questions.
- 3. Factors Influencing Adherence:** Explore what specifically helps or hinders adherence for your client.
  - **Counselling about Side Effects:** Remember, the doctor has already met with the client and discussed side effects. Your role is to understand how your client's side effects are affecting his/her life and to help your client cope with them.
    - Empathise with client's difficulties with his/her treatment regimen.



- Do not underestimate the daily challenge of side effects and other symptoms of HIV treatment.
  - Never minimise what the client is experiencing.
  - Assess the side effects' influence on the functioning ability of the client. How much of a problem is the side effect for the client? Is it manageable or not? Do not assume that the client is capable of dealing with his/her side effects.
- Explore the client's adherence concerns while also reinforcing the positive things he/she has done with the treatment plan. Make sure to comment on what the client has done well.
  - Explore areas that are difficult for adherence. Discuss options to overcome these barriers.

**4. Personalised Adherence Plan:** You are trying to understand how the client has adapted to being on HIV treatment.

- How has the client adjusted his/her lifestyle? How does he/she remember to take the tablets, and what kind of support is he/she receiving from others?
- What is working with the adherence plan? Does anything need to change? Explore anything that needs to change – develop options and strategies.
- What role has the treatment supporter taken? Is this working?

**5. Monitoring Adherence and Treatment:** In this section, you are finding out how the client monitors his/her adherence, as well as making sure he/she understands when to return to the clinic.

- Do not assume that the monitoring tools the client is using are working. Find out what is and is not working for the client. Help him/her brainstorm other options if the tools are not working for him/her.

**Suggested Role Play Scenario:**

Agatha is a 30-year-old single woman. She started on HIV treatment (ARVs) two months ago. She has experienced a number of side effects, including nausea, diarrhoea and headaches. She is very discouraged because she thought that ARVs would make her feel better, not worse. She has brought her mother, who is her treatment supporter, to the counselling session.

## The Roles We Play (Review)

It is important for counsellors to develop an awareness of the roles that we can play in our counselling relationships. We are discussing this in HIV Treatment Maintenance because it can become an issue when working with clients on maintaining their HIV treatment adherence.

We are going to look at three main types of roles:

1. The Parent
2. The Child
3. The Adult

### 1. The Parent:

- Key points:
  - This is a role that has authority.
  - Uses frequent statements of what is right and wrong, with a judgement attached.
  - This role expects certain behaviour and can be controlling.

Common words or phrases that represent the **parent**:

Should/should not	Let me help you	Try
Ought	Disobedient	Duty
Don't/do not	Unreasonable	Must
Why? (in criticism)	If I were you	Careless
Sweetheart	Uncooperative	Poor thing
How dare you!	Thoughtless	Now what?

### 2. The Child:

- Key points:
  - Words and actions are for the purpose of getting satisfaction from pleasant feelings or relief from unpleasant feelings.
  - The child role expresses our basic needs, such as our need to eat, sleep, be warm, and “play” (this includes having sex).

Common words or phrases that represent the **child**:

I can't	I hope	Give me
I want	I hate	I will try
I won't	It is your fault	I wish
I don't care	Do it for me	I am scared
I don't know	Why? (in protest)	

### 3. The Adult:

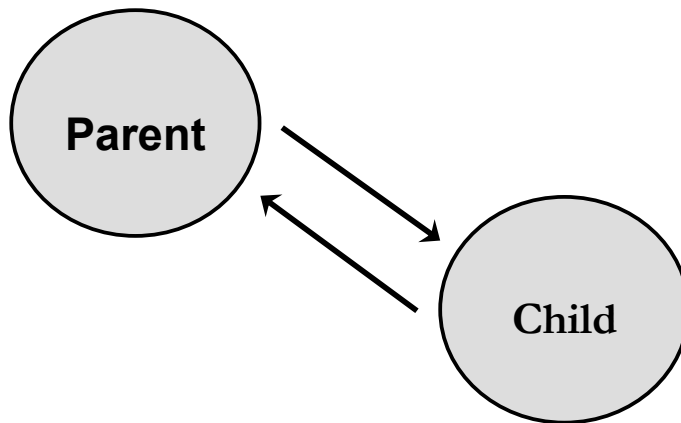
- Key points:
  - Focused on and attempts to deal with the present.
  - Does not place values on behaviour, but describes things the way they are.
  - Usually mature, level-headed, responsible and “human.”



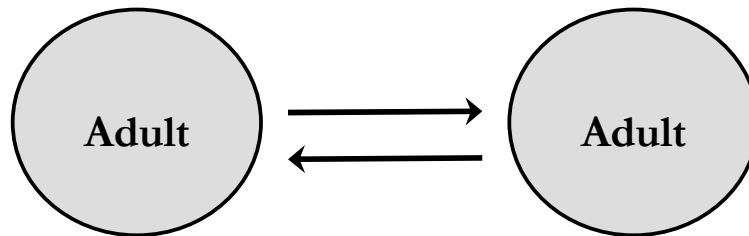
Common words or phrases that represent the **adult**:

Helpful	I see	Rational
Easier	Alternatives	Realistic
Productive	What are the facts?	Responsible
Objective	Why?(for information)	Probability
Authentic	My choice is	No
I choose	I'd rather	Yes
What has been done so far?	Let's take it apart and look at it.	Let's look for the causes.

If you operate primarily in parent role, then people respond to you in their child role. The child role complements the parent role; they fit together like pieces of a puzzle.



If you operate primarily in your adult role, you are most likely to have other respond to you in their adult mode.



**Key Points:**

- The counsellor can tend to behave as the parent, which makes the client take the role of the child. This means that he/she is less likely to take an active, responsible role in his/her treatment adherence.
- Likewise, the client can take the role of the child, which makes the counsellor want to take the role of the parent. You must resist this and respond in the adult role. How do you do this?

### Stage 3: HIV Treatment Maintenance Counselling Checklist\*

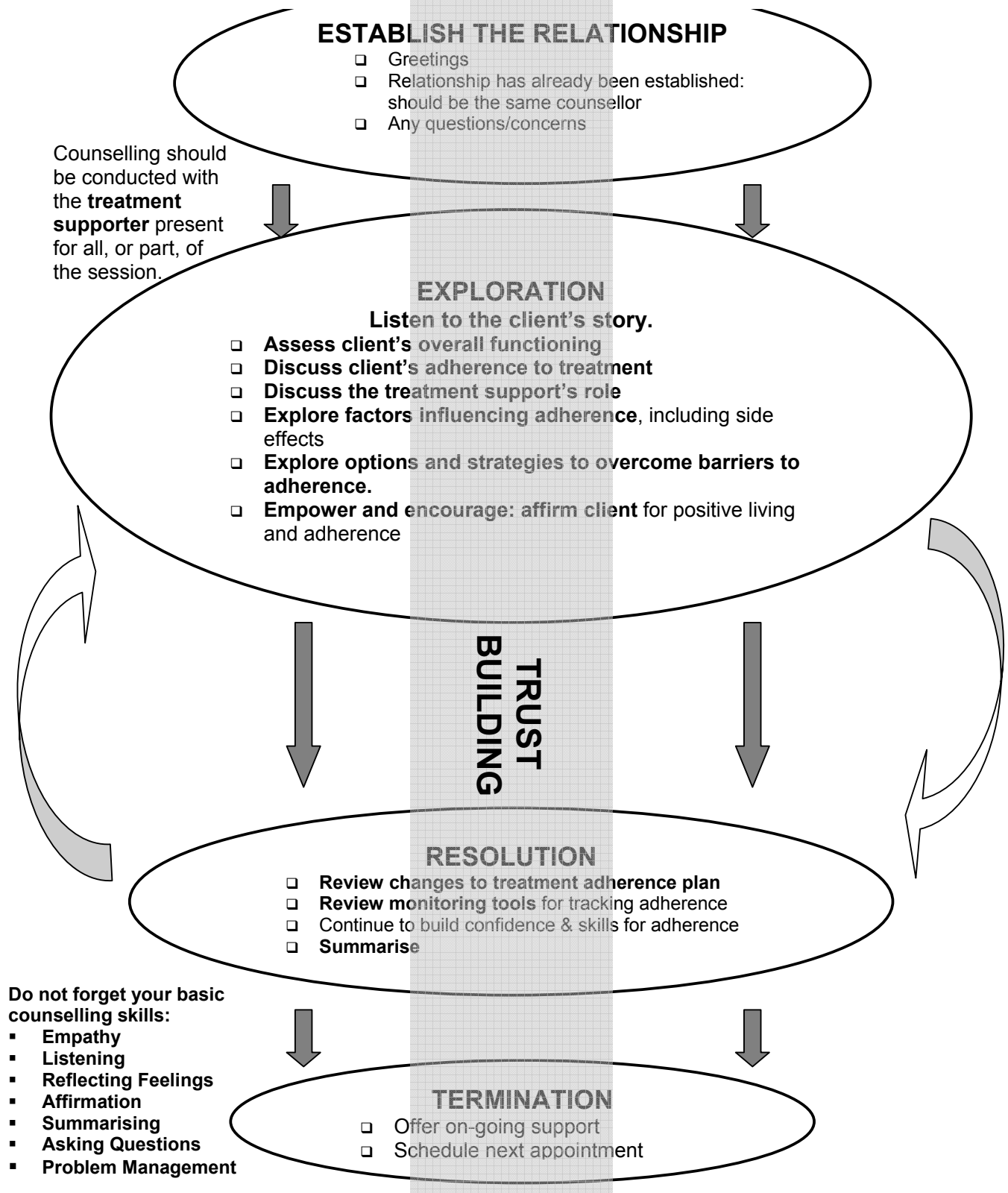
1.	<p><b>Overall Functioning</b></p> <ul style="list-style-type: none"> <li>❑ <b>Emotional Responses:</b> Explore how the client feels and how he/she is doing. <ul style="list-style-type: none"> <li>○ How are you feeling? How are you doing?</li> </ul> </li> <li>❑ <b>Expectations:</b> <ul style="list-style-type: none"> <li>○ What is different/the same about treatment than what you expected?</li> </ul> </li> <li>❑ <b>Concerns:</b> Listen to concerns. <ul style="list-style-type: none"> <li>○ Do you have any concerns about your treatment so far?</li> </ul> </li> <li>❑ <b>Encourage and support</b> the client.</li> </ul>
2.	<p><b>Regimen Adherence</b></p> <ul style="list-style-type: none"> <li>❑ <b>ART Regimen:</b> Determine how the client has been taking HIV treatment. <ul style="list-style-type: none"> <li>○ Tell me how you have been taking your tablets.</li> <li>○ What times have you been taking them in the morning and evening?</li> <li>○ Many people find it difficult taking the medication. Do you ever have trouble taking the tablets?</li> <li>○ What kinds of problems make it hard to take your tablets?</li> </ul> </li> <li>❑ <b>Late and Missed Doses:</b> <ul style="list-style-type: none"> <li>○ It is difficult to take medication every day, and many people miss a dose now and then. When was the last time you missed a dose?</li> <li>○ When is it most difficult to remember your medication?</li> </ul> </li> </ul>
3.	<p><b>Factors Influencing Client's Adherence:</b> personalise it.</p> <ul style="list-style-type: none"> <li>❑ <b>Side Effects:</b> <ul style="list-style-type: none"> <li>○ Have you experienced any side effects from your HIV treatment?</li> <li>○ If so, how have you dealt with them?</li> </ul> </li> <li>❑ <b>Personal Adherence Concerns:</b> Explore any and all adherence concerns and help client think of solutions. <ul style="list-style-type: none"> <li>○ What sorts of things have affected your adherence?</li> <li>○ How do you think you can solve these adherence problems? (Problem-solving with client)</li> </ul> </li> <li>❑ <b>Identify Personal Positive Adherence Factors:</b> Help the client identify characteristics about him/herself, lifestyle or past experiences that help the client adhere to HIV treatment. <ul style="list-style-type: none"> <li>○ Can you identify anything about yourself that helps you stick to your HIV treatment?</li> <li>○ Offer encouragement for areas where the client has adhered to his/her treatment plan.</li> </ul> </li> </ul>

4.	<p><b>Personalised Adherence Plan:</b> Make changes to the plan based on adherence difficulties.</p> <ul style="list-style-type: none"> <li>□ <b>Lifestyle Adjustments:</b> <ul style="list-style-type: none"> <li>○ How has HIV treatment fit into your lifestyle? What has been easy? What has been challenging?</li> </ul> </li> <li>□ <b>Memory Aids:</b> <ul style="list-style-type: none"> <li>○ How have you remembered to take your tablets?</li> <li>○ What things help you remember to take your tablets?</li> </ul> </li> <li>□ <b>Support:</b> <ul style="list-style-type: none"> <li>○ Whom have you gotten support from during the process of starting on HIV treatment?</li> </ul> </li> <li>□ <b>Treatment Supporter:</b> <i>The treatment supporter should be part of the counselling session.</i> <ul style="list-style-type: none"> <li>○ Has your treatment supporter been involved in your adherence?</li> <li>○ What role has he/she taken? Has this worked?</li> </ul> </li> </ul>
5.	<p><b>Monitoring Adherence and Treatment</b></p> <ul style="list-style-type: none"> <li>□ <b>Personal Monitoring Tools:</b> suggest pill diaries, charts <ul style="list-style-type: none"> <li>○ How have you kept track of your adherence?</li> <li>○ What has worked? What has not worked?</li> </ul> </li> <li>□ <b>Hospital/Clinic Monitoring:</b> <ul style="list-style-type: none"> <li>○ When are you supposed to return to the clinic?</li> <li>○ When will you collect your next set of tablets?</li> </ul> </li> </ul>

\* Counselling should be conducted with the treatment supporter if possible.



## STAGE 3: HIV TREATMENT MAINTENANCE





## REVIEWING A COUNSELLING EPISODE

### Adherence Counselling Episode # 1

**Client:** Good Morning. I've come for my monthly visit.

**Counsellor 1:** Good morning, Maria. It's two months now since you began HIV treatment. How are you doing?

**Client:** Fine, thanks. It's not easy, but I am managing.

**Counsellor 1:** Do you want to tell me a bit about how it has been going?

**Client:** Well, I've been taking my medication as I'm supposed to. I just feel very tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired when I wake up that I'm scared that I'll sleep through my morning dose.

**Counsellor 1:** It sounds like treatment has been difficult for you. Do you think your tiredness could be a side effect of the medication?

**Client:** Yes, I think it is. The doctor told me that I might feel like this. He also said that I might get diarrhoea from the AZT/3TC.

**Counsellor 1:** Has knowing this made it any easier for you to cope, knowing that what you're experiencing is common?

**Client:** (Laughs) Yes, but some days I'm tempted not to take my medication. I don't like the way it's making me feel.

**Counsellor 1:** Perhaps you have days when you wonder if this is worth it. Maybe the side effects make you feel worse than the HIV was making you feel before you started treatment?

**Client:** Yes. (Starts crying) I know that it is really important for me to take the drugs every day. But, I'm scared that I'll forget and then the drugs won't work anymore and I'll get sick and die. There will be nothing left for me.

**Counsellor 1:** I can see that you realise how important it is to be adherent to your medication, but it seems like you are putting a lot of pressure on yourself too. Would you like to spend some time looking at how you can manage these side effects more easily?

**Client:** Yes, please. I really need to see if there are things that will help me to get through this.



## **Adherence Counselling Episode # 2**

**Client:** Good Morning. I've come for my monthly visit.

**Counsellor 2:** Good morning, Maria. It's two months now since you began HIV treatment. How are you doing?

**Client:** Fine thanks. It is not easy, but I'm managing.

**Counsellor 2:** Have you been taking your medication all the time?

**Client:** Well, I think I've been taking my medication as I'm supposed to, but I'm not really sure.

**Counsellor 2:** It is very important that you do not miss any doses. You know that you have to take your medication at the same time every day!

**Client:** Yes, I know that I'm supposed to, but sometimes I forget and lately I think my medicine has been making me feel sicker. I just feel very tired all the time and then I want to sleep. I can't cook and clean like before. I'm so tired when I wake up that I'm scared that I'll sleep through my morning dose.

**Counsellor 2:** You cannot miss your doses. You know that you have to keep taking your medication.

**Client:** (Laughs) Yes, but some days I'm tempted not to take my medication. I don't like the way it's making me feel.

**Counsellor 2:** You know that it's really important to keep persisting. Everyone feels that way.

**Client:** Yes. (Starts crying) I know that it is really important for me to take the drugs every day. But, I'm scared that I will forget and then the drugs won't work anymore and I'll get sick and die. There will be nothing left for me.

**Counsellor 2:** You have to pull yourself together; otherwise you will make yourself sicker than you are now. Do you want that?

**Client:** No, I definitely don't want to get sicker.



### **Small Group Discussion Questions:**

- What is your overall view of these counselling sessions?
- Comment on each of the responses made by the first counsellor. What type of skill is being used? Why is this effective or ineffective?
- Comment on the responses made by the second counsellor. What is this counsellor doing? How is this effective or ineffective?
- According to “The Role You Play,” what type of roles do you think each of the counsellors is playing? Remember the “adult”, “child” and “parent” roles.

*Adapted from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.*



### **Adherence Scenarios: What Would You Do?**

1. A client has not disclosed his status to anyone at work. He is on HIV treatment and is afraid to take his medication at work. How would you use the problem-solving model to brainstorm possible options?
2. George is on HIV treatment and committed to adherence. His job entails shift work, and this interferes with his medication regimen. How would you approach this problem together with George?
3. Sheena has been on HIV treatment for a few months. She is responding well and is feeling physically and emotionally stronger. She has met a man and feels that a serious relationship could develop, but she is anxious and unsure if she should disclose her status to him and when the right time would be. What would you say to her?
4. Randeera has gone through Pre-HIV treatment Initiation Counselling and feels ready and committed to the programme. The health care worker is unsure whether he should begin treatment because he has not disclosed to anyone. What would you do?
5. Your client has completed the Pre-HIV Treatment Initiation Counselling. Some of her friends are on HIV treatment. She is confused as to whether she should go onto the treatment because she has heard so many different opinions about the side effects, how difficult it is to keep the routine and the success of the treatment. How can you assist her in making a decision about whether she should go onto treatment?
6. Peter has been your client for 6 months. He presents as being committed to adhering to the programme. However, you have been told that he frequently goes to the shebeen and drinks a lot. You begin to notice a change in his attitude and physical and emotional wellbeing. What do you do?
7. Your client has been on HIV treatment for a few months. The side effects have not decreased. He is feeling despondent and considering stopping the treatment. What would you say to him?

#### **Small Group Discussion:**

- What are the primary issues in the scenario?
- Provide at least two alternative ways of handling this scenario. You can come up with more options as well.
- Which do you think is the best approach? Is your whole group in agreement?

*Taken from Kerry Saloner. 2005. Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.*



#### **Stage 4: Re-Motivation or Treatment Change**

Remember that HIV treatment is treatment for life. As a result, there will be many things that happen in a person's life while he/she is on treatment. Many of these events will directly impact the person's treatment and ability to adhere to his/her treatment regimen. We are going to take a look at the psychological themes that may come up in HIV Treatment Maintenance Counselling.

Psychological Themes in HIV Treatment Maintenance (Supportive) Counselling:

- Empowerment and control
- Survivor guilt: guilt that he/she is alive and loved ones have died
- Grief and loss: client's own and others
- Treatment failure
- Pain management
- Existential struggles: a philosophical search for meaning in life

There are a few options for adjusting a client's ART regimen. Of course, this would be done by the doctor, in consultation with the client, the Health Care Team, and other professionals.

The reasons for changing anti-retroviral treatment are:

- Client intolerance of a medication
- Significant adverse effects
- Treatment failure

HIV treatment can also be interrupted for many different reasons. However, when HIV treatment is interrupted, it is best to stop ALL of the HIV treatment medications at the same time.

#### **Treatment Change and Counselling**

If a client changes treatment regimens, he/she will need to be re-counselled from Stage 1: Pre-HIV Treatment Initiation.

- Do not assume that the client has any former knowledge.
- Treatment change may have psychological effects, including feelings of failure, shame, guilt, embarrassment or fear of failure. Explore those feelings with the client.
- Be careful not to judge the client for failing on his/her previous treatment plan.
- Reflect on the client's previous experience on HIV treatment: what worked and what did not work? Adjust the new treatment plan to take these issues into account.
- Return to the client's original reason for taking HIV treatment. Re-motivate from time to time.



- Encourage your client to celebrate successful perseverance on treatment, i.e. celebrate HIV treatment initiation anniversaries.

### **Suggested Role Play Scenarios:**

1. The client is a 42-year-old man whose wife recently died from AIDS-related illnesses. He has been on HIV treatment for 3 years and is doing well on treatment. He has followed his treatment regimen and rarely misses doses. However, in the last couple of months he has been depressed and finding it difficult to stick to treatment. He feels guilty for doing well on treatment after his wife so recently passed away.
2. A 21-year-old woman has been on treatment for 4 years. For years, she adhered to treatment and besides some side effects in the beginning, she has felt good until recently. She was admitted to the hospital with TB a month ago and the doctor has suggested a change in treatment. The new regimen will be harder to adhere to, with more dosing requirements.
3. A 32-year-old man has been on treatment for 5 years. However, his health has started to decline and he has been sick a lot and in and out of the hospital. He recently lost his job because he had been sick so much and missed so much work.
4. A 27-year-old woman found out her positive HIV status when she was pregnant. She missed her follow-up visits at the clinic and had her child at home. The child was a girl, and she got sick not long after she was born. The child died three months ago when she was 14 months old. Your client started on HIV treatment 4 months ago and her health has improved greatly. However, she has been feeling guilty about her child's death and has been very depressed lately.



## Adherence Review: Roller Coaster of HIV

Remember our lifelines from Personal Growth: we drew the highs and lows of our lives and then shared them with each other in our small groups. In this session, we are going to look at the highs and lows of a person living with HIV.

An HIV-positive diagnosis can be the beginning of an often unexpected journey of new highs and lows. The challenges and benefits of HIV treatment will also be triggers for ups and down in clients' lives. Our role as counsellors and supporters is to help prepare clients for the emotions that the various stages might bring, and also to support clients through the highs and lows they experience.

The diagram shows some possible high and low points of living with HIV and being on HIV treatment.

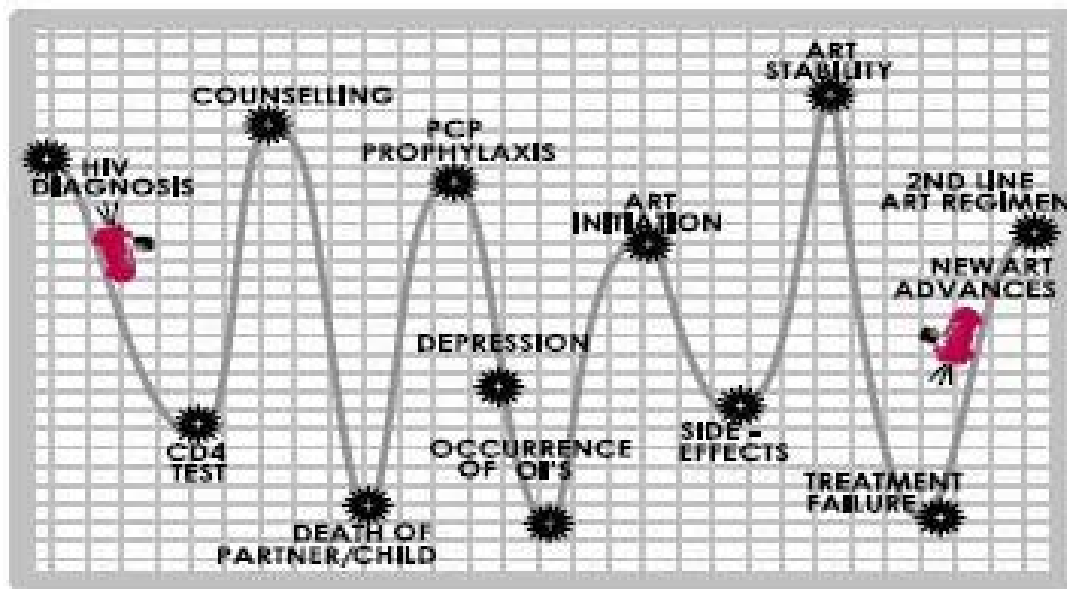


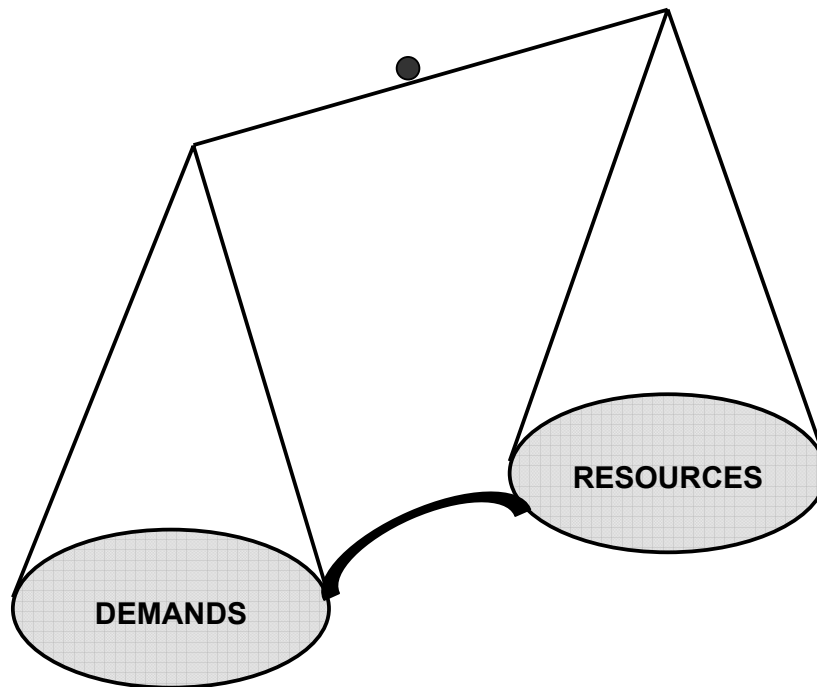
Diagram taken from Kerry Saloner. 2005. *Adherence Resource Pack for Anti-retroviral Treatment (ART) Adherence Counselling and Support*. The Centre for the Study of AIDS, University of Pretoria; and the Perinatal HIV Research Unit, University of the Witwatersrand. Pretoria, Johannesburg.

## Self Care

Stress: when our perceived demands (both internal and external) are greater than our perceived coping ability (both internal and external coping ability).

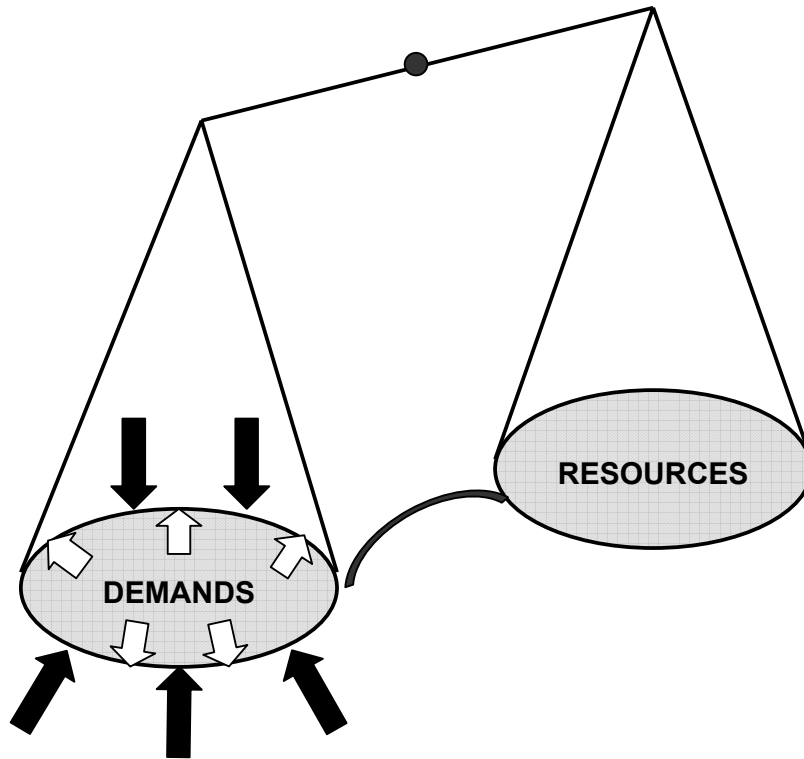
**Key Point:** Our goal is to learn how to better manage stress and to use it a positive force in our lives.

**Stress:** Perceived demands are greater, or heavier, than perceived resources.



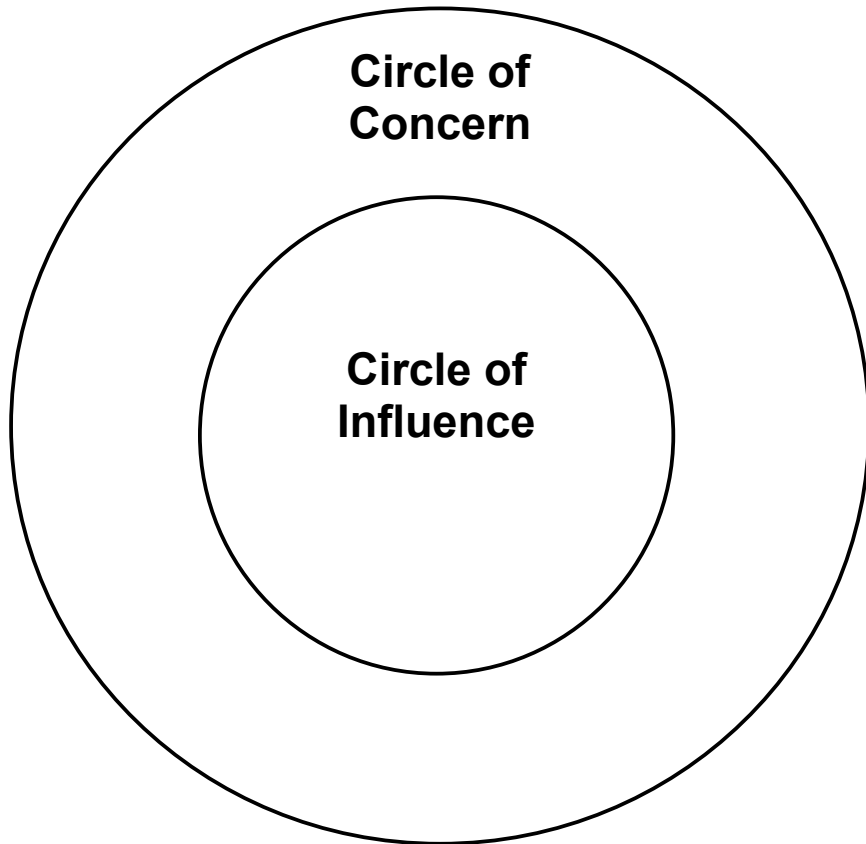


**Stress/Distress: Perceived internal and external demands are greater, or heavier, than perceived resources, both internal and external.**



**Written Exercise:**

- Write down all of your concerns about being an HIV counsellor. What are your concerns related to counselling? Write them all down.
- Now, think back to Personal Growth. Do you remember our circles of influence and circles of concern? Remember that the circle of concern is the bigger circle: these are all the things that we are concerned about. The smaller circle on the inside is the circle of influence. There are all the things that we have some influence, or control, over.
- Divide up all of your concerns on your list into the circles of influence and circles of control. What do you have some control or influence over and what is out of your control or influence? Make sure that you are realistic about what you can change.



### **Small Group Activity:** Circles of Influence and Concern as Counsellors

- Help each other distinguish between what belongs in the different circles and to focus on the circle of influence in order to be pro-active instead of re-active.
  - **Re-active People:** focus on their circle of concern. They focus on the weaknesses of other people, the problems in their life and environment, and circumstances over which they have no control. Their focus results in blaming and accusing attitudes, reactive language and increased feelings of victimisation. The negative energy generated by this causes their Circle of Influence to shrink.
  - **Pro-active People:** work on things they can do something about. They focus on the circle of influence and try to make changes to things in their life that they have some control over. The nature of their energy is positive, enlarging and magnifying, causing their Circle of Influence to grow/expand.
- Discuss how to reduce the intensity of emotional reactions; this is within the circle of influence:
  - Are you viewing your stressors in exaggerated terms and/or taking a difficult situation and making it worse?
  - Do you expect to please everyone: clients, supervisors, colleagues, and family members?
  - Do you put pressure on yourself to do a perfect job? Is perfection possible in HIV counselling?
  - Do you ever feel that situations are more serious than they later turn out to be?
  - Try to view stress as something you can cope with rather than something that overpowers you.
  - Put the situation into perspective.
  - Do not focus on the negative aspects of your job. Find ways to celebrate your accomplishments and those of your clients, even if they seem small, i.e. showing up for HIV test results or going a week without missing a dose of ARVs.

## Self-Assessment and Improvement Worksheet

### Strengths:

#### **My strengths as a counsellor or the basic counselling skills I am good at:**

*Example: I am good at establishing the relationship and making the client feel comfortable in counselling.*

#### **How will I use this to build on my skills as a counsellor?**

*Example: I will expand my ability to make an initial connection with a client to build trust and allow the client to explore very personal things that are often hard to talk about, such as sexual behaviour.*

### Areas for Improvement:

#### **The areas where I need to improve as a counsellor or the skills I struggle with:**

*Example: I am uncomfortable when my client is emotional. I try to make her feel better by reassuring her, and then I usually give advice instead of helping the client explore her feelings and options.*

#### **How will I work on improving these skills?**

*Example: I will write in my journal every day about my own feelings to get comfortable with my own emotions. I will role play with my counselling colleagues, focussing on simply validating the feelings and not giving advice.*

Date of Assessment \_\_\_\_\_



## TIPS FOR POSITIVE LIVING

(For reference)

### 1. Be Informed

- Encourage the client to learn what he/she can about HIV infection. Understanding more about HIV may lessen fears the client has related to HIV, and he/she can learn ways to stay healthy.
- Knowing more about HIV may help the client be more adherent to any medicines he/she takes to treat HIV or prevent other illnesses.

### 2. Medicines

- HIV has no cure, but medicines can help a person with HIV be healthier and live longer.
- Some medicines need to be taken even if the client feels well. These are for opportunistic infection prevention, i.e. cotrimoxazole, or ARVs.
- Some medicines help manage some side effects, such as pain, vomiting and diarrhoea.
- Some medicines can be taken to treat opportunistic infections, i.e. antibiotics.
- Many herbal or traditional medicines can interact with ARVs. Clients should not take them without first consulting their doctor.
- People with HIV and those on HIV treatment should avoid alcohol, non-prescribed or illegal drugs, and cigarettes.

### 3. Work

- Those living with HIV should be encouraged to continue working as long as they are well, or to return to work after recovering from illness.
- Work provides income, stability, routine, friendships and fulfilment to many people that can promote health, both physically and emotionally.

### 4. Stress

- Avoiding stress and dealing with worries is important to maintaining health.
- People with HIV need to find positive ways to deal with stress, i.e. talking with friends or family, exercise, etc. and to avoid negative ways of dealing with stress, i.e. taking alcohol or drugs.

### 5. Nutrition

- There is an interaction between HIV and nutrition that causes poor nutrition and weight loss.
  - Nutrients from food are not absorbed well into the body, often due to diarrhoea, vomiting, etc.
  - Less food is eaten because of nausea, pain, poverty, etc.
  - Because of HIV, the body has a higher need for nutrients.
- Many HIV-related illnesses cause low appetite or difficulty in eating.
- Side effects of HIV treatment can include nausea or vomiting.
- When people have poor nutrition, their immune systems do not function well and they tend to get more infections.
- Many people do not have resources to buy enough food.



- People with HIV should:
  - Eat a well-balanced diet with regular meals, even if not hungry.
  - Wash vegetables with clean water.
  - Drink plenty of clean water, up to 2 litres a day.
- People with HIV who feel nauseous or have low appetite should:
  - Eat small, frequent meals.
  - Eat bland foods, i.e. rice, porridge, toast
  - Do not eat greasy or spicy foods.
  - Take HIV treatment tablets with food.
  - Ask someone else to cook for them.

## **6. Prevent Infection**

- Since HIV affects the immune system, a person with HIV is more susceptible to infections, or gets infections more easily.
- People with HIV should take steps to prevent infections, including:
  - Drink clean water. Boil water for a few seconds, then let cool.
  - Wash vegetables and fruits with clean water.
  - Eat well-cooked food, i.e. meat is brown and soups are boiled.
  - Wash hands with soap frequently, including after using the toilet.
  - Avoid STIs and HIV re-infection by abstaining from sex or using condoms.
  - Take steps to avoid malaria, such as using bed nets.
  - Avoid contact with others who are sick.
  - Clean and cover any cuts or wounds.

## **7. Exercise and Rest**

- Benefits of regular exercise include:
  - Increased energy levels
  - Increased appetite
  - Decreased nausea
  - Maintenance of muscle tone
- Exercise can range from moderate, i.e. being active around the house, to active, i.e. team sports, jogging, or walking.
- Sufficient rest and sleep help to restore energy.

## **8. Prevention**

- HIV can still be spread to others, even if the client is on HIV treatment
- People with HIV should take measures to prevent spreading HIV to others, such as remaining faithful in current relationships, using condoms and abstaining from sex.

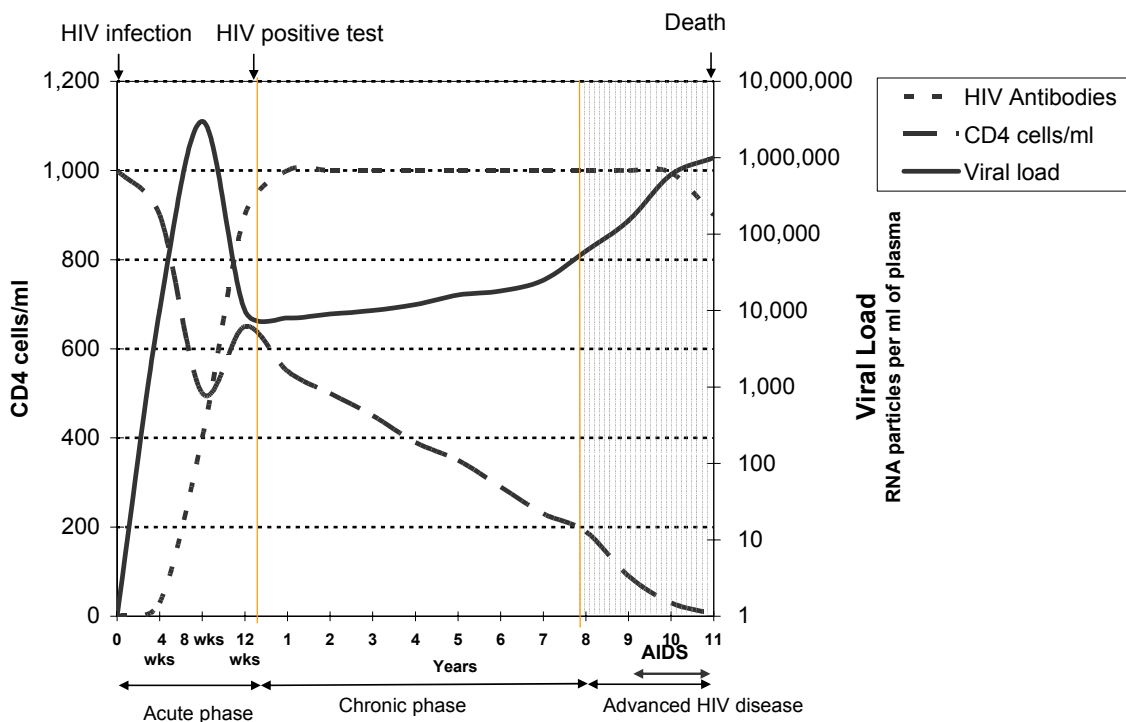
## **9. Regular Medical Care**

- People who are living with HIV should regularly visit the hospital or clinic to monitor their progress.
- If a person is taking ARVs, he/she will be given a regular schedule for visiting the doctor, refilling his/her medicines and counselling. The client should keep all of these appointments.
- Clients should go to the clinic or hospital promptly when they are feeling ill. Early treatment of infection can prevent further illness.

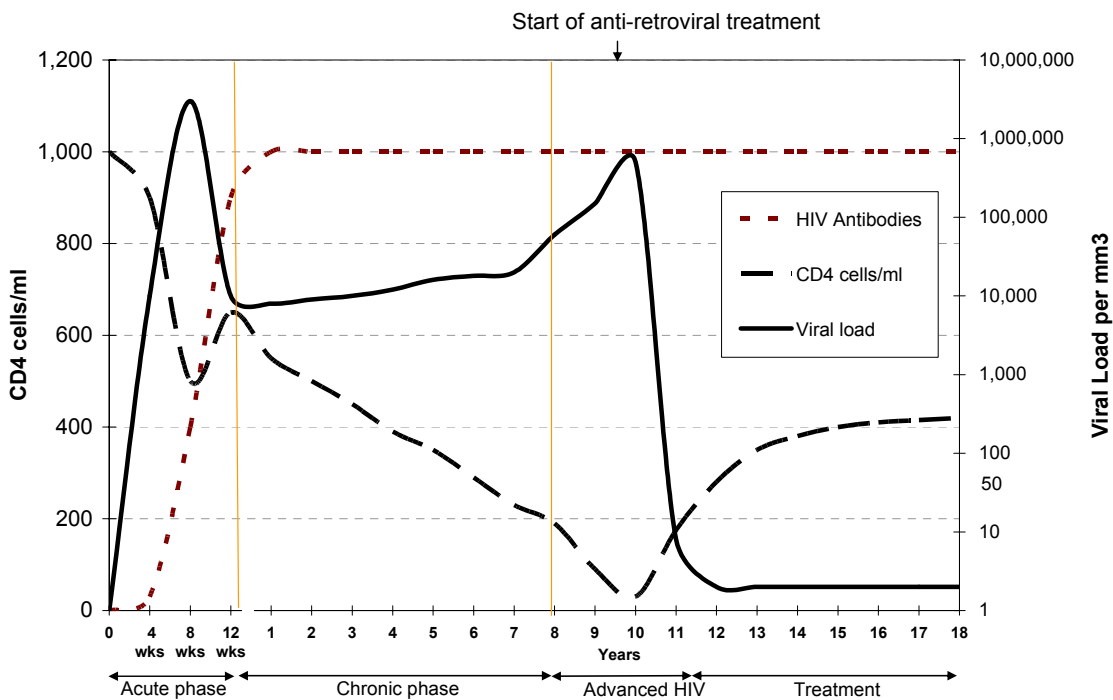


# CHARTS

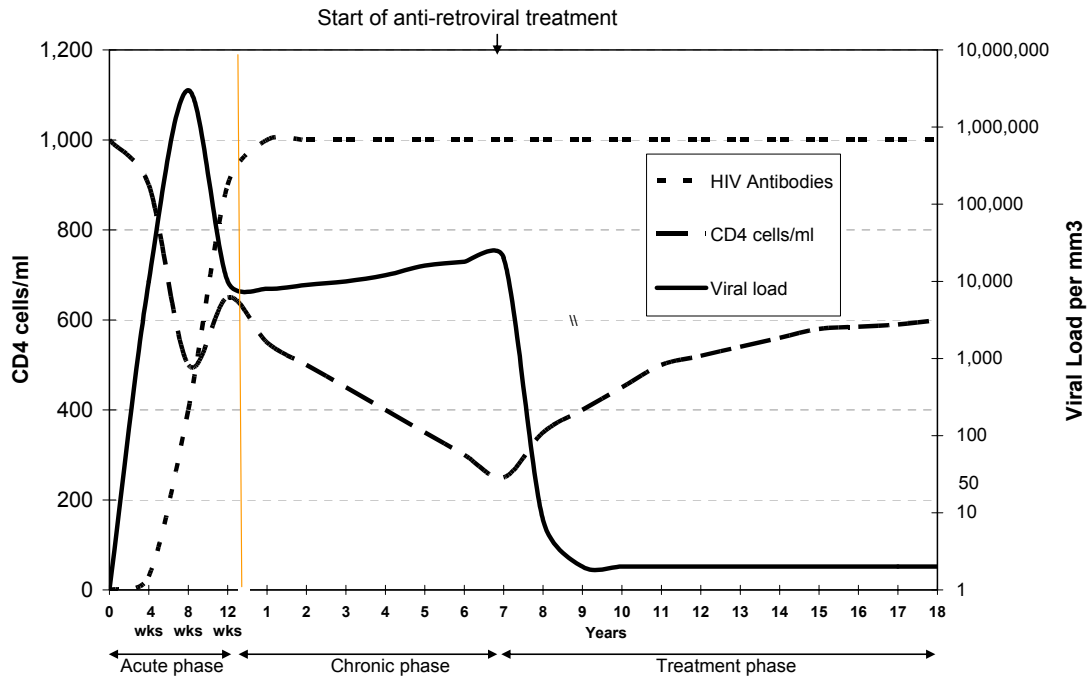
## HIV PROGRESSION



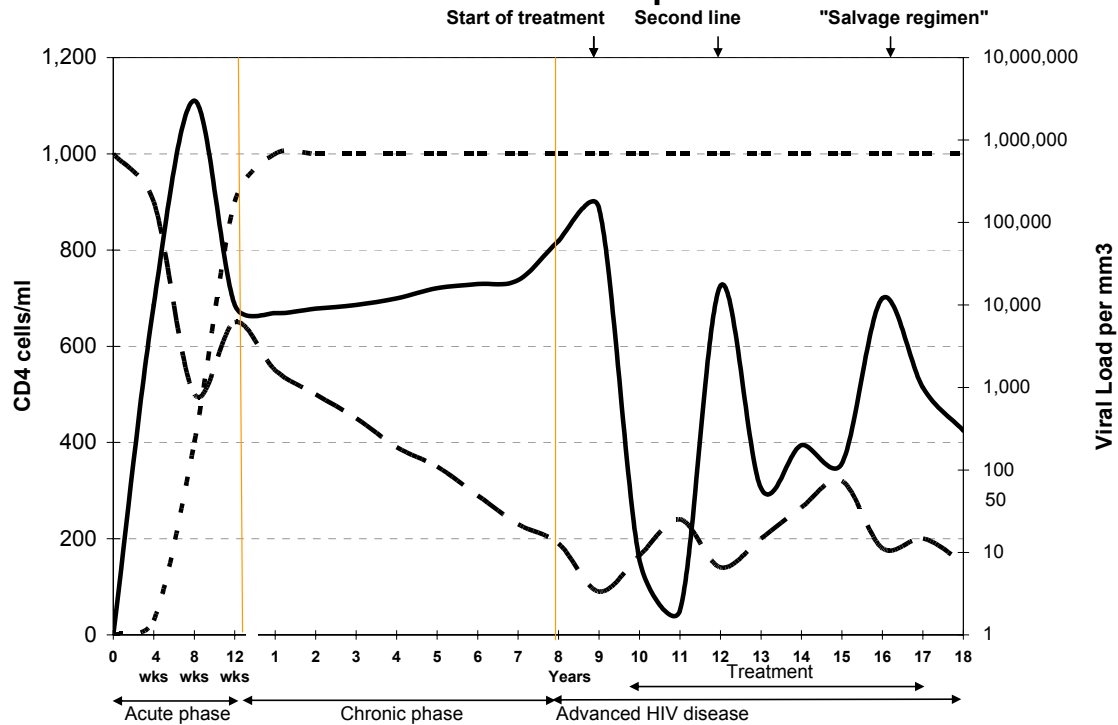
## HIV Treatment in advanced disease



## HIV Treatment before advanced disease



## HIV Treatment and inadequate adherence





## GLOSSARY

**Abrupt stopping of breastfeeding/abrupt weaning:** Completely stopping breastfeeding with a switch to replacement feeding. Mixed feeding should be avoided during this time.

**Adherence:** The extent to which a person's behaviour (taking medication, following a treatment regimen, making lifestyle choices, etc.) corresponds with recommendations made by the health-care team. ART adherence is taking the correct dose at the correct time and in the correct way.

**AIDS (Acquired Immune Deficiency Syndrome):** late-stage HIV infection.

**Acquired:** obtained or contracted; not inherited.

**Immune:** the body's defence system that provides protection from most diseases.

**Deficiency:** a defect, weakness or inability to respond; when linked with the immune system, this refers to the inability of that system to perform its functions and combat antigens or germs.

**Syndrome:** a group of symptoms and diseases that indicate a specific condition; it is not by itself a disease.

**ANC:** Antenatal clinic or antenatal care.

**Antenatal care:** Care of a pregnant woman and her unborn child or foetus.

**Antibody:** the substance that the body makes to fight an antigen (foreign substance in the body such as a germ). Its purpose is to protect the body from disease by countering or identifying the antigen to be destroyed.

**Antigen:** any foreign substance that gets into the body and causes the immune system to respond. Antigens include bacteria and viruses such as HIV.

**Antiretroviral drugs (ARV):** drugs that slow the growth and replication of HIV and the progression of HIV disease.

**Antiretroviral prophylaxis (HIV prophylaxis):** use of antiretroviral drugs to reduce the likelihood (or possibility) of HIV transmission, for example, the use of single-dose Nevirapine for prevention of HIV transmission from mother to child.

**Antiretroviral treatment (ART):** Use of antiretroviral drugs to treat HIV infection or AIDS.

**Asymptomatic:** without symptoms of illness or disease. People who are infected but asymptomatic may transmit HIV or other STIs (sexually transmitted infections).

**CD4 cell:** The white blood cell within the immune system that is targeted and destroyed by HIV.



**CD4 count:** The number of CD4 cells in the blood, which reflects the state of the immune system. A normal count in a healthy adult is 500-1,200 cells/mL<sup>3</sup>. When the CD4 count falls below 200 cells/mL<sup>3</sup>, there is a high risk of opportunistic and serious infection.

**Complementary food:** Any food used as in addition to breast milk or to a breast milk substitute when feeding an infant.

**Cup feeding:** Feeding an infant from an open cut without a lid.

**Diarrhoea:** illness characterised by loose, watery bowel movements more than three times a day, every day.

**Disclosure:** sharing personal information, thoughts or feelings with others. In the context of HIV, disclosure is usually used to refer to sharing one's HIV status with others.

**Discrimination:** treating one particular group in society in an unfair way.

**Embryo:** fertilised egg (egg & sperm) until 2 months of development.

**Exclusive breastfeeding:** an infant receives only breast milk and NO other liquids or solids, not even water. The only exceptions are drops or syrups that contain vitamins or minerals, or any medicine prescribed by a doctor.

**Foetal** (also spelled fetal): connected with a foetus, i.e. foetal blood is the blood of the foetus.

**Foetus** (also spelled fetus): a baby before birth, while the baby is still in the mother's uterus/womb; from 2 months to birth.

**Gender:** our maleness or femaleness, often including our social roles.

**HIV (Human Immuno-deficiency Virus):** the virus that causes AIDS.

**Human** means that it affects only humans and lives only in humans.

**Immuno-deficiency** means a deficiency or a breakdown of the immune system; a decrease in the body's ability to fight disease.

**Virus:** A virus is a germ that invades the body and causes diseases. A virus is a type of antigen.

**Health care worker (Health care provider):** A doctor, nurse or midwife who work with clients in a health care facility, i.e. hospital or clinic.

**Immune system:** the body's resistance or the body's defence mechanism for fighting off infections. The immune system defends the body against infections; it includes the white blood cells, which include CD4 cells, T cells and B cells.



**Infant:** a person from birth to 12 months of age; a baby.

**Infant formula:** a breast milk substitute that contains the nutrients an infant needs. It is a powder sold in tins.

**Intercourse:** sex that involves one partner entering another's body. Intercourse may refer to oral, anal and vaginal sex.

**Intervention:** Specific action or strategy to address a particular problem or issue and to accomplish a specific action or outcome.

**Maternal:** of the mother, or related to being a mother, i.e. maternal blood is mother's blood.

**Mixed feeding:** feeding both breast milk and other foods or liquids, including water. Mixed feeding increases the risk of transmission of HIV from a positive mother to her child.

**Mother-to-child transmission (MTCT):** transmission of HIV to a child from an HIV-infected woman during pregnancy, delivery, or breastfeeding.

**Nutrients:** substances that come from food and are needed by the body, i.e. carbohydrates, proteins, fats, vitamins and minerals.

**Opportunistic infection:** infections that occur in the presence of immune deficiency (weakened immune system), or HIV-related diseases. Any disease that occurs more frequently in people with HIV.

**Oral thrush:** a fungal infection of the mouth that looks like white patches or curdled milk.

**PCP (Pneumocystis carinii pneumonia):** a severe, life-threatening lung infection that causes fever, dry cough and difficulty breathing. It is an opportunistic infection.

**PCR (polymerase chain reaction) test:** This test detects HIV in the blood and can be done at 6 weeks following possible exposure; it is also may be used to test infants.

**PEP (post-exposure prophylaxis):** medicine given after someone has been exposed to a virus or disease, such as HIV, in order to prevent infection.

**Placenta:** organ in the womb that filters the mother's blood and allows oxygen and nutrients to pass through the umbilical cord to nourish the growing foetus.

**Postnatal care:** care given to mother and baby after the child is born. It includes medical treatment, services on breastfeeding, immunisations, maternal nutrition and support for the mother and her family.



**Prevention of mother-to-child transmission (PMTCT):** prevention of mother-to-child transmission of HIV.

**Replacement feeding:** feeding infants who are receiving no breast milk with a diet that provides all the nutrients they need until they can eat family foods. During the first six months of life, replacement feeding should be with a breast milk substitute such as infant formula or modified cow's or goat's milk.

**Replicate:** to duplicate or make more copies of something.

**Resistance (viral resistance):** changes in the genetic makeup of HIV that decrease the effectiveness of antiretroviral drugs (ARVs).

**Safer sex:** Ways to have sex that reduce the danger of acquiring or transmitting HIV or other sexually transmitted infections (STIs).

**Sex:** sexual activity or behaviour; sexual intercourse.

**Sexual orientation:** determined by whom a person is physically and emotionally attracted to; common divisions are **heterosexual** (attracted to people of the opposite gender), **bisexual** (attracted to people of either gender) or **homosexual** (attracted to people of the same gender).

**Sexuality:** the experience of being sexual; this is shaped by behavioural, psychological, emotional, social and orientation factors.

**Sexually Transmitted Infection (STI):** infection that is spread from one person to another through sex or sexual activity. The unprotected sex may include vaginal, oral and anal sex.

**Side effect:** unintended action or effect of a medication or treatment.

**Stigma:** mark of shame or discredit; the strong feeling in a society that a type of behaviour is shameful. An attribute of a person that is considered unacceptable.

**Symptomatic HIV infection:** the stage of HIV infection when a person experiences symptoms. Common symptoms include fever, weight loss and swollen lymph glands.

**Transmit (transmitted):** to pass on, as in a disease. To transmit HIV is to pass on the virus to another person.

**Tuberculosis (TB):** A highly contagious (easy to get) bacterial infection that attacks the lungs and other parts of the body.

**Umbilical cord:** connects the foetus (unborn baby) to the placenta. The umbilical cord carries oxygen and nutrients from the mother to the unborn baby. The umbilical cord is cut after the baby is born and forms the belly button.



**Unprotected sex:** sexual intercourse without a condom or other barrier to prevent contact with the partner's body fluids. This can be vaginal, anal or oral sex.

**Vaginal fluids:** liquids produced by the female reproductive system that provide moistness and wetness in the vagina and serve as lubrication during intercourse.

**Viral load:** The amount of HIV in the blood as measured by a blood test (usually the HIV RNA polymerase chain reaction test, or PCR).

**Viral replication:** the process by which a virus makes copies of itself, using genetic material in human cells.

**Virus:** a type of germ that causes infection.

**Wasting (syndrome):** condition characterised by loss of more than 10% of body weight, and either unexplained chronic diarrhoea lasting more than a month or chronic weakness and unexplained fever lasting more than a month.

**Window period:** the time between infection with HIV and a definitive positive result on an antibody test. For HIV, the window period is usually about 3 months.



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